# Factors affecting patients' decisions about their therapy when beginning courses of treatment for depression

Thesis submitted in accordance with the requirements of the University of London for the degree of Doctor of Philosophy by Sara Garfield.

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#### Abstract

The World Health Organisation (2001) has predicted that depressive disorder will be the highest cause of disease in the developed region by 2020. Studies have shown that compliance with antidepressant medication is approximately 50% after 3 months of therapy (Maddox et al. 1994; Lin et al. 1995) whereas it is recommended that medication is taken for at least 4 to 6 months (Paykel and Priest, 1992). Little is known about patients' perspectives of treatment at the initial stages of therapy and the influence of these on decision-making. This thesis presents an in-depth view of patients' decision-making regarding medication at the beginning of treatment for depression in primary care and informs the development of healthcare services in supporting individuals in their decision-making.

Preliminary fieldwork involved meeting with local self help groups of national organisations for people with depression. Further to this, patients beginning courses of antidepressant medication were identified through general practice surgeries. A semi-structured interview, based on the combination of a qualitative interview and 3 quantitative instruments, was administered on 2 occasions after commencement of therapy. The qualitative component of the interview was audio taped, transcribed verbatim and coded. With regards to the quantitative data, bivariate analysis was carried out to identify factors which distinguished between those who continued with their mediation and those who discontinued.

Out of 171 eligible patients who were invited to participate, 51 completed a first interview and 41 of these subsequently completed a follow-up interview. Twenty two respondents were male and 29 were female. The age of respondents ranged from 19 to 61. The majority reported their ethnic group as White Non Irish. All social classes were represented amongst the respondents. Antidepressant medication which had been prescribed included SSRIs, tricyclics and venlafaxine. Analysis of interview data demonstrated that decision-making about taking antidepressant medication was a complex process. Few factors distinguished between those who continued with their medication and those who discontinued. Respondents identified both positive and negative aspects of taking antidepressant medication. Positive aspects included a return to normal life and functioning whereas negative aspects included stigma, adverse drug reactions and dependency. Respondents assessed their circumstances at a particular point in time and made a decision as to whether or not it would be beneficial to take medication. Decisions about taking antidepressant

medication were made alongside consideration of other treatment strategies. The level of personal involvement which respondents wished to have concerning decisions with their medication varied both between respondents and at different points of therapy.

Respondents required a large amount of information to support their decisionmaking, including that concerning adverse drug reactions, process of recovery, dosage and dependency. Current healthcare services did not provide all information needs. Roles were identified for the community pharmacist in order to meet information needs, thereby enabling them to support individuals in maintaining adherence to treatment. This role of maintaining adherence to treatment has been identified for pharmacists in the management of people with mental health problems by the RPSGB (2000). The constraints which need to be overcome in order for pharmacists to fulfill such roles are also reviewed.

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## **LIST OF ABBREVIATIONS**

- ICD-10 = International Classification of Disease 10 Symptoms of Depression
- SSRI = Selective Serotonin Reuptake Inhibitor
- MAOI= Monoamine-oxidase Inhibitor
- SKB = Smithkline Beecham Quality of Life Questionnaire.
- SIQ= Symptom Interpretation Questionnaire
- **BNF=** British National Formulary
- SPSS= Statistical Package for the Social Sciences
- NUD\*IST = Non Numerical Unstructured Data Indexing, Searching and Theory Building
- UPA = Underprivileged Area score
- RPSGB = Royal Pharmaceutical Society of Great Britain

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# **Section 1-Introduction**

# CHAPTER 1 MEDICAL BACKGROUND

The research presented in this thesis aimed to identify factors which affected the decision-making of patients with a diagnosis of depression, when beginning courses of medical treatment for depression. Chapter One defines the term depression and discusses the methods by which a diagnosis of depression is made. The epidemiology of depression is then discussed, in terms of the types of people who would be expected to be prevalent in a population of patients with a diagnosis of depression. Finally, the chapter describes medical treatments for depression.

## **<u>1.1 Diagnosis of depression</u>**

Section 1.1 defines and classifies depression. The section discusses tools which have been developed to aid in the diagnosis of depressive disorders and considers some difficulties which may occur when obtaining accurate diagnoses.

## **1.1.1 MEDICAL DEFINITION**

Depression has been defined as, 'A mental state characterised by excessive sadness' (Martin, 1998). Depressed mood is insufficient alone to justify the diagnosis of depression. Depression is a syndrome and not a symptom and hence several symptoms are required before depression is diagnosed and treatment commenced. Psychological symptoms include depressed mood, loss of enjoyment of life, anxiety, worthlessness or guilt and suicidal thoughts. Examples of biological symptoms are early morning awakening, lack of energy, poor appetite, loss of libido, constipation and menstrual disorders. However, atypical features may also be present, including increased sleep agitation, hypochondria, cancer phobia and atypical pain.

# **1.1.2 CLASSIFICATION OF DEPRESSION**

# 1.1.2.1 Depression as a mental health disorder

Depression is classified as a mental health disorder (Sartorias and Janca, 1996). Mental health disorders have been divided into psychotic and neurotic classes (Jenkins et al, 1997) In neurotic disorders insight remains intact, whereas delusions and distorted thinking are likely to be present in psychosis. Depression and anxiety are classified as neurotic disorders. The distinction between depression and anxiety can be blurred but depression is retrospective whereas anxiety is anticipatory.

# 1.1.2.2 Subclassifications of depression

Depression has been classified according to different criteria. In the past depression was considered as either reactive, in response to a particular event or series of events or endogenous, occurring with no apparent precipitating factor. More recently, depression has been classified as mild, moderate or severe (World Health Organisation, 1993). In addition, depression has been identified as being either unipolar or bipolar (Andreasen and Black, 2001). The former presents as depression alone whereas the latter will be seen as a rapid cycling between mania and depression. Bipolar depression can include psychotic features and may be more difficult to attribute to specific causes than unipolar depression.

## **1.1.3 DIAGNOSTIC INSTRUMENTS**

A number of tools have been developed to aid in the diagnosis of depression and have been used by clinicians and researchers. These include diagnostic guidelines, clinical interview schedules and symptom scales.

The World Health Organisation (1993) has published international guidelines for diagnosis known as the, 'International Classification of Disease 10 Symptoms of Depression' (ICD-10). To fulfil the criteria for depression, patients must present with:

At least 2 (mild/moderate depression) or 3 (severe depression) of: Depressed mood Loss of interest and enjoyment Increased fatiguability and at least 2 (mild), 3 (moderate) or 4 (severe) of: Reduced concentration and attention Reduced self-esteem and self confidence Ideas of guilt and worthlessness Bleak and pessimistic views of the future Ideas or acts of self harm or suicide Disturbed sleep Diminished appetite. In addition to the ICD-10, another commonly used set of criteria is the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)(The American Psychiatric Association, 2000). Clinical interview schedules have been developed using the ICD-10 and DSM diagnostic criteria, for example the Schedule for Affective Disorders and Schizophrenia (SADS)(Endicott and Spitzer, 1978).

In addition to clinical measures, symptom scales have been developed to detect or measure the severity of depression. Symptom scales consist of a series of statements which require a ranked numerical or categorical response. The psychiatric symptom scales which have been developed differ from each other in a number of respects, including their purpose, contents and method of administration. Some scales are able to detect depression whereas others are only capable of measuring severity once depression has been diagnosed. The latter are particularly useful for measuring the impact of treatment and have been used in clinical trials. Furthermore, some scales, such as the General Health Questionnaire (Goldberg, 1978) detect a range of mental health problems including depression, anxiety and psychosis whereas others, such as the Beck Depression Inventory (1961), are specific indicators of depression. In terms of their content, some instruments such as the Zung's Self Rating Depressive Scale (1965) rely on the clinical diagnostic criteria most commonly used to diagnose depression whereas others focus on more specific aspects, for example the Montgomery Asperg Depression Rating Scale, which is particularly orientated towards psychic symptoms. The methods of administration can involve self report by the patient or an observer's perceptions of the patient's mental condition.

#### 1.1.4 DIFFICULTIES ASSOCIATED WITH THE DIAGNOSIS OF DEPRESSION

Due to a coexistence of other conditions with depression, a specific diagnosis of depression may be difficult to obtain. Anxiety and depression have been shown to frequently coexist (Lecrubier and Hergueta, 1998) and researchers have referred to, 'mixed anxiety/depressive disorder' (Jenkins et al. 1992) or simply classified the 2 conditions together (Lloyd et al. 1996). Although depression is a neurotic disorder, psychotic features may be present, causing further diagnostic difficulties. The term depression includes a wide range of depressive conditions.

There is increasing reference to depression as a continuum of pre-clinical and clinical states. This means that mild, moderate and severe depression are not distinct conditions but that one is developed from the other. It follows that before the

diagnostic criteria for depression is met there will be a sub-therapeutic state of depressive symptoms. It may be difficult to place a numerical value on where the line is drawn and a diagnosis of depression is made. All scales will have a score above which a patient is considered to be depressed but quality of life may be affected before this stage is reached. Identifying patients at this early stage may assist in the prevention of the development of clinical depression.

#### **1.2 Epidemiology of depression**

Section 1.2 describes the prevalence of depression and reports associations between depression and socioeconomic characteristics. Much of the discussion in section 1.2 relates to Britain. However, indications are also given that similar trends occur internationally (World Health Organisation, 2001). Methodologically, it is difficult to examine trends in psychological morbidity over time and across locations because different studies have used different diagnostic criteria and geographical groups. The British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997) was commissioned by the Department of Health, to give a national picture of the prevalence, severity and duration of mental health disorders and their accompanying disability. A random sample was recruited, using the Postcode Address File (the main address database for Royal Mail, containing all known UK Postal Addresses and their associated Postcodes and Delivery Point Suffix information) as a sampling frame (n= 10108, response rate 79%). The sample was stratified according to area. The British Psychiatric Morbidity Survey is frequently quoted in section 1.2 as it provides nationwide cross-sectional data.

Depression has not been reported to occur in response to one particular circumstance alone. Rather the aetiology is a complex result of many interwoven past and present events as well as genetic factors. The outcomes of past experiences and behaviours will affect the response to present experiences. Therefore, the epidemiology of depression is complex. Although it is possible to statistically adjust for the interrelation of different factors associated with depression, it would be very difficult to account for all the circumstances involved. It is also hard to identify which are the causes and which the effects. There may be a vicious circular relationship where aetiology and illness each precipitate each other. Another possible relationship is that an independent variable precipitates aetiology and illness. There is still scope for further research in the area of the epidemiology of depression.

#### 1.2.1 PREVALENCE

## 1.2.1.1 Prevalence in Britain

In 1993 the British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997) found that 7.7% of adults between 16 and 64 years in Great Britain had suffered from mixed anxiety and depressive disorder in the past week and that 2.1 %

had suffered from a depressive episode as diagnosed by the Revised Clinical Interview Schedule (Lewis et al. 1992). Just under 1% of patients reported having suicidal thoughts in the past week. However, only one-fifth were receiving antidepressant medication and one-sixth psychotherapy. One in 4 people with a neurotic disorder had not consulted anyone about their health, usually because they thought nobody could help. Even amongst those who did present to their general practitioner, diagnosis was made in only 50% of cases. However only 5% of patients volunteered psychological problems as the main reason for the visit which may have made diagnosis more difficult. The General Practice Research Database on consultations, prescriptions and referrals over the whole age range of the population indicated that the prevalence of treated anxiety/depression in England and Wales in 1996 was 3.6.% for men and 8.2% for women (Department of Health, 1998a). The prescribing of antidepressant medication had increased by 19% in men and 15% in women between 1994 and 1996. The General Practice Research Database also found that general practitioners view mental health as the second most common reason for a primary care consultation. Figures regarding treated depression (Department of Health, 1998a) were lower than those found by the British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997). The under-recognition of depression will be discussed further in chapter 2.

#### 1.2.1.2 International prevalence

In 2000, the one-year international period prevalence of depression amongst adults was estimated to be 5.8% for men and 9.5% for women (World Health Organisation, 2001). The World Health Organisation (2001) is predicting that depression will be the second biggest cause of disease burden worldwide by 2020 and that in the developed region it will be the highest ranking cause of burden of disease.

# 1.2.2 Associations between gender, age and family unit type with Depression

Depression has been found to be higher amongst women than men (World Health Organisation, 2001; Jenkins et al. 1998; Jenkins et al. 1997). This is an international finding (World Health Organisation, 2001). With regards to the United Kingdom, The British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997) showed that women were twice as likely to suffer from depression as men. Research has suggested that this higher prevalence rate amongst women only exists in certain age groups (Angold and Costello, 1998; Bebbington et al. 1998). Before the age of puberty prevalence of depression is similar in boys and girls (Angold and Costello, 1998). In addition, The British Psychiatric Morbidity Survey found a higher prevalence amongst women until the age of 55, after which men had higher rates (Bebbington et al. 1998). This was due to a reduction in the prevalence of depression amongst women of this age group, rather than an increase in prevalence amongst men. The higher prevalence of depression amongst men compared with women after the age of 55 persisted after adjustments were made for marital status, employment status and having children living at home. The exact point where the reversal occurs was not clear from the analysis because the ages of 55-64 were banded together. An upper age reversal has not been found in all studies. The part that sociological factors, such as differences in the roles performed in society between the genders, as opposed to biological factors, such as hormonal differences, play in trends regarding gender and depression are unknown although these factors have led to much discussion (Bebbington, 1998; Angold and Costello, 1998).

According to The British Psychiatric Morbidity Survey the overall prevalence of depression increases until the age of 55 and is then significantly reduced (Jenkins et al. 1998; Jenkins et al. 1997). However, international studies have found conflicting results regarding the prevalence of depression in people aged over 65 (World Health Organisation, 2001). Divorced, widowed and separated respondents have been shown to have a higher prevalence of neurotic disorder (Jenkins et al. 1998; Jenkins et al. 1997). The higher rate persisted after adjustments for other sociodemographic variables.

#### **1.2.3 ASSOCIATION BETWEEN SOCIOECONOMIC FACTORS AND DEPRESSION**

Socioeconomic status, employment status, accommodation and general standard of living have all been shown to have an association with the prevalence of depression (Jenkins et al. 1998; Jenkins et al. 1997; Weich and Lewis, 1998a; Weich and Lewis 1998b). The British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997) measured social class according to the Registrar General's classification and found that there was a social class gradient, with those in the manual groups having a higher rate of neurotic disorder than those in non-manual occupations. The higher rate persisted after adjustment for age, sex, urban or rural residence and family type. Unemployed persons were found to be more than twice as likely to suffer from neurotic disorders than those in employment. The sex ratio of women to men, was largest in the unemployed group. The survey also found that the economically inactive, such as housewives, students, retired and the permanently ill had higher rates of neurotic disorder. However, as the economically inactive were all banded together in the analysis it is difficult to identify differences between divergent subgroups. Those who rented accommodation had significantly higher rates of neurosis than those who were owners even after adjustments for other sociodemographic variables. Neurosis was highest of all amongst the homeless.

Other research findings agree with the results of the British Psychiatric Morbidity Survey regarding associations between standard of living and depression (Weich and Lewis, 1998a; Weich and Lewis 1998b). A large cross sectional survey was conducted across England, Wales and Scotland (Weich and Lewis, 1998b), using a randomised sample stratified according to postcode sectors (n = 9064, response rate =88%). Weich and Lewis (1998b) found that not saving from income, low household income, structural housing problems, living in rented accommodation and not having access to a car or van were independently and significantly associated with prevalence of common mental disorders as defined by the General Health Questionnaire (Goldberg, 1978) (see section 1.1.3). The subjects were reinterviewed 12 months later (n=7726, follow-up rate = 85%) (Weich and Lewis 1998b). Poverty and unemployment were significantly associated with nonparticipation in the second interview. However, a large follow-up rate was achieved and financial stress was not associated with non-participation in the second interview, making it unlikely that loss of patients had a large effect on the findings. It was found (Weich and Lewis, 1998a) that financial stress, that is subjects' own perception of their economic situation, was significantly associated with the onset and maintenance of common mental disorders as defined by the General Health Questionnaire (Goldberg, 1978). This significant association persisted after adjustments for patients' actual level of poverty and for unemployment (in addition to adjustments for age, sex, social class, dependent children, education, ethnic group, number of physical problems and region of residence).

#### **1.2.4 ASSOCIATION BETWEEN GEOGRAPHICAL LOCATION AND DEPRESSION**

A complex relationship exists between location and the rate of neurosis. Research has shown that the rate of neurosis is higher in some parts of a country than in others (Lewis and Booth, 1992). However, such studies have also shown that geographical location is not an independent factor but is due to trends in socioeconomic factors in

different locations. The Health and Lifestyle Survey (1985) used a random sample of individuals in the United Kingdom, stratified for electoral wards and regions. Analysis of data collected from this survey (n = 9003, response rate 54%) found that there were significantly higher rates of mental morbidity, as defined by the General Health Questionnaire, in the north compared with the south of England, (Goldberg, 1978) but that differences in rate no longer occurred when adjustment was made for other factors such as sex, age, marital status, social class and urban areas with open space (Lewis and Booth, 1992). In a later analysis using a multilevel model, Duncan et al (1995) found that variance in psychiatric morbidity was due to individual effects rather than electoral wards or regions. However, individuals living in more urbanised areas were found to have higher scores on the General Health Questionnaire, that is higher levels of psychiatric morbidity. In contrast to the results of The Health and Lifestyle Survey (1985), The British Survey of Psychiatric Morbidity (1993) found no significant difference between the rate of psychiatric morbidity in the north and south of England (Jenkins et al. 1998; Jenkins et al. 1997). A possible reason that a difference was not observed between the different parts of England is that The British Psychiatric Morbidity Survey was performed at a time when there were less variation in unemployment rates across the region than The Health and Lifestyle Survey. The contrast between the results of The Health and Lifestyle Survey and The British Psychiatric Morbidity Survey therefore supports the hypothesis that it is economic factors which determine geographical patterns. However, in agreement with The Health and Lifestyle Survey, The British Psychiatric Morbidity Survey found that those living in urban locations were one and a half times as likely to develop mental disorders than those living in rural/semi rural places, even after adjustment for age, sex, social class, family type and employment status. It may therefore be surmised from these surveys, that the distinction between urban and rural dwellings is more likely to be associated with the prevalence of mental disorder than other locality factors.

The studies discussed in the paragraph above, demonstrate national differences but results may be different when looking at international trends because other cultural and value differences may be important.

Focussing on London, the King's Fund (1997) identified specific issues which need to be considered, concerning mental health (Johnson et al. 1997). Rates of psychiatric illness have been reported to be higher than in any other large city in England. There is a shortage of secondary care services and the quality of primary care had been found to be variable. The report made many recommendations, in order to improve mental health services in London. The need for increased funds was identified and has now been actioned (Dean, 1998).

#### 1.2.5 ASSOCIATION BETWEEN ETHNIC GROUP AND DEPRESSION

Previous research suggests that the prevalence of depression is higher amongst people from ethnic minority groups but the findings have been inconclusive (Jenkins et al. 1998; Jenkins et al. 1997o; Nazroo, 1997). Minority groups who have been researched include Asian, Oriental, Afro-Caribbean and Irish. In the British Psychiatric Morbidity Survey (Jenkins et al. 1998; Jenkins et al. 1997), both psychotic and neurotic disorder appeared higher in Asian and Afro-Caribbean ethnic groups than 'Whites' but as the survey was nationwide, the proportion of ethnic minorities was too small to demonstrate statistically significant differences. However, after adjustment for other variables such as age, family type and social class, an association between psychiatric morbidity and ethnic group was no longer apparent. The National Fourth Survey of ethnic minorities (Nazroo, 1997)(n= 2867 White, 1205 Caribbeans, 3777 African Asians) was carried out in 1995 as a followup to the British Psychiatric Morbidity Survey and found that rates of depression varied amongst different ethnic groups. Response rates for the Whites, Caribbeans and South Asians were 46%, 33% and 42% respectively. Validation testing of the Revised Clinical Interview Schedule (Lewis et al. 1992) (which was used to measure the prevalence of depression) with Present State Examination (Wing et al. 1974) suggested that the instrument was not valid with the South Asian group. Therefore results from the South Asian group need to be treated with caution. According to the results from the Revised Clinical Interview Schedule, Caribbeans had significantly higher rates of depression than Whites, whereas the results of South Asians were significantly lower. Multi-variate analysis showed that the difference in prevalence of depression between the Whites and Caribbeans was no longer significant when adjusted for age, gender and marital status. For the South Asian group, when adjustment was made for age of migration to Britain, there was no significant difference in the prevalence of depression. The authors suggested that the factors contributing to an individual's risk of mental illness, may make important contributions to ethnic variation in risk of mental illness. However, the association between demographic variables and risk of illness varied among ethnic groups, implying that the relationship is complex. With regards to the Irish, Bracken et al (1998) have analysed data about hospital admissions in England and Wales from

mental health enquiries between 1971 and 1981 (Cochrane and Bal, 1987) and have found that men and women born in the Republic of Ireland were 2.5 times more likely to be admitted to hospital with depression than those born in England. Bracken et al (1998) suggested that the mental health needs of people from the Republic of Ireland are often overlooked in surveys because they are simply classified as White.

## 1.2.6 ASSOCIATION BETWEEN STRESSFUL LIFE EVENTS AND DEPRESSION

Major adverse occurrences in past and present situations have been found to be associated with high rates of depression (World Health Organisation, 2001). Examples of these are bereavement, marital problems, sexual abuse, work related problems, physical illness in oneself or a member of one's family, conflicts and natural disasters. The relative importance of stressful events themselves compared with the cognitive processes involved in dealing with them is unclear. However, post-disaster support has been found to reduce the likelihood of developing depression as a response to conflicts and natural disasters (World Health Organisation, 2001).

It can be concluded that the prevalence of depression is higher amongst women, the lower social classes and those who have experienced stressful life events, after adjustments for other factors. Age, ethnic group and geographical location may be associated with depression but findings have not been conclusive.

## **<u>1.3 Treatment of depression</u>**

The therapies which are used for the treatment of depression are described in section 1.3. While the emphasis of this thesis concerns patients' decisions about the use of antidepressant medication, pharmacotherapy is only one of a range of available treatments. Other available therapies are also briefly discussed, as beliefs about medication have been compared to beliefs about other therapies for depression (see section 2.3.10.).

## 1.3.1 PHARMACOTHERAPY

Medication which is used in the treatment of depression includes tricyclic antidepressants, selective serotonin re-uptake inhibitors, monoamine-oxidase inhibitors and newer types of medication, for example venlafaxine. The medical properties of antidepressant medication are summarised below in terms of pharmacology, onset of action, frequency of administration and adverse drug reactions.

# 1.3.1.1 Tricyclic antidepressants

Tricyclics are amongst the oldest antidepressants which have been prescribed by doctors and are still in use in the UK (Andreasen and Black, 2001). Examples include amitriptyline, dothiepin, lofepramine and mianserin (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Although termed 'tricyclics' because of their ring structure, some of the newer agents in the class actually have a tetracyclic structure. The mode of action of tricyclics is complex and is thought to involve changes to receptors over time (Stoudemire, 1998). Research has indicated that tricyclics inhibit the uptake of monoamines, such as noradrenaline, in the central nervous system (Stoudemire, 1998). Typically, there is a 2 to 4 week lag period before onset of action occurs (Stoudemire, 1998). This lag period is thought to affect compliance due to the fact that patients are unable to associate medication use and recovery (Demyttenaere, 1997). However, the fact that most tricylics have a long half life and can be given as a once daily dose is thought to increase compliance (Demyttenaere, 1997).

A vast number of adverse drug reactions can occur with tricyclics. These are important in terms of quality of life and patients' perceptions of therapy. The structure of most tricyclics is similar to that of cholinergic compounds and many act as antagonists at cholinergic receptor sites, that is tricyclics bind to cholinergic receptors preventing cholinergic compounds from doing so (Andreasen and Black, 2001). This leads to a range of anti-cholinergic effects such as urinary retention, dry mouth, constipation and blurred vision (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Patients tend to develop tolerance to these effects over the first couple of months (Andreasen and Black, 2001). It follows that in the initial stages of treatment, when efficacy is at its lowest, the adverse drug reaction profile is greatest. Anti-cholinergic effects can be reduced by starting at a low dose and which is gradually increased (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). However this slow dosage adjustment will result in a greater time interval between beginning medication and a therapeutic effect being reached (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Another common adverse drug reaction of tricyclic antidepressant medication is drowsiness, which is caused by antagonistic action at the H1 receptor site (Andreasen and Black, 2001). This may be an advantage or disadvantage, depending on the patient's sleeping patterns. Some tricylics, such as amitriptyline, cause a much greater amount of sedation than others. Most of the agents belonging to the tricyclic group of antidepressant medication are also cardiotoxic. Cardiotoxicity is a particular problem in the elderly, who are more prone to postural hypotension, and in patients with pre-existing cardiac disorders (Andreasen and Black, 2001). Cardiotoxicity is an important consideration when prescribing therapy to patients with suicidal ideation as over dosage can have fatal consequences (Kaplan and Sadock, 1996). Lofepramine has less cardiotoxic effects and is deemed to be a safer option in patients at risk of suicide (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). All tricyclics can lower the seizure threshold and must be used with caution in patients suffering from epilepsy (Kaplan and Sadock, 1996). Loss of libido is an adverse drug reaction that can be very distressing in depressed patients who may already be experiencing sexual dysfunction as part of the disease process. Weight gain can also be experienced in some patients. Mianserin has a unique adverse drug reaction profile. It does not cause any anti-cholinergic effects but can cause blood dyscrasias which can be dangerous (British Medical Association and Royal Pharmaceutical Society of Great Britain). Careful monitoring for symptoms of neutropenia, such as sore throat and fever is deemed essential (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Unpleasant reactions such as nausea, vomiting, giddiness, insomnia and panic, anxiety and extreme motor restlessness may occur if

tricylics are withdrawn suddenly (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

#### 1.3.1.2 Selective Serotonin Re-uptake Inhibitors

Selective Serotonin Re-uptake Inhibitors (SSRIs) are a newer group of antidepressant medication than the tricyclics. The first SSRI to be used in treatment was zimelidine in 1981. Zimelidine was withdrawn due to toxicity but others have been marketed since 1987 including: fluoxetine, fluvoxamine, paroxetine, citalopram and sertraline (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). The SSRIs selectively block serotonin re-uptake into nerve endings at synapses (Kaplan and Sadock, 1996). SSRIs therefore increase serotonin levels in the central nervous system. Serotonin is thought to affect behavioural states such as sleep, appetite, aggression and anxiety. For the majority of the agents belonging to this group the same period of time is necessary to achieve onset of action as for tricyclics. However, data from clinical trials has suggested that citalopram has an onset of action of one to 2 weeks (Stahl et al. 2001). A trial specifically designed to test onset of action is needed to substantiate the indications that have arisen from clinical trials regarding the faster time of onset of citalopram (Leon, 2001; Stahl et al. 2001). Like the tricyclics, most SSRIs are given in once daily dosages (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

The SSRI group of antidepressant medication is generally considered to be less toxic than tricyclic antidepressants but distressing adverse drug reactions can still occur (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Gastro-intestinal effects are commonly reported but tend to wear off over time (Andreasen and Black, 2001). Again, though, they are at their worst during the period of time prior to efficacy occurring. These gastro-intestinal effects can be reduced be taking tablets after food. Sedation or insomnia can occur with the SSRI group depending on the agent chosen and the individual's patient response. Timings of medications can subsequently be changed accordingly. Sexual dysfunction is another common adverse drug reaction (Andreasen and Black, 2001). This effect is reported to be more common in men but it has been reported that less data have been collected for women (Fyre and Berger, 1998a). Cyproheptadine has been used for the treatment of sexual dysfunction but concerns have been raised that it may antagonise the antidepressant effect (Fyre and Berger, 1998a). Reducing the dose of SSRI has also been suggested but, again, a balance will need to be maintained

between efficacy and non-toxicity (Fyre and Berger, 1998b). SSRIs are reported to have few cardiotoxic effects and therefore be safer in overdose than the tricyclics (Andreasen and Black, 2001). However, there have been anecdotal accounts to the contrary. Citalopram overdose has been reported to be responsible for 6 deaths (Ostrom et al. 1996). Additional evidence that cardiac effects can occur is that postural hypotension was observed in a patient taking paroxetine (Andrews, 1998). It has been stated that although suicidal ideation has been linked with some SSRIs, causality has not been established (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Convulsions have been reported with SSRI use and therefore they must be used with caution in epilepsy (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Abrupt withdrawal of SSRIs has been associated with headache, nausea, paraesthesia (pins and needles), dizziness and anxiety (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

#### 1.3.1.3 Monoamine-oxidase Inhibitors

The mood elevating effect of Monoamine-oxidase Inhibitors (MAOIs) was first noted in 1951 following the introduction of iproniazid for the treatment of tuberculosis (Stoudemire, 1998) ). Iproniazid was first used in the treatment of depression in 1957. Currently available MAOIs are isocarboxazid, phenelzine, tranylcypromine and moclobemide (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Like the tricyclics, MAOIs are thought to work by causing monoamine depletion but they do this by acting as enzyme inhibitors rather than reuptake inhibitors at nerve endings. Most of the MAOI group are irreversible3 inhibitors but moclobemide is a reversible inhibitor. Moclobemide is also more selective than the other MAOIs, inhibiting MAO type A but not type B (this is claimed to reduce interactions (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000) (see later in this section). A similar onset of action has been observed as for the tricyclics (personal communication, Maudsley Hospital Information Dept. 2002).

Patients are limited when using MAOIs. A considerable difficulty is the interaction which occurs with tyramine containing food substances (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Tyramine causes the release of noradrenaline into the circulation leading to constriction of blood vessels. Normally monoamine-oxidase enzymes in the gastro-intestinal tract and the liver

inactivate tyramine in foods, preventing it reaching the systemic circulation. Patients receiving an MAOI are unable to inactivate tyramine (Kaplan and Sadock, 1996). This effect results in over-stimulation of the cardiovascular system leading to increased blood pressure and a potentially fatal hypertensive reaction (Kaplan and Sadock, 1996). Tyramine is found in many different foods, including mature cheese, yeast extracts, smoked or pickled animal products, red wine and fermented meat or soya bean products (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). This imposes a strict constraint on patients and dietary restrictions need to be taken into careful consideration when commencing treatment. In addition many over the counter cough medicines contain sympathomimetics. As sympathomimetics can also cause a hypertensive crisis they should be avoided (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Interactions with food and other medication occur with moclobemide to a lesser extent than with the other MAOIs but caution is still necessary (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

Other adverse reactions of MAOIs include postural hypotension, sexual dysfunction, sleep disturbances, weight gain, anti-cholinergic effects and neuromuscular effects (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). The anti-cholinergic effects have however been reported to be minimal (Andreasen and Black, 2001). The timing of adverse drug reactions varies. Some, such as sexual dysfunction, are worst at the start of treatment whereas others, such as postural hypotension, occur about 3 to 4 weeks after treatment starts. Adverse drug reactions may be lessened by dose reduction. Unpleasant reactions on withdrawal are similar to those of the tricyclics and treatment needs to be stopped slowly (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). An interval of 2 to 3 weeks is needed between stopping MAOIs and commencing other antidepressant medication (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000), which results in a period of time where patients are not receiving therapy.

#### 1.3.1.4 Newer medications

Some recently introduced antidepressant agents are venlafaxine, nefazodone, mirtazapine and reboxetine. They all have different modes of action.

Venlafaxine potentiates neurotransmitter activity in the central nervous system by

inhibiting re-uptake of serotonin and noradrenaline (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Data from clinical trials have suggested an onset of action of between one and 2 weeks (Leon, 2001). However as with citalopram, more evidence is needed to establish this finding (Leon, 2001; Stahl et al. 2001). Venlafaxine is available in a slow release preparation and can therefore be taken as a once daily dose (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Nausea may be a particular problem while insomnia, dry mouth, drowsiness and headache can also occur. Elevation of blood pressure may occur at high doses. Venlafaxine, however, lacks the sedative and anticholinergic effects of the tricyclic antidepressants. Unpleasant symptoms such as fatigue, nausea and dizziness have been reported to occur on abrupt withdrawal of treatment (Association of the British Pharmaceutical Industry, 2002).

Nefazodone is another newer agent and acts by blocking the re-uptake of serotonin (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). However, nefazodone selectivity blocks serotonin type 2 receptors and inhibits re-uptake of serotonin (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Onset of action has been reported as being similar to the tricyclics (personal communication, Maudsley Hospital Information Dept. 2002). Nefazodone needs to be taken in divided doses (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Sleep disturbances and sexual dysfunction are less than with the typical SSRIs. However, dry mouth, nausea and dizziness have all been reported (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Discontinuation reactions have been reported on abrupt withdrawal of treatment (personal communication, Maudsley Hospital Information Dept. 2002).

Mirtazapine is the first to be licensed in a new group of antidepressant medication called noradrenergic and specific serotonergic antidepressants (Wheatley, 1998). It inhibits noradrenaline and serotonin re-uptake at 3 receptor sites. Onset of action has been suggested to be one to 2 weeks (Leon, 2001) but more evidence is still required (Leon, 2001; Stahl et al. 2001). Like nefazodone, it has selective 5HT1 action and has been reported to have a lower incidence of some adverse drug reactions (Fyre and Berger, 1998b). However it can cause sedation with initial treatment. There is also a rare incidence of blood dyscrasias (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

Reboxetine selectively inhibits noradrenaline uptake and has recently been introduced for the treatment of depressive illness (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Onset of action has been reported to be similar to the tricyclics (personal communication, Maudsley Hospital Information Dept. 2002). It is taken in divided doses (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). A number of adverse drug reactions have been associated with its use including insomnia, sweating, dry mouth, constipation and tachycardia (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Discontinuation reactions have been reported with abrupt withdrawal of treatment (personal communication, Maudsley Hospital Information Dept. 2002).

#### 1.3.1.5 Other agents

The agents described in section 1.3.1.5 have been used to augment the effect of other antidepressant medication.

Pindolol is a beta blocker which has been used in depression although it is unlicensed for this purpose. Pindolol has been found to shorten the time needed to onset of action during SSRI treatment (Blier, 2001). It is given in divided doses personal communication (personal communication Maudsley Hospital Information Dept. 2002). Adverse drug reactions such as cardiac effects and gastro-intestinal effects may occur (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

Tryptophan is an amino acid which is indicated for patients who are resistant to other forms of treatment (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Onset of action of antidepressant therapy is usually slower in such patients and little information is available regarding the specific onset of action of tryptophan (personal communication Maudsley Hospital Information Dept. 2002). Tryptophan is restricted to use by hospital specialists as Eosinophilia-myalgia syndrome has been associated with its use (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). This condition has been associated with a high eosinophil count (a type of white blood count) and debilitating muscle pain. Specific information concerning the withdrawal of tryptophan is not reported in the BNF (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000) or Medicines Compendium (2002) and was not available from The Maudsley Hospital. However, there is a general recommendation (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000) that antidepressant medication is withdrawn slowly.

Lithium is licensed for use in bipolar depression but is recommended for treatment of any type of depression which has been resistant to other medication (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Lithium has a very narrow therapeutic index and careful monitoring is required. Patients also need to be careful regarding the amount of salt they use in their diet as large changes will affect lithium levels. Many interactions occur between lithium and prescribed and over the counter medication. While there is no clear evidence of withdrawal reactions, abrupt discontinuation of treatment has been reported to increase the risk of relapse (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

A symptom of depression is sleep disturbance (World Health Organisation, 1993). Benzodiazepines are occasionally used in patients with severe insomnia to try to reestablish sleeping patterns. However there is concern about overuse and addiction of benzodiazepines and they are only recommended for short term use (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). As already noted, some antidepressant medication can cause insomnia and a change in timing or in the medication used may be a more appropriate option.

## 1.3.1.6 Choice of antidepressant medication

The majority of the antidepressants discussed in section 1.3 have been reported to have similar efficacy in randomised controlled trials and choice will be made according to individual response and adverse drug reaction profile. The National Prescribing Centre (2000) has recommended that choice be based on patient factors such as likely tolerability, risk of suicide and previous treatment response. Treatment choice will also be affected by the individual preferences of the healthcare professionals concerned. It is recommended that SSRIs are used as first line agents in patients with cardiac problems or suicidal tendencies (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). However, there is a debate as to whether SSRIs should be used as first line treatment in all patients. Although efficacy is reported theoretically identical for tricyclics and SSRIs (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000), effectiveness of tricyclics may be reduced in practice by increased drop out rates from treatment and use of sub-therapeutic doses. In a randomised controlled trial (n =621) patients prescribed SSRIs were significantly less likely to discontinue medication within one month, due to adverse drug reactions, than those prescribed tricyclics. The use of SSRIs is increasing. Donoghue and Tylee (1996a; 1996b) examined 3 independent general practice databases and found that although more prescriptions were issued for tricyclic antidepressants than SSRIs, the difference greatly reduced between 1993 and 1995. Newer medication is a treatment option where first line treatments have failed (National Prescribing Centre, 2000). MAOIs are reported to be particularly effective in depression with atypical features (National Prescribing Centre, 2000). Venlafaxine, at a dose of 150mg or more, may be more effective than SSRIs for major depression of at least moderate severity (British Medical Association and Royal Pharmaceuotical Society of Great Britain, 2000).

Combination therapy has been used, under specialist supervision, where individual agents have failed to have adequate effects. However, care is required because many interactions between antidepressants may occur. Combinations of tricyclics and MAOIs are considered dangerous but are used by some psychiatrists (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). The combination of tricyclics and venlafaxine is also considered to be very toxic. It is generally considered better to try to change to different groups of agents or increase the dosage of a single agent before resorting to combination therapy (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000).

In 1992, a consensus statement concerning the management of depression was produced by the Royal College of Psychiatrists and General Practitioners. It states that an advantage of the tricyclics is that they are cheap but that newer agents may be beneficial where there is a risk of suicide or where adverse drug reactions are likely to be problematic. The National Institute for Clinical Excellence have been commissioned to produce guidelines by the year 2003.

## 1.3.1.7 Complementary medicines

In addition to conventional antidepressant medication, a range of both herbal and homeopathic treatments are available. Many complementary medicines have been recommended for use in emotional conditions but there is little clinical evidence to support this application. However, although clinical trials with herbal remedies are
viewed as problematic, there has been increasing evidence to support the effectiveness of St John's Wort in the treatment of depression. Newall et al (1998) have documented the properties and usages of St John's Wort. The chemistry of St John's Wort is complex and many structurally diverse constituents have been identified. There are likely to be many different constituents present which will interact with each other. It is therefore difficult to identify associations between individual constituents and effect, although the issue has been addressed in animal studies. Newall et al (1998) identified human studies in which St John's Wort had been used in combination therapies making it difficult to assess its individual efficacy. In addition, different batches were likely to contain different constituents and to vary in activity. Reliability in studies is therefore very difficult to obtain. A review of studies into the efficacy of St John's Wort (Linde et al. 1996) has determined that it has efficacy over placebo in the treatment of depression. Outcomes were measured for a maximum of 8 weeks and the number of patients in the studies ranged from 49 to 162. The authors suggested that standardised longer term studies are necessary to clarify the place of St John's Wort in treatment. Recently, a larger randomised controlled trial (n=324) concluded that St John's Wort was therapeutically equivalent to imipramine in the treatment of mild to moderate depression (Woelk, 2000). However only short term outcomes (up to 6 weeks) were measured. In contrast, a trial in patients with major depression (n=200) did not show St John's Wort as having a significant effect when compared to placebo (Shelton et al. 2001). Short term outcomes (8 weeks of treatment) were again used. A recent meta analysis concluded that St John's Wort is an effective antidepressant (Whiskey et al. 2001). The number of patients in the studies ranged from 40 to 324. The meta analysis produced the same results when both lenient and more stringent inclusion criteria for trials were applied. However, none of the studies assessed outcome beyond 8 weeks of treatment and do not therefore assess the use of St John's Wort as a longer term therapy. Trials investigating the effectiveness of St John's Wort versus placebo and equivalence trials versus conventional antidepressant medication were included. The authors noted only 2 equivalence studies compared St John's Wort with an SSRI. Therefore, more studies are necessary to investigate whether St John's Wort is as effective as SSRI treatment.

Alongside the rising evidence of the effectiveness of St John's Wort, there has also been increasing recognition of the interactions which may occur between St John's Wort and other medication (Yue et al. 2000; Ruschitzka et al. 2000; Piscitelli et al. 2000; Ernst, 1999) and much publicity has been associated with this. In addition adverse drug reactions which have been reported include gastro-intestinal effects, headaches, dry mouth, dizziness, restlessness (Whiskey et al. 2001) and photosensitivity (Newall et al. 1998).

#### 1.3.2 NON-PHARMACO THERAPY

A range of non pharmacological approaches have been used in the treatment of depression including psychological therapy, electroconvulsive therapy, phototherapy colour and art therapies and relaxation therapy. These are described briefly below.

#### 1.3.2.1 Psychological therapy

As with pharmacotherapy, psychological therapies are diverse. A range of different methods and personnel are available and the treatment chosen will depend on patient and practitioner preference. Approaches include psychodynamics, behaviour therapy, cognitive modification and humanistic counselling. Therapy may be carried out on an individual basis or maybe group or family orientated. Many of the therapists concerned are trained psychologists or counsellors but there is no legal limitation to using the titles, 'psychotherapist' or 'counsellor' and some practitioners may have had no formal training. For further information regarding these psychological approaches to treatments, review papers have been published (Richardson, 1997).

#### 1.3.2.2 Electroconvulsive therapy

Electroconvulsive therapy involves passing a brief electrical pulse through the brain between 2 electrodes attached to the skull of an anaesthetised patient. This induces changes to an electroencephalogram which are characteristic of a major epileptic seizure. A muscle relaxant is used to prevent a physical fit. Electroconvulsive therapy affects brain amines and receptor sensitivity in a way similar to antidepressant medications.

Electroconvulsive therapy is a very controversial treatment and is considered to be inhumane by some people. However it is also argued that it may be life saving in suicidal patients as it is immediately effective, unlike all other therapies. It is also used in refractory patients for whom all other treatments have failed. It has few adverse effects but headache and confusion sometimes occur on recovering consciousness. There are also concerns about long term brain damage which has resulted in treatment being generally limited to 12 sessions.

#### 1.3.2.3 Phototherapy

Phototherapy may be used in a particular group of depressed patients who suffer from seasonal affective disorder. They become depressed during winter time due to the lack of sunlight. Standard clinical treatment is 2 hours of artificial sunlight, which is continued throughout the winter season.

#### 1.3.2.4 Other treatments

Many other treatments exist which may be explored by patients in an effort to relieve their depression. These include colour therapy, art therapy and relaxation techniques. In conclusion, available treatments are wide ranging and clinical evidence does not distinguish between the effectiveness of different therapies. Therefore treatment choice will be influenced by the individual preferences of patients and practitioners and individual's medical histories.

# CHAPTER 2CURRENT ISSUES CONCERNING DEPRESSION AND THE USE OFANTIDEPRESSANTS IN PRIMARY CARE: POLITICAL, MEDICAL,<br/>PSYCHOLOGICAL AND SOCIOLOGICAL PERSPECTIVE

Chapter 2 examines issues which are currently prominent in relation to the treatment of depression in primary care with reference to United Kingdom government policy and medical and sociological studies.

# 2.1 Government policy concerning depression and issues relating to service provision

Section 2.1 draws on UK policy documents relating to mental illness and depression that have been published in the last 5 years. The documents will be discussed with reference to their impact on the future development of the role of pharmacists. Health policy relating to partnership between patients and prescribers is discussed in section 2.3.

Depression is a widespread chronic illness which the UK government has recognised as a priority area. Mental health is one of the 4 key areas in the recently published White Paper, 'Saving Lives: Our Healthier Nation' (The Department of Health, 1999a). Government targets for improvement in mortality rates have been set in each of the 4 key areas. The target for mental health is to reduce the suicide rate by at least one fifth by 2010. The Government's initial plans for improving mental health services had been set out in the earlier White Paper, 'Modernising Mental Health Services.'(Department of Health, 1998b). This document identified the development of a National Service Framework for Mental Health to determine service models and national standards. The National Service Framework for Mental Health (Department of Health, 1999b) has subsequently set out 7 national standards for the promotion of mental health and treatment of mental illness. These standards address the areas of mental health promotion, primary care and access to services, effective services for people with severe mental illness, support of individuals who care for people with mental health problems and action necessary to achieve the target of reducing suicides as set out in, 'Saving Lives: Our Healthier Nation.' Each of the 7 standards is supported by service models for implementation. Standards 1 and 7 are general to all healthcare services for patients with mental health problems. Standards 2 and 3 of The National Service Framework for Mental Health relate to the quality of primary mental health care, including access to treatment; whereas standards 4, 5 and 6 relate

to more severe mental illness. Standards 2 and 3 are particularly relevant to this thesis, which seeks to identify patients' perspectives of treatment in primary care. Standard 2 states that any service users who contact their primary health care team should have their mental health needs identified and assessed and be offered effective treatments, including referral to specialist services for further assessment, treatment and care if they require it. Standard 3 states that any individual with a common mental health problem should be able to make contact round the clock with the local services necessary to meet their needs and receive adequate care. The National Service Framework for Mental Health has reported that patients may access health or social services in a number of ways and that help and advice should be easily available and consistent at every point of contact. The document has reported that most of the 4,000 suicides committed each year are attributed to depression and has recommended that assessment and management protocols are implemented throughout primary care. The report also states that presently, patients often feel they that they do not receive adequate information about their antidepressant treatment and that there is scope for healthcare professionals to improve their communication skills.

In primary care, the majority of cases of depression are managed by the general practitioner. One third of general practices in England and Wales have psychological treatment services (Craig and Boardman, 1997).

#### 2.1.1 THE ROLE OF PHARMACISTS IN THE TREATMENT OF DEPRESSION

Section 2.1.1 discusses the potential roles which have been identified for pharmacists in the management of depression. It then describes studies which have investigated pharmacists' current roles and perceived constraints to developing these roles further.

Roles for pharmacists in the management of depression that have been identified include identifying and referring patients suspected of suffering from depression to their GPs, monitoring treatment and advising prescribers, patients and their carers on the appropriate use of medicines (Donoghue, 1998; Wells, 1999). The Mental Health Task Force of the Royal Pharmaceutical Society was set up to look at the pharmacist's role in the management of people with mental health problems (RPSGB, 2000). It included representatives from pharmacy, medicine, nursing, the voluntary sector and social care, all with a specialist involvement in the field of mental health. The Mental Health Task Force has discussed the ways in which pharmacists can contribute to the application of the standards set out in the National Framework for Mental Health. In addition to the roles described by Donoghue (1998) and Wells (1999), other proposals include reducing the stigma attached to mental health, raising awareness and becoming involved in multi-disciplinary activities.

However, constraints have been identified which may be associated with difficulties in developing the pharmacist's role. For example, Bell et al (1997) interviewed 20 pharmacists in a large urban area. A purposive sampling strategy was used to include pharmacists with a range of demographic details such as gender, year of registration and place of work. Barriers which were identified to the provision of pharmaceutical care included lack of time, remuneration, training, pharmacists' perceived roles and lack of promotion of pharmacists by professional bodies. Anderson et al (1998) interviewed 6 pharmacists both before and after they had completed a training programme in health promotion. Perceived barriers to carrying out a health promotion role were lack of time and remuneration, a business versus professional role, design of the pharmacy premises, lack of access to medical histories and legal constraints. The sample size was small and all pharmacists were owners of a single pharmacy, rather than a range of different types of pharmacists being included which may have influenced these findings. Krska et al (2000) conducted semi structured interviews with 16 individuals who represented pharmaceutical organisations in Scotland or provided pharmaceutical care. They found that the 3 factors identified most frequently as being of great importance in constraining the development of pharmaceutical care in community pharmacies were the current remuneration structure for providing pharmaceutical care, pharmacists' clinical knowledge and relationships with general practitioners. Although each of the sample sizes was small and restricted to specific geographical areas, similar issues were identified between studies, which supports the findings' cumulative validity.

Other studies have specifically identified constraints to pharmacists in dealing with patients with mental health problems (Maslen et al. 1996; Gardner et al. 2001). A survey was sent to community pharmacists in one administrative region in the South of England (n= 534, response rate = 44%) to explore the level and nature of their current involvement in the treatment of schizophrenia and perceived constraints to giving advice to patients and their carers (Maslen et al. 1996). The authors reported that there was no significant difference between responders and non-responders. However, this interpretation needs to be treated with caution as data were only

collected for 27% of non-responders. In addition, the findings cannot be considered generalisable to pharmacists in other regions. The study discusses schizophrenia, rather than depression but the findings give some insight into constraints to pharmacists giving advice to people with mental health problems. Responders were found to be significantly less confident in dealing with schizophrenia than asthma, diabetes, hypertension, depression and drug addiction. Differences in the responders' confidence in dealing with depression, in comparison to asthma, diabetes and hypertension were not tested for significance. However the median confidence score for dealing with depression, was identical to the median confidence score for dealing with schizophrenia and drug addiction and was higher than the median confidence score for dealing with asthma, diabetes and hypertension (possible scores ranged from 1, indicating very confident to 5, indicating not confident). Therefore, it is possible that pharmacists were less confident in dealing with depression, than asthma, diabetes and hypertension. Responders were asked to state what they perceived to be the major constraints to giving advice to patients with schizophrenia and their carers. Constraints expressed by respondents most commonly fell into the category of a perceived lack of knowledge, training and experience. In addition, issues were raised related to poor liaison with other healthcare professionals, poor communication skills and practical resource limitations such as lack of time, remuneration and privacy.

Gardener et al (2001) performed a survey to evaluate the communication and barriers to communication between community based pharmacists and antidepressant users. The sampling strategy for pharmacies was initially random but due to a lower than expected response rate (initially 38%) a convenience strategy was subsequently employed. Pharmacists were asked to complete a survey and to distribute 'user surveys' to the first 10 consumers receiving an antidepressant. Overall 24 pharmacists (overall response rate = 48%) and 69 antidepressant user surveys were returned. The authors reported that the response rate for antidepressant users was unknown. Gardner et al (2001) gave no information comparing the responding and non-responding pharmacists. Due to the sampling strategy used and lack of information about non-responders, it is difficult to determine the generalisability of the findings. In addition, the study was carried out in Canada and it cannot be assumed that similar findings would be found in the UK. However, the study gives some insight into the provision of services by pharmacists to antidepressant users and to constraints which currently occur in practice. Pharmacists were asked to rank a list of perceived barriers to effective communication between pharmacists and users

of antidepressant medication (7 pre-specified barriers were included with the option for the respondent to add others). The most commonly first-ranked barrier as perceived by pharmacists was having no private space to discuss personal health issues. In addition, 3 further items were ranked as the greatest barriers to effective communication by some pharmacists. These included being too busy, being uncomfortable discussing antidepressant medication due to the nature of the illnesses associated with their use and perceiving that patients were not interested in such discussions. Antidepressant users were asked a series of closed questions about information they had been given by pharmacists at the time of starting treatment. In the majority of cases antidepressant users reported that they had been asked if they had taken the medication before and that the directions for use were reviewed. In addition, the majority of antidepressant users stated that they were informed of the onset to benefit and of possible adverse drug reactions. However, less than half reported that pharmacists had clarified the purpose of the medication, the usual duration of treatment and risks associated with poor compliance. Antidepressant users were also given the opportunity to add qualitative remarks to the survey. Some identified their pharmacists as having been supportive or having alleviated their concerns. Critical comments included lack of privacy or sensitivity about the subject matter, lack of information sharing and too much emphasis on reimbursement. Therefore, although many roles have been suggested for pharmacists in the area of mental health, some constraints to performing these roles have also been identified.

#### **2.2 Medical Issues**

Section 2.2 discusses findings of studies which have investigated the diagnosis, treatment and outcome of depression in primary care.

#### 2.2.1 MISDIAGNOSIS

Difficulties associated with the diagnosis of depression have been discussed in section 1.1.4. Section 2.2.1 discusses issues relating to the process of obtaining a diagnosis of depression in primary care.

Medical diagnosis relies on the patient seeking help from the healthcare services. The British Psychiatric Morbidity Survey (Jenkins et al. 1998), found that a quarter of people with neurotic disorder, as defined by the Revised Clinical Interview Schedule (Lewis et al. 1992), had not consulted any medical professional about their health, usually because they thought no-one could help. These findings may have been influenced by beliefs concerning depression and the psychological responses to the disease, which will be discussed further in section 2.3.

After the patient has consulted the doctor, the next stage towards obtaining appropriate treatment is for the doctor to recognise cases of depression. A World Health Organisation study (14 countries, n= 5438, response rate not stated) has shown that internationally, only 54% of people with depression as defined by ICD-10 criteria are diagnosed as such by primary care doctors (Lecrubier and Hergueta, 1998), a finding consistent with other studies (Coyne et al. 1995; Paykel and Priest, 1992). The reasons for this low detection rate have been identified and reviewed (Paykel and Priest, 1992; Floyd, 1997). Factors concerning the patient, doctor, the consultation process and the nature of the depression have been observed to be important. For example, Goldberg (1992) found that physicians' observation of patients' verbal and non-verbal behaviours was associated with the likelihood of an accurate diagnosis being made. A complication of diagnosis is that mental disorder rarely presents in the absence of physical symptoms. Some patients somatize i.e. they consult their doctor about their physical problems and do not discuss underlying emotional difficulties. Where both physical and psychological symptoms co-exist, it may be difficult for the doctor to identify a psychological illness. Even when a psychological illness is diagnosed the practitioner will still need to distinguish depression from anxiety and other mental disorders in order to ensure appropriate

treatment. Of 54% of patients suffering from depression identified as having a psychiatric disorder according to ICD-10 criteria in the World Health Organisation study, only 28% were recognised as, 'depressed' or 'depressed and anxious' by their doctor. The study was carried out in 14 different countries and this result may partly reflect differences in the way different classification systems and treatments are used by doctors cross culturally.

Alongside the discussion of under recognition of depression, there has been some concern about over diagnosis. Floyd (1997) has discussed the types of physical illness which may be wrongly diagnosed as depression. An example is hypothyroidism, which often presents with very similar symptoms to a major depressive episode. Depressed mood, loss of interest and sleep and appetite disturbances are common characteristics of both hypothyroidism and depression. Floyd also argued that some medication causes depression as a side effect and that the physician may not identify this as the reason for the patient becoming depressed.

#### 2.2.2 THE EFFECT OF DETECTION OF DEPRESSION ON OUTCOME

In combination with the work being carried out to improve rates of detection, another question being asked is whether this will lead to better outcomes, in terms of improved scores on symptom scales (see section 1.1.3). There is a realisation that if outcomes are not improved there is little point in improving detection rates alone. (Coyne et al. 1997). The studies which have been carried out have found conflicting results. Some have found that detection greatly improves outcomes (Ormel et al. 1993; Coyne et al. 1997) whereas others have observed little difference (Dowrick and Buchan, 1995; Klinkman et al. 1997).

The contradictions as to whether or not detection improves outcome may be due to methodological issues. Both the symptom scales used and the times at which outcomes are measured differ between studies. In addition, patients are likely to have been at different stages of therapy when recruited into the studies as they do not distinguish between new and existing cases. Many of the projects carried out investigating the relationship between detection and outcome have been naturalistic follow-up or longitudinal cohort studies. These have the advantage of being reflective of ordinary practice but also have their limitations. There is likely to be a difference in the patients who are detected and treated by general practitioners and those who are not. Patients with more severe depression are more likely to be treated

but are also likely to have worse outcomes (see later in this section). Therefore follow-up studies which do not control for level of severity will confound the effect of treatment and outcome. Other methodological limitations are that the studies have been carried out in small areas and the practices chosen have not been randomly selected.

Factors other than medical treatment have been found to affect the outcome of depression in primary care (Katon et al. 1994; Priest et al. 1995; Leenstra et al. 1995; Brown et al. 1996; Lloyd et al. 1996; Tomaszewska et al. 1996; Ronalds et al. 1997; Mynors-Wallis and Gath, 1997). The presenting illness and the life circumstances of the patients have been found to be important factors. For example, in a naturalistic follow-up study of patients who had been recognised as depressed and started on antidepressant medication in the USA (n=164), Katon et al (1994) found severity of depression and high neuroticism were significant predictors of the persistence of depression after 4 months of treatment. (Neuroticism was measured by the Eysenck Personality Inventory (Eysenck, 1969). Eysenck (1969) described neuroticism as a personality factor independent of extroversion - introversion which 'hysterics and psychoasthetics have in common, compared with normal persons'). In a naturalistic follow-up study of all general practice attenders at a surgery in the UK, (n = 148)Ronalds et al (1997) found that a significant reduction in depression score was significantly associated with younger age, mild depression at initial assessment, high education level, being in employment and a reduction in social difficulties during a 6-month treatment period. Both these studies (Katon et al. 1994; Ronalds et al. 1997) used robust methodology. It is perhaps not surprising that factors which are causative of depression continue to be important as the disease progresses. It does not mean that treatment does not make a difference to patients with more severe depression or more unfavourable life circumstances. Doctors are believed to have little chance of influencing social circumstances themselves (Kendrick, 1996). However it may be important for general practitioners to take the social situation of patients into consideration when providing treatment.

Various research interventions have been carried out in an attempt to determine factors which improve detection and outcome (Dowrick and Buchan, 1995; Lin et al. 1997; Peveler et al. 1999; Thompson et al. 2000). A randomised controlled study (n = 1099, response rate 76%) was conducted to investigate whether telling doctors that patients (who had been previously undetected) are depressed, according to the Beck Depression Inventory (1961), would improve outcome (Dowrick and Buchan, 1995). Patients who had a Beck Depression Inventory score above 14, but were not recognised as depressed by their GP were recruited. The patients were subsequently divided into 2 groups. In the intervention group the patients' GPs were informed of the Beck Depression Inventory score and diagnostic interpretation, and in the control group no such disclosure was made. The intervention was found to have no effect on outcome. However the doctors had already made their own judgement, which they may have viewed as more important than that of the Beck Depression Inventory (1961) and this may have affected the way in which they treated patients. Another approach has been educating primary care physicians to detect cases of depression and to treat them appropriately. A controlled trial (n = 134 intervention group, response rate 62%, size and response rate of control group not stated), examined the effects of a physician education project and increasing consultation length (Lin et al. 1997). Although the educational programme lasted for a year, benefits (measured as adequacy of dosage and duration of pharmacotherapy, improved patient satisfaction and improved depression outcomes) were not detected 6 months following the completion of the programme. The authors reported accounting for differences between the 2 patient groups at baseline. Using a randomised controlled trial, the Hampshire depression project (Thompson et al. 2000) sought to determine whether a GP education programme and clinical guidelines would improve detection and outcome of depression (n > 1900 at all stages of the trial). Doctors were randomised to either receive an education programme or not. Although the education programme was well received, no differences were found in recognition of depression or clinical outcome of patients. Therefore both the above studies (Lin et al. 1997; Thompson et al. 2000) found that the education strategies adopted for doctors did not improve outcome. Kendrick (2000) suggested that more research is needed to substantiate the clinical guidelines that GPs were given. He recommended that future research should investigate the impact of social factors on the outcome of depression in the medium to long term, in order to substantiate the claim that antidepressant medication is effective in the face of social problems. In addition, he emphasised the need for research to assess the outcome of depression over the whole range of severity in order to determine the threshold for diagnosis and treatment. In a randomised, interviewer-blinded controlled trial (n=250, response rate = 94% ofreferred patients), Peveler et al (1999) found that only patients classified as having major depressive disorder according to the DSM-III-R criteria had a significant difference in depression score after 12 weeks of treatment. (This study will be discussed further in section 2.3).

#### 2.2.3 PRIMARY VS SECONDARY CARE AND THE USE OF ANTIDEPRESSANT MEDICATION

Most studies concerning antidepressant medication have been carried out on hospitalised patients and therefore have limited relevance to primary care patients (Tyrer, 1988). The majority of patients who are suffering from depression are treated in the community. Only 10% of people with depression are referred to psychiatrists and 3.33% are admitted to hospital (Paykel and Priest, 1992). Klinkman et al (1997) compared a sample of adult family practice patients in the USA, weighted to over sample for those suffering from depression, (n = 425) and psychiatric outpatients with a diagnosis of depression (n= 123). He found that patients being treated in secondary care were more severely depressed, more likely to be male, more highly educated and younger than primary care patients. Depressed primary care patients were less likely to have received prior treatment for depression and were more likely to have past and current psychiatric morbidity. Floyd (1997) has noted that women have been 'virtually absent' from clinical trials but are more likely to be treated with antidepressant medication than men. Therefore, the sample of patients involved in clinical trials cannot be considered as representative of the general population.

The differences in care which patients receive by specialised psychiatrists as opposed to general practitioners has also been investigated (Scott and Freeman, 1992). As part of a randomised control trial in the UK (n=143, response rate = 85%) patients either received amitriptyline from a psychiatrist or usual care from a general practitioner. The researchers concluded that specialised treatment made very little difference in terms of patient outcome but that the cost was twice as much. Since the general practitioner was able to adjust therapy to an individual patient's needs whereas psychiatrists were only able to prescribe one drug at a particular dose, the validity of the results may be questionable. There is also likely to have been a Hawthorne effect as the doctors knew that their patients were taking part in the study, which may have affected doctors' decisions about treatment. A randomised controlled trial in the USA (n= 127) found that joint care with primary care physicians and psychiatrists was associated with improved compliance to treatment, increased patient satisfaction with depression care and improved depression outcome compared with usual care by primary care physicians alone, (Katon et al. 1997). However, in addition to psychiatrists becoming involved in treatment, primary care physicians were given training and consultation time was increased. It is therefore difficult to distinguish which aspect of care led to the improved compliance, satisfaction and outcome.

Research has identified that older tricyclic antidepressant medication is prescribed in lower than recommended dosages in primary care (Donoghue and Tylee, 1996b; Lecrubier and Hergueta, 1998; Demyttenaere, 1998; Macdonald et al. 1996). Donoghue and Tylee have extensively researched general practice databases in the UK (Donoghue and Tylee, 1996a; Donoghue and Tylee, 1996b). They have validated their work by using three independent sources and examined data concerning 71, 721 prescriptions. They found that between 1993 and 1995, 41% to 53% of people who had been prescribed tricyclic antidepressants received doses which are considered to be sub-therapeutic according to medical guidelines (Paykel and Priest, 1992). In contrast, lofepramine and SSRIs were prescribed in therapeutic doses. Although clinical guidelines recommend that tricyclics are initially prescribed in sub-therapeutic doses (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000), the authors considered it very unlikely that the large numbers of low doses identified could be starting doses. In addition, no evidence that doses were to be increased were found in patients' notes. Macdonald et al (1996) investigated prescribing of antidepressant drugs using a database covering Tayside, Scotland ( $n = \sim 400, 000$ ). They found that not only were tricyclics prescribed in ineffective doses in 72% of cases but also that both tricyclics and SSRIs were prescribed for under 90 days (approximately 3 months) in 68% of cases, whereas the recommended minimum treatment time is 4 to 6 months (Paykel and Priest, 1992). However Donoghue and Tylee (1996b) pointed out that findings regarding sub-therapeutic dosing did not agree with previous research that has investigated doctors' own reports of what they prescribe. The studies cannot explain the reasoning behind the use of lower doses, nor can they identify the effect on outcome. Clinical information regarding the effectiveness of sub-therapeutic doses is inconclusive. Clinical guidelines based on the results of controlled clinical trials (Paykel and Priest, 1992) may not be generalisable to the general population (see earlier in this section). Although the doses may be ineffective for patients in secondary care, they may still be useful for patients seen in the community setting. Arris et al (1999) have investigated primary care patients' perceptions of the effectiveness of sub-therapeutic doses (n=52, response rate = 72%). Patients were recruited from 3 general medical practices in the Grampian region. There was no evidence that the surgeries were selected randomly. In addition, 24 patients were excluded from the study as the GPs thought that they would be unsuitable to participate. Therefore the results cannot be considered generalisable. However, ninety five percent of patients who were prescribed tricyclics for depression reported improvement in their condition even though 19 out of 22 received lower than

recommended treatment doses. Peveler et al (1999), nevertheless, found that after 12 weeks treatment, significant differences in depression scores only occurred in patients receiving doses greater than 75mg of dothiepin or amitriptyline. Therefore although it is clear that tricyclic antidepressant medication is not being prescribed in recommended dosages, the therapeutic effect of using low dosages in primary care is unknown.

#### 2.2.4 ANTIDEPRESSANT MEDICATION IN THE CONTEXT OF OTHER THERAPIES

The clinical effectiveness of pharmacotherapy versus psychological therapy for the treatment of depression have been compared. Blackburn (1995) has reviewed the research carried out comparing the 2 treatments. Randomised clinical trials comparing the 2 treatments have been carried out by psychologists and psychiatrists. Some studies have also compared the effects of combination therapy with either treatment alone. The results produced have been variable. Blackburn (1995) has discussed the possible reasons for these differences, in terms of methodological problems associated with the design of the studies.

Issues concerning optimum therapy choice have implications for the provision of services. In recent years there has been an increase in the availability of counselling services in primary care. King (1995) has reviewed the literature concerning the quality and availability of counselling services and the effect of these therapies on outcomes. He has noted that the elevation in service provision has not arisen in response to Government policy and has not been systematic. This has resulted in counselling being more accessible to some patients than others in the National Health Service. The King's Fund report on London's mental health showed enormous differences in accessibility to services within the city (Johnson et al. 1997). Doctors need to make judgements as to which patients they should refer to psychological services. Prioritisation criteria will probably also differ between practices. There is a scepticism about the benefits of psychological therapies among healthcare professionals. Wessely (1996) reported that there is little research evidence to support the use of counselling. He has also argued that there may be little point in replacing drug therapy with counselling unless an advantage is proven. Economic factors are also an important consideration concerning health policy. Blackburn (1995) has stated that psychological therapy is far more expensive than drug therapy. However, in a randomised controlled trial with patient preference arms (n = 464), Bower et al (2000) have found psychological therapies to be more cost effective than

routine general practitioner care after 4 months of therapy. Greater improvement in depressive symptoms was found, with no extra associated cost. Psychological therapies and routine general practice care were equally cost effective after 12 months of therapy.

#### 2.3 Lay perspectives of antidepressant medication

Section 2.3 discusses wider sociological issues connected with depression and the use of antidepressant medication. Research which has investigated beliefs of the general public is discussed, in addition to studies identifying patients' perspectives.

Patients' own perceptions of therapy cannot be ignored in the debates concerning treatment and outcome. Patients' views of their treatment will affect whether or not they will use it. In addition, if drug therapy is to be used effectively to help patients recover from their depression, it is essential to know how they respond to treatment and how it becomes integrated into their everyday lives. Figures concerning non-compliance during antidepressant therapy in primary care vary but previous research has found that approximately half of patients stop taking their medication within the first 3 months (Maddox et al. 1994; Lin et al. 1995) whereas the recommended minimum treatment time is 4 to 6 months. As figures rely on self report measures it is possible that they are an underestimation. Two approaches concerning compliance with antidepressant medication have been identified (Demyttenaere, 1998; Demyttenaere, 1997): the biomedical approach and the medical psychological approach.

The biomedical approach towards treatment compliance views the patient as either conforming or not, to a prescribed regimen. Factors associated with non-compliance have been investigated, including illness characteristics, type of drug regimen, drug characteristics, patients' characteristics, doctors characteristics and practice characteristics. Interventions, such as educational programmes or the development of compliance aids, have been made in an attempt to increase compliance. For example, a randomised controlled trial (n=250, response rate = 96%) sought to determine the effects of 2 interventions on compliance to antidepressant treatment: an information leaflet and drug counselling (Peveler et al. 1999). Four groups were set up (treatment as usual, leaflet, drug counselling or both interventions). It was found that while verbal drug counselling given by a nurse improved compliance, written patient information leaflets did not. However, 18 out of 126 patients in the groups which were not allocated to receive leaflets, reported receiving information leaflets from elsewhere. Whether or not the information contained in these leaflets differed from that contained in the study leaflets was not specified.

The medical psychological approach identifies non-compliance as a patient response

to his/her circumstances which may be very meaningful rather than needing to be corrected. Various models of health behaviour have been developed (Leventhal and Difenbach, 1992; Wallston et al. 1978; Becker et al. 1977; Ajzen and Fishbein, 1980). For example, the health locus of control model was developed using the principles of Rotter's social learning theory (1966). Rotter's theory was based on the principle that if an individual expects a particular reward for an action they are more likely to carry it out. Rotter (1966) divided individuals into 2 types; internals and externals. Internals are those who believe that outcomes occur as a result of an individual's own actions and are therefore under personal control. Externals believe that outcomes are determined by factors beyond individual control. Wallston et al (1978) applied this theory to health behaviour. He described individuals who believed their health was controlled by their own actions as having an internal health locus of control. He divided external health locus of control into 2 categories, powerful others and chance. These 2 categories concern individuals' beliefs that their health is related to powerful others or chance respectively. The model predicts that individuals having an internal locus of control will be more likely to engage in health promoting activities. However, this will only be true for individuals who value health. Medical sociological research has examined patients' perspectives of taking medication. Previous research into patients' perspectives of taking medication has shown that patients' decision-making is based on personal beliefs about their illness and medicines (Conrad, 1985; Donovan and Blake, 1992; Adams et al. 1997; Helman, 1981; Britten, 1994; Morgan and Watkins, 1988; Dowell and Hudson, 1997). Further to the development of the understanding that patients are actively involved in making decisions about their medicines, there has been increasing recognition that patients and prescribers should work in partnership to decide upon treatment strategies. The Royal Pharmaceutical Society of Great Britain launched the initiative, 'From Compliance to Concordance.' in 1997 (RPSGB and Merck Sharp & Dohme, 1997). Concordance has been defined as,

'a new approach to the prescribing and taking of medicines. It is an agreement reached after negotiation between a patient and a health care professional that respects the beliefs and wishes of the patient in determining whether, when and how medicines are to be taken. Although reciprocal, this is an alliance in which the health care professionals recognise the primacy of the patient's decisions about taking the recommended medications.'

Patient partnership in medicine taking has been highlighted as an area for

pharmacists to develop their role within the context of the NHS Plan (Department of Health, 2000a). Further to the NHS Plan, the document ' The Expert Patient: A new approach to chronic disease management for the 21<sup>st</sup> century' (Department of Health, 2001) has been published. The document has reported that an observation often made by healthcare professionals involved in the treatment of chronic illness is that patients understand their disease better than the healthcare professional. The report identifies that patients and professionals have their own areas of expertise and need to work together. Whereas clinicians possess medical knowledge, patients understand the experience of the illness. The document acknowledges that knowledge and experience held by the patient has been largely ignored in the past but that patients in Britain can become key decision makers in treatment processes. Not only can they become involved in their own treatment but they can contribute their skills and insight for the future development of services.

Published research papers very rarely focussed on patients' experiences of taking antidepressant medication but have included some insights in this area (Karp, 1993; Karp, 1994). Studies using quantitative methodology have been carried out and have used techniques such as questionnaires and structured interviews. However focus groups, less structured interviews and more open questions in surveys have produced some more qualitative findings. Themes regarding depression and the use of antidepressant medication are discussed in the remainder of section 2.3.

#### 2.3.1 Help-seeking behaviour

In order to obtain antidepressant medication, medical advice must first be sought. Mechanic (1968) and Zola (1973) identified social and psychological factors which affected general help-seeking behaviour in the population.

Mechanic (1996) stated that much of the behaviour of sick persons is a direct product of the symptoms they experience: their intensity, the quality of discomfort they cause and their persistence etc. He listed 10 variables that studies have shown to influence response to illness. The variables are:

- 1) Visibility and recognisability of symptoms
- 2) The perceived seriousness of the symptoms
- 3) The extent to which symptoms disrupt family, work and other social activities
- 4) The frequency and persistence of symptoms

5) The tolerance thresholds of those who are exposed to the deviant signs and symptoms

6) Bases of appraisal of the symptoms

7) Needs for denial (e.g. due to high levels of fear over diagnosis, stigma)

8) Needs competing with illness responses

9) Competing possible interpretations that can be assigned to the symptoms once they are recognised

10) Availability of treatment.

Each of these 10 variables can either influence an individual's response to illness, or the response of others.

In a later paper, Zola (1973) found that although symptoms influenced help-seeking behaviour, it was the sociological effects of those symptoms which caused patients to seek advice for health problems. He identified 5 circumstances which triggered an individual to seek healthcare advice. These included 1) an interpersonal crisis, such as bereavement, 2) perceived interference with social and personal relations, 3) perceived interference with vocational or physical activity, 4) temporising symptoms i.e. those which persisted for longer than the sufferer had expected and 5) sanctioning to seek help by others.

Insight into the help-seeking behaviour of those suffering from depression can be gained from some research. Researchers conducting cross sectional surveys have found that the general public of Britain (Priest et al. 1996; Paykel et al. 1998) and Australia (Jorm et al. 1997a) believed that a general practitioner would be helpful to someone suffering from depression (see sections 2.3.2 and 2.3.3 for more details of these studies). However, in another cross sectional survey, Angermeyer et al (2001) found that 67% of the general public of Germany, (n= 1564, response rate = 71.2%) thought that lay people such as family, friends and self help groups should be the first port of call for those suffering from depression. Professional support was suggested where this failed to help. Studies which have researched the illness career pathway of those suffering from depression (Karp, 1994; Hagerty et al. 1997) have found that individuals go through a series of stages of recognising that something is wrong with them until they reach a 'crisis point' where they seek medical advice. It may therefore be hypothesised that although professional advice is considered helpful, there is a delay in obtaining it.

#### 2.3.2. ADDICTIVENESS OF ANTIDEPRESSANT MEDICATION

Concern regarding dependence on medication in the UK has been well documented across a variety of diseases (Morgan and Watkins, 1988; Donovan and Blake, 1992; Britten, 1994). The Royal Pharmaceutical Society has reviewed research on compliance and have noted that the public may regard medication as addictive which the medical profession do not (RPSGB and Merck Sharp & Dohme, 1997). For example, Morgan and Watkins (1988) found that West Indian patients with a diagnosis of hypertension (n=30, response rate 95%) frequently reported stopping their medication because of fears of becoming addicted to it. Similarly, Donavan and Blake (1992) found that a quarter of patients in a sample of rheumatology patients (n=54, response rate unstated) expressed concern about becoming dependent on their medication. Dependence on medication was also a theme which emerged from a study of patients ideas about medicine in a general practice population (Britten, 1994) (n=30, response rate unstated). Although the representativeness of each of the samples in the studies above (Morgan and Watkins, 1988; Donovan and Blake, 1992; Britten, 1994) was unknown, the fact that concerns over dependency emerged in a number of studies investigating different disease states, suggests that the finding has cumulative validity.

Conflict between lay and professional opinions concerning the addictiveness of medication has been reported (Bonn, 1998). Bonn (1998) discussed the debate which has moved onto the Internet regarding the addictiveness of antidepressant medication. The debate is partly associated with whether or not unpleasant reactions on stopping medication are regarded as signs of addictiveness. The consumers' watchdog association has claimed that antidepressants are addictive whereas the Government's Defeat Depression Campaign (Priest et al. 1995) aimed to try and dispel such beliefs. Priest et al (1996) sought the attitudes of the British general public to patients suffering from depression and to beliefs on causes and treatments, in December 1991, prior to the Defeat Depression Campaign. Eight focus groups were set up and these were followed by a quantitative survey using a sample of 2003 people, stratified according to parliamentary constituency, sex, work status, age and social class. The authors reported that the sampling method used did not permit identification of refusals. The study was valuable as a combination of qualitative methodology to identify important issues and a national quantitative survey to test the generalisability of the findings was used. Seventy eight percent of the general population of Britain were found to believe that antidepressant medication was

addictive. This belief had only been reduced by 4% in 1997, following the campaign (Paykel et al. 1998) (n=1946, number of refusals reported as unknown due to sampling method used). The authors suggested that the public may have extrapolated from what they had heard about the addictiveness of benzodiazepine tranquillisers.

Previous research has demonstrated that some patients discontinue antidepressant medication due to fears of dependency (Maddox et al. 1994). Maddox et al (1994) and Lin (1995) both investigated the extent of non-compliance with antidepressant medication (see earlier in section 2.3) and the self reported reasons for noncompliance. In Maddox et al's study (1994) of 46 patients (response rate = 87%) beginning courses of antidepressant treatment in the UK, 17% were categorised as discontinuing medication for 'other reasons' after a mean duration of 8 weeks treatment. This category included, 'not wanting to become dependent on tablets,' amongst other reasons. (Further details about the study findings are given in sections 2.3.8 and 2.3.9). However, Lin et al (1995) did not state fears of dependency amongst the self reported reasons for patients discontinuing antidepressant treatment during the first 3 months of treatment in the USA (n=247, response rate =67%). (Further details about the study findings are given in sections 2.3.8 and 2.3.9). Several reasons may be suggested for the differences in the findings regarding dependency between the 2 studies. Firstly, beliefs regarding dependency may have been greater in the UK than the USA. Secondly, Lin et al (1995) do not state whether the question which asked about reasons for non-compliance was open or required a fixed response. It is possible that patients were not given the opportunity to state dependency as their reason for discontinuation. Thirdly, although every eligible patient was approached from all the practices participating in the study, very little information was given about the selection of the practices used in either study. If random selection procedures were not used, the surveys cannot be considered to have produced findings which were generalisable to the populations that they were representing.

Lader (1979) has defined a psychological dependency which can develop in relation to psychotropic drugs. He has described this dependency as the need the patient experiences for the psychological effects of a drug. This need has been categoried into 2 types (Lader, 1979). Firstly the patient may crave the drug-produced symptoms or changes in mood. Secondly, the patient may take the drug because of fears of the reaction on withdrawal.

# 2.3.3 THE EFFECT OF STIGMATISATION OF MENTAL ILLNESS ON PERCEPTIONS OF MEDICATION

Researchers have been concerned with a labelling approach to illness, which has focussed on the nature and effects of illnesses, such as mental disorders, that carry a negative social evaluation or stigma (Morgan et al. 2001). Parsons (1951) stated that people adopting the sick role are not held responsible for their status and are exempt from social obligations. However, they are expected to recognise that the sick role is only a temporary state and take steps to get well. Freidson (1970) argued that not all illnesses carry such an exemption from responsibility. In some instances, conditions which are medically defined as illness are reacted to like crimes in the wider social context. Freidson was of the opinion that even where patients are not held technically responsible for their condition stigma is still sometimes attached to illness. Goffman (1964) noted that the word stigma originated with the ancient Greeks, who used it to refer to bodily marks or brands that were designed to expose infamy or disgrace. He observed that the word is still used today but is applied to the disgrace itself rather than the bodily evidence of it. Both Goffman and Friedson noted that there are plural value systems concerning stigma. Therefore attributes which are considered normal in one society may have a stigma attached in another.

Researchers have discussed the approaches to the management of stigma (Goffman, 1964; Anspach, 1979; Rogers and Buffalo, 1974; Scambler and Hopkins, 1986). Goffman (1964) noted that possessing a stigma causes great difficulty for the stigmatised person when interacting with those not possessing the stigma (normals). He defined 3 strategies which are employed to cope with a stigmatising attribute in social encounters: passing, covering and withdrawal. Passing involves an attempt to conceal the stigmatising attribute and gain acceptance as a normal. The possibilities of passing depended on whether the stigmatising condition is immediately visible or known by those involved in the interaction, on the obtrusiveness of the stigma, that is the extent to which it interferes with the flow of the interaction, and on the perceived focus of the stigma, that is the particular sphere of activity from which an individual's stigma is regarded as disqualifying him. Covering involved trying to reduce the significance of the stigmatising condition rather than denying its existence. Finally withdrawing from social activities with normals may be resorted to if the above mechanisms prove too difficult. Ansbach (1979) identified an additional response to stigma which was to reject the dominant social values and not aspire to 'normal attainments'. The result was either retreatism or political activism.

Rogers and Buffalo (1974) further suggested that active rejection of a label consists of either individual or group strategies to reduce the significance and personal effects of the label. Using in-depth interviews, Scambler and Hopkins (1986) distinguished between 'enacted' and 'felt' stigma in a sample of people with a diagnosis of epilepsy (n=94, response rate = 87%) 'Enacted' stigma refers to actual instances of discrimination whereas 'felt' stigma relates to the fear of such discrimination and to feelings of shame. Scambler and Hopkins argued that the lives of people suffering from epilepsy were affected more by 'felt' than 'enacted' stigma. The study obtained a very high sample size for an in-depth interview study and the authors stated that those who declined did not seem to differ from those who offered to help. The sample was recruited from GP surgeries. However, the authors do not state how the surgeries were selected. Therefore although there are indications that the sample was representative, generalisability cannot be assumed.

Research concerning public views about depression has determined that there is a stigma attached to suffering from depression (Priest et al. 1996; Paykel et al. 1998; Crisp et al. 2000; Jorm et al. 1997b). In a cross sectional survey of the general public, Priest et al (1996) found that stigma was associated with depression prior to the Depression Awareness Campaign in the UK (see section 2.3.2 for further details of the study). The number of people with stigmatising attitudes towards depression had been reduced by 1997, following the campaign (Paykel et al. 1998) but was still present. Another campaign, 'Changing Minds: Every Family in the Land' (White, 1998) has sought to further reduce the stigma attached to all mental illnesses. A national cross sectional survey (n=1737, response rate = 65%) carried out prior to the campaign determined that the majority of respondents regarded patients suffering from severe depression as hard to talk to (Crisp et al. 2000). In another large cross sectional survey (n= 2164, response rate = 66%), Jorm et al (1997b) found that half of a random sample of the population of Australia believed that having weakness of character was a likely cause of depression, which implied a negative evaluation of the disease. In contrast to the above studies, (Priest et al. 1996; Paykel et al. 1998; Crisp et al. 2000; Jorm et al. 1997b) another cross sectional survey, using a random sample, stratified for age, sex, marital status, social economic class and regional and area divisions (n= 1403, response rate not stated) by McKeon and Carrick (1991) found that the majority of the Irish public had positive attitudes to depression, although respondents over 65 years had significantly more negative views. Forty three percent of the sample expressed the opinion that people who had suffered from depression could be trusted to mind children, but 30 percent disagreed. Again, those over 65

years were significantly more likely to disagree. These cross sectional surveys (Priest et al. 1996; Paykel et al. 1998; Crisp et al. 2000; Jorm et al. 1997b; Mckeon and Carrick, 1991) all used large, representative samples. It is possible that the differences in findings between the surveys were due to the Irish population having more positive attitudes towards those suffering from depression.

The stigma attached to depression has been found to be more prominent amongst some cultures than others (Furnham and Malik, 1994). In a survey comparing the views of women born in Britain and women born in Asia, (n= 152, response rate stated to be >90%), Furnham and Malik (1994) found that Asian women living in Britain were significantly more likely to believe that the depressed patient should, 'Pull themselves together' than British women. However the views of younger Asian women were found to significantly differ from middle aged Asian women and were more similar to the views expressed by British women. The survey had limitations as the majority of the younger sample was recruited through universities, rather than being representative of the general population. This means that although the response rate was high, the findings cannot be considered generalisable. It is possible that those attending university were more integrated into British society than those who did not and their views may therefore have been more influenced by those held by the British population.

People suffering from depression have been found to be concerned about stigma; Coyne and Calcaro, 1995; Schreiber, 1996; Karp, 1993, Karp, 1994). Coyne and Calcaro (1995) set up 2 focus groups of people who had suffered from depression and had been treated at a specified Department of Psychiatry in the USA. Seventeen participants took part in total. The number per group was not reported (Coyne and Calarco, 1995). Interactions between participants in the group were recorded, making the study particularly valuable. The authors noted that participants received considerable agreement from others in the group when they expressed concerns about being stigmatised as a result of other people knowing about their vulnerability to depression. More generally, participants noted that other people in society did not comprehend their experience and used knowledge that they had been depressed to dismiss their opinions. Some participants reported trying to conceal their symptoms from others. Similarly, in a study using in-depth interviews, Schreiber (1996) found that a snowball sample of women suffering from depression, in the USA (n=21) sensed that the illness was attached to a social stigma and therefore experienced difficulty with telling those around them. Researchers, using in-depth interviews,

have found that being formally diagnosed with depression was often a very prominent point in the illness career of those suffering from the illness in the UK (Lewis, 1995; Rogers et al. 2001). In another in-depth interview study in the USA, Karp (1994) reported that respondents (n=20, response rate unknown due to sampling strategy used) reacted to receiving a formal diagnosis of depression in 2 ways. On the positive side, diagnosis was a step towards understanding the condition and obtaining treatment. However, it also placed respondents in the devalued category of people with mental illness. Similarly, Schreiber (1996) reported that many respondents had conflicting beliefs about whether or not they were stigmatised by their illness. Studies in different geographical areas all found that people suffering from depression were concerned about stigma, giving the finding cumulative validity.

Stigma has been found to affect medication taking behaviour (Conrad, 1985; Karp, 1993; Karp, 1994; Adams et al. 1997) in a range of conditions. Conrad (1985) used a snowball sampling strategy to recruit respondents suffering from epilepsy. Employing in-depth interview methodology, she found that amongst people suffering from epilepsy, on occasion, stopping medications was an attempt to vacate the stigmatised status of being epileptic. Similarly in an in-depth interview study (n= 30), Adams et al (1997) identified a group of patients in the UK who chose not to take preventative medication, as a means of denying that they had asthma. Karp (1993; 1994) noted that people with a diagnosis of depression had an initially strong negative reaction to taking drugs. He attributed this to the fact that medication was one indicator of the severity of the patient's problems and helped to define their status as chronically ill. This negative approach to medication was sometimes altered in the course of the treatment process, with respondents reporting that medication had been a 'miracle.' These studies (Conrad, 1985; Adams et al. 1997; Karp, 1993; Karp, 1994) provide cumulative evidence that stigma has associations with medication taking behaviour.

#### 2.3.4 SOCIAL CONTROL

Antidepressant medication has been viewed as a means of social control (1991). As noted in section 2.3.3, one of the patient's responsibilities in Parson's sick role (1951) is to take steps to becoming well. Patients can then return to carrying out the tasks to which they have been socialised, from which they had been excused while they had been ill. The application of Parson's sick role to patients with chronic conditions is more complex than to patients with acute illness. Patients with chronic

conditions are not in a temporary state of ill health, from which they can be expected to recover. However, Parsons (1975) argued that such patients can often be managed so that they are able to maintain a relatively normal pattern of physiological and sociological functioning. The sick role can therefore be applied. Kleinman and Cohen (1991) have researched the portrayal of work in psychiatric drug advertisements in America. An advertisement for Sinequan, showed a mother raking the yard with her 2 children. The caption stated that Sinequan, 'helps save what matters most... her family life.' In an advertisement for a non drowsy antidepressant a patient was shown falling asleep at work while taking an older antidepressant. The caption read 'asleep at the switch. This calls for a change in antidepressants.' This type of advertisement would be illegal in Britain as prescription only medicines cannot be marketed directly to the public. However such advertisements may be reflective of societies' views on antidepressant medication. Antidepressant medication may be viewed as a means to allowing people to return to performing their normal social roles. Kleinman and Cohen (1991) noted that advertisements portray depression as a pathology of the individual which has implications for the whole of society. However, they stated that such representations do not appreciate that the depressed state has occurred as a product of the patient's interactions with society.

#### 2.3.5 DOCTOR-PATIENT RELATIONSHIP

Charles et al (1999) developed a conceptual framework of different decision-making approaches within the medical encounter. Different types of doctor-patient relationships with varying levels of control for the patient were described. At one extreme, in the traditional paternalistic model, the doctor takes full responsibility for making decisions on behalf of the patient. At the other extreme, in the information exchange model, the doctor merely gives the patient information and it is the patient who then decides on treatment. Between the 2 extremes, in the shared model, the doctor gives the patient information about the available treatment options and the patient gives the doctor information about his values and preferences. The decision-making process is then shared. A shared model is being advocated as that which should be used in consultations between patients and healthcare professionals (Department of Health, 2000a).

Difficulties in the doctor-patient relationship have been found to affect patients' compliance with their medication (Barry et al. 2000). Barry et al (2000) used a

purposive sampling strategy to recruit patients (n= 35) in the West Midland area who consulted for a new problem for which a prescribing decision was likely and patients who wanted to discuss a previously prescribed drug. Patients were interviewed both prior to and following the consultation. In addition the consultation was audiotaped and the doctor was interviewed on the day following the consultation. The methodology was robust. A small purposive sample was used but the purpose of the study was not to produce generalisable findings. Barry et al (2000) found that patients had agendas which were unvoiced during the consultation and which led to unwanted prescriptions, non-use of prescriptions and non-compliance with treatment.

The quality of the doctor-patient relationship has been identified as a significant factor affecting medication use in depression (Lin et al. 1995; Weiss et al. 1997; Bultman and Svarstad, 2000). For example, Bultman and Svarstad (2000) interviewed patients in the USA, within 6 weeks of having being issued a new prescription for antidepressant medication. The sample was recruited from randomly selected community pharmacies (n= 100, response rate unstated). They found that a collaborative communication style by the physician enhanced patients' knowledge, belief and satisfaction with their medication, as well as increasing its use. Researchers have examined the doctor's role in improving compliance by giving patients educational messages about their drug therapy (Frank, 1997; Kaplan, 1997). Analysis of quantitative interviews (n = 155, response rate = 67%) determined that patients who received key messages from doctors were more likely to comply with treatment (Lin et al. 1995). The information given included efficacy of the medication, adverse drug reactions and alternative treatments. The level of empathy between doctor and patient has been found to be associated with general medication compliance (Squier, 1990). Patients suffering from depression have themselves identified that support and encouragement from healthcare professionals was essential in enabling them to gain relief (Hagerty et al. 1997). Heszen-Klemens (1987) examined tape recordings of consultations between doctors and patients in Poland (n= 109). He found that some doctors put themselves in an authoritarian position and saw it as their role to ensure patients took their prescribed therapy. He suggested that such doctors subconsciously saw non-compliance as a personal issue and felt that it resulted from their own ineffectiveness. They then projected these negative feelings onto their patients and blamed them for their non-compliance, which resulted in negative communications, such as anger and anxiety. Patients suffering from depression may be particularly vulnerable to these negative communications as they already have feelings of failure. Compliance is greatest

when practitioners attempt to empathise with the patient and gain a more personal perception of the way they view their illness and treatment (Demyttenaere, 1997). However, White (1998) has pointed out that some doctors stigmatise patients with mental illness, causing difficulties in the doctor-patient relationship. Demyttenaere (1997) suggested that the way in which the doctor asks about compliance affects the openness of discussions. If the doctor assumes that the patient has been non-compliant, the patient will be more likely to admit to it. This is important as many patients will not tell their doctor that they have stopped taking their medication (Maddox et al. 1994).

Researchers have found that some people suffering from depression are dissatisfied with their doctor's role in therapy (Hagerty et al. 1997; Rogers et al. 2001). Hagerty et al (1997) reported the disappointment some people suffering from depression reported experiencing when they initially sought help. Similarly, in The Knowing Your Own Mind Survey (The Mental Health Foundation, 1998) (see section 2.3.2.10 for further details) some people with mental health problems reported being unable to get what they wanted or needed when making contact with mental health services. Misjudgement by healthcare providers was a theme which emerged from a study investigating the experiences of depression in women (Schreiber 1996). Rogers et al (2001) compared doctors' (n= 10, response rate unstated) and patients' perspectives of depression (n= 27, response rate unstated) in Greater Manchester, UK. A purposive sampling strategy was used to include respondents of differing age, gender and type of practice. Rogers et al (2001) noted that when patients accessed primary care services for depression, the existence of a mutuality and predictability in the relationship between the patient and doctor could not be assumed. Respondents expressed initial concern that their problem was not a medical one and was not therefore one which was legitimate for their doctor to be dealing with. Respondents reported that their doctors knew them as a case rather than a person and some expressed the view that consultations were too short.

Patients' views of doctors have been found to vary between patients of different cultures (Fenton 1996). Fenton (1996) has investigated patients from Asian cultures and has found that they see the doctor as someone who can help with only physical problems, and are sometimes unaware that treatment is available for depression. Kleinman (1999) has discussed the different meanings, which different cultures attach to depression. He carried out a study in China, in which he investigated a group of patients known as, 'neuroasthenic.' Eighty seven patients met the DSM-III

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criteria for depression. The patients were treated with antidepressant drugs and improved in their psychiatric symptoms. However they continued to be impaired, to function badly and to seek help for their condition. They also remained sceptical of the treatment that they were given.

The level of control which patients have over the prescribing of antidepressant treatment has been researched (Sleath et al. 1997). Sleath et al. (1997) investigated whether it was patients or prescribers who initiated the prescribing process with psychotropic drugs in primary care. Audiotapes of consultations (n= 508, response rate unstated) were recorded and transcribed. Forty two percent of prescriptions were initiated by patients. However, all patients in the sample had seen their physician on at least 2 separate occasions prior to this consultation and often had had experience of using the same medication before. Patients on repeat prescriptions were more likely to initiate prescribing than those with new prescriptions, indicating that patients are more likely to take a more active role further into the treatment process.

#### 2.3.6 INFLUENCE OF FAMILY ON TREATMENT DECISIONS

Charles et al (1999) have noted that decision-making about treatment is shared with persons other than, or in addition to, the doctor. Leventhal and Diefenbach (1992) have identified that individuals' representations of illness and treatment and procedures for coping tend to be shared rather than private. The authors have stated that compliance appears to be higher when the family, physician and patient agree on illness beliefs. However, a focus group of individuals suffering from depression discussed the fact that their family did not fully know about or understand their condition, leading to it being hidden from them (Coyne and Calarco, 1995). The family relationship has been reported to sometimes affect interactions with the doctor. Some patients see the family as conspiring with the doctor to make the patient more compliant (Demyttenaere, 1997). Frank (1997) has discussed the importance of the doctor involving a patient's social support system in therapy. However, to be effective, the interaction between doctor, patient and family needs to be a shared rather than a conflicting experience.

### 2.3.7 ASSOCIATIONS BETWEEN PAST CONTACT WITH DEPRESSION THROUGH PERSONAL EXPERIENCE OR THAT OF RELATIVES AND FRIENDS AND TREATMENT DECISIONS

Studies have found that beliefs about depression are affected by past experiences (Jorm et al. 2000; Mckeon and Carrick, 1991). Jorm et al (2000) found that having sought help for depression was associated with higher commitment to a medical belief system. Interestingly, it was not the experience of depression in itself but the help-seeking factor which was important. In addition, having contact with others who have been treated for depression has been associated with more positive beliefs towards sufferers (Mckeon and Carrick, 1991). White (1998) noted that people are more likely to be empathetic with depressed people if they personally know or can identify with someone who has had the experience. He suggested that television soaps which portray a popular character going through depression may have more effect in promoting positive beliefs than a health awareness campaign. Jorm et al (1997b) found that patients who could identify depression on a vignette were less likely to state that weakness of character was a cause. Although chi-square tests were used to test for the association, the significance level chosen is not stated. As part of a longitudinal study, Kendler (1995) studied help-seeking behaviour in female twins with major depression in America (n= 2163, follow-up 92.5%). The study used robust methodology. Kendler (1995) found that having a relative who had previously sought help for depression was a predictor of patients themselves seeking help. He suggested 2 possible reasons for this prediction. Patients either observed the benefits of seeking help for their relatives or felt a lower sense of stigma as a result of their relative seeking help.

# 2.3.8 PATIENTS' PERCEPTIONS OF THE EFFECTIVENESS OF ANTIDEPRESSANT MEDICATION

Patients' perceptions of the effectiveness of their medicines have been associated with medication taking behaviour (Mcgavock, 1996). Psychological models of health behaviour predict that patients are more likely to use their medication if they see that it has a direct effect on their state of health (Leventhal and Difenbach, 1992; Wallston et al. 1978; Becker et al. 1977; Ajzen and Fishbein, 1980). Studies investigating patients' perceptions of medication in chronic conditions found that some patients were unsure of whether their medication was still necessary after a period of time or whether recovery had taken place. Some patients therefore discontinued their medication to assess whether or not any changes took place on stopping the medicine (Conrad, 1985; Karp, 1993). In a quantitative interview study with patients starting antidepressant therapy, Maddox et al (1994) found that 35% of patients stopped taking their antidepressant medication after approximately 6 weeks because they felt better. Lin et al (1995) also found that feeling better was a reason for discontinuation. Patients possibly did not attribute improvement to their tablets or felt that the tablets had completely cured them and that they no longer needed them. The 2 weeks lag time which is thought to exist before antidepressant treatment takes affect maybe significant in patients' perceptions of the effectiveness of their tablets. Maddox et al (1994) found that those patients who stopped taking antidepressant medication due to lack of effect stopped within the mean time of a week.

## 2.3.9 PATIENTS' PERCEPTIONS OF ADVERSE DRUG REACTIONS WITH ANTIDEPRESSANT MEDICATION

Patients' perceptions of adverse drug reactions with medication have been found to affect medication taking behaviour (Conrad, 1985; Donovan and Blake, 1992). Donavan and Blake (1992) found that fears about taking anti-rheumatology drugs sprang from patients' own or others' experiences of adverse drug reactions. Conrad (1985) discovered that people suffering from epilepsy were more likely to change medication practice as a result of adverse drug reactions which affected social skills than those affecting bodily functioning.

Patients with a diagnosis of depression have reported discontinuing their medication due to adverse drug reactions (Maddox et al. 1994; Lin et al. 1995). Maddox et al (1994) observed that 30% of patients who stopped taking their antidepressant medication attributed this to the adverse drug reactions which they were experiencing. The mean time for discontinuing therapy due to adverse drug reactions was 4.5 weeks. Lin et al (1995) found that more than 60% of patients reported adverse drug reactions as the reason for discontinuing their medication within the first 4 months of treatment. They also found that the number of severe adverse drug reactions experienced had a significant effect on compliance, although the definition of a severe adverse drug reaction was not reported. However, figures relying on self report of discontinuation of medication due to adverse drug reactions may be an overestimate, according to psychodynamic literature (Book, 1987). In the psychodynamic literature (Book, 1987), some patients who discontinued medication due to side effects were considered to have refrained from it for other reasons. According to the psychodynamic theory they may be projecting other fears about their illness or control of it onto adverse drug reactions. Demyttenaere (1997) has suggested that patients may view some reactions as a worsening of the disease state rather than as a side effect. An example of this is sexual dysfunction which may aggravate the lack of sexual interest which is caused by depression. Demyttenaere stated that where adverse drug reactions are experienced as a possible harm they will probably be over reported, whereas when they are interpreted as proof of efficacy they will be under reported. However, the source of evidence for this was not stated. Maddox et al (1994) found that patients were significantly more likely to report adverse drug reactions as a reason for discontinuation if they have previously been told about them by their GP. The authors suggested it is possible that patients were more likely to report experiencing adverse drug reactions as the reason for discontinuation because prior warning meant that they knew it would be considered valid.

### 2.3.10 LAY VIEWS OF ANTIDEPRESSANT MEDICATION IN RELATION TO OTHER THERAPIES

The public have been found to view antidepressant medication as only one of the available options for dealing with depression (Mckeon and Carrick, 1991; Priest et al. 1996; Jorm et al. 1997a) (for further details of these studies see sections 2.3.2 and 2.3.3). Alternatives include psychotherapy, alternative remedies, self help measures or simply talking to a friend or relative. The general public have been found to view these alternatives favourably in comparison to taking antidepressant medication. In an opinion poll of the general UK public, 91% of respondents thought that people suffering from depression should be offered counselling. In contrast only 16% thought that they should be offered antidepressant medication (Priest et al. 1996). A national survey of the Irish population (Mckeon and Carrick, 1991) found that 32 per cent were of the view that counselling would be helpful, as oppose to 23% who suggested medication. An Australian study found that the public were more likely to see antidepressants as harmful, whereas health care professionals regarded them as very helpful (Jorm et al. 1997a). The public rated minerals, vitamins and tonics as helpful, whereas healthcare professionals considered them harmful. The public also rated activities such as reading, attending self help groups, becoming more physically active, getting out and about more and courses on relaxation, stress management, meditation or yoga as more helpful than healthcare professionals. The statistical significance of discrepancies between the beliefs of the public and healthcare

professionals was not reported.

It is possible that preferences for alternative therapies over medication were partly due the public's view of depression. The public may have not distinguished between depressed mood and a state of depression. This hypothesis is supported by the fact that patients in a focus group noted that the public did not understand what they were going through and that their experience was different (Coyne and Calarco, 1995).

Other studies have shown that patients suffering from severe mental illness view medication as helpful (Rogers and Pilgrim, 1993; The Mental Health Foundation, 1998). In one survey (Rogers and Pilgrim, 1993) (n = 516, response rate not stated) patients regarded antidepressant medication nearly as positively as talk therapy (69% as oppose to 74%). In the Knowing Your Own Minds Survey (n = 401, response rate = 62% (The Mental Health Foundation, 1998), 67% of respondents viewed antidepressant medication as helpful, although 88% of patients receiving psychological treatments believed them to be helpful. There was a strong correlation between receiving antidepressant medication and receiving psychological therapy. Respondents made some very positive comments concerning the latter. However there were some comments from respondents about the damage that psychological therapies could cause. Although both these studies (Rogers and Pilgrim, 1993; The Mental Health Foundation, 1998) obtained large numbers of respondents, the samples were self selected and the findings cannot be considered to be generalisable.

In contrast to the relatively positive views concerning antidepressant medication which have been found in those with severe mental illness, Rogers et al (2001) found that primary care patients reported that their treatment made little difference to their overall illness. Some studies have identified factors affecting patients' preferences for treatment (Churchill et al. 2000; Chilvers et al. 2001). Churchill et al (2000) found that counselling was more popular among women than men, in a cross sectional survey of general practice attenders (n= 895, response rate = 91%). However, the survey was restricted to the Trent region and the findings cannot be assumed to be generalisable to other areas. A recent randomised controlled trial included patient preference arms (Chilvers et al. 2001). Analysis of the patient preference groups ( n=140, 80 for counselling and antidepressant medication respectively) demonstrated that patients who were more severely depressed favoured antidepressant medication whereas those with milder depression were more likely to choose counselling.

#### 2.4 Summary

Studies have been carried out investigating depression and the outcomes of taking antidepressant therapy but the focus of the majority of these studies has not been on personal experiences of taking antidepressant medication. Demyttenaere (1997; 1998) has noted that many such studies have investigated depression from a medical model where the patient is expected to comply with prescribed treatment. However patients' actions may be as a result of their own informed decision-making. With the focus of patient involvement moving to concordance between patient and prescriber it is essential that we understand this decision-making process (RPSGB and Merck Sharp & Dohme, 1997). Structured interviews have obtained quantitative information and identified that many patients do not comply with therapy mostly due to lack of efficacy, adverse drug reactions or because patients felt better (Maddox et al. 1994; Lin et al. 1995). However these studies (Maddox et al. 1994; Lin et al. 1995) did not address those factors as part of the whole process of patients' management of their condition. Research needs to identify the social and personal factors concerned with decision-making as these have an important role. Qualitative studies in the USA have investigated personal experiences of depression (Coyne and Calarco, 1995; Karp, 1994; Schreiber, 1996, Hagery et al, 1997, #108). Karp (1993; 1994) identified healthcare treatment and use of medication as an important feature in the illness career pathway of depression. However, little work has specifically focussed on patients' decision-making at the start of treatment. This thesis aims to present an in-depth view of patients' decision-making at the beginning of treatment for depression in primary care in the UK.

Section 2-Methodology
# CHAPTER 3 PRELIMINARY FIELDWORK

Chapter 3 describes the preliminary fieldwork which was carried out prior to the main study which is presented in this thesis.

# <u>3.1 Aim</u>

The aim of the preliminary fieldwork was to determine the issues of importance to people suffering from depression, when making decisions about their medication. Different perspectives concerning medication use were to be identified. The results of this preliminary part of the project were to be used to aid the development of the protocol for the main study.

# **3.2 Recruitment of self help groups**

The preliminary fieldwork was carried out at the beginning of January 1999. Self help mental health groups were used as a source of contacts. Although support groups are self selecting, they provided readily available access to people who it was thought would be willing to express views on their illness and treatment. The research took place in Northwest and Central London. Addresses of groups were obtained from the Internet, self help group directories and a list at Hendon library. From the mental health groups identified, organisations were selected which dealt specifically with depression. These were Depressive Anonymous and Depression Alliance. A local Mind office ran a specific depression support group and this was also included. A letter of invitation to participate in the project, was sent on 11/01/99 (see appendix 1) to the co-ordinators of each of these 3 groups. This was followed up with a telephone call on 15/01/99. Arrangements were made for face to face meetings.

# 3.3 Procedures used for arranging and performing interviews

Section 3.3 describes the procedures by which interviews were arranged and conducted. The procedures differed for each of the 3 support groups and are therefore described individually. Issues relating to the dynamics of the meetings are also discussed. The themes identified from the analysis of interviews of all 3 support groups are described collectively in section 3.6.

### 3.3.1 DEPRESSIVE ANONYMOUS

Depressive anonymous is a self- help group which meets at the home of the group co-ordinator, a lay individual, on a weekly basis. The researcher attended a group meeting on 19/01/99. Six participants were present at the group, in addition to the group co-ordinator. At the start of the meeting the group co-ordinator introduced the researcher and asked her to address the group. The researcher gave a brief introduction to the aims of the research, requested permission to audio tape the discussion and asked for comments concerning participants' medication, using a prepared interview schedule (see section 3.4). One participant was uncomfortable for the session to be audio taped and consequently no equipment was used. However, brief notes were taken.

Concerning the group dynamics at the meeting, each participant gave some views. There were some shared ideas amongst the group but there was a hierarchy within the group, with the co-ordinator taking a more dominant role.

At the end of the discussion, arrangements were made to individually interview 4 of the participants in more depth. Three of these participants agreed to the researcher contacting them. They were contacted by telephone and interviewed in the researcher's office within the next week. The interviews were transcribed and analysed. The 4th participant expressed a wish to contact the researcher. The participant attempted to do this but did not leave sufficient information to allow her call to be returned, although the researcher made several efforts to obtain it.

The 3 participants who were interviewed individually raised issues that they did not discuss at the group. Each of these participants had greater opportunity to express their views and they discussed experiences which were more specific to themselves. For example, one participant discussed her phobia of being sick, which was related to her decisions about taking antidepressant medication as she knew this was one of the adverse drug reactions.

Of the 3 group participants who did not agree to participate in an individual interview, one was strongly against drug therapy and was suspicious of the study motives. Another was attending the meeting for the first time. The 3rd did not give a reason. However, the group participants not participating in individual interviews

expressed their thoughts on their medication at the group meeting. The participant who had strongly negative views against drug therapy, did not accept a medical model of depression and may therefore have significantly differed from the other people in the group. However the other 2 expressed opinions which were not widely divergent from the rest of the group.

## 3.3.2 MIND IN BARNET

The depression group co-ordinator for Mind in Barnet agreed to speak to the group with a view to the researcher meeting with them. A meeting between the group members and the researcher took place on 04/02/99. There were 4 participants present in addition to the group co-ordinator. The researcher obtained permission to audio tape the meeting. The meeting was therefore audio taped, and transcribed.

The group discussed their personal experiences of medication. Two described symptoms resembling anxiety rather than depression. However the researcher did not have access to the participants' medical notes to confirm their diagnoses. Three of the 4 had been taking benzodiazepines and largely discussed these. The 4th participant became distressed during the meeting and left early. However, data on the negative aspects of taking psychotropic medication was obtained from the group, including fears of dependency and experiences of adverse drug reactions. There was some domination by one of the group participants who had particularly strong antimedical views and interpreted experiences of others in the group within this framework. Some interchange took place between this participant and another participant who felt more favourably towards the medical profession. However, the opinions of the former were put across much more dominantly.

Further to the meeting, a member of the group who was not present was given information about the study by the group co-ordinator. This person was given the telephone number of the researcher's department and contacted her. She was subsequently interviewed individually at the researcher's home address. The interview was not audio taped as the interviewee expressed a preference for hand written notes to be taken.

#### **3.3.3 DEPRESSION ALLIANCE**

A meeting was arranged with the executive director of Depression Alliance for

05/02/99. The executive director presented the researcher with the contact information of a person who had details of a list of people suffering from depression, who had agreed to talk to the media. This individual was contacted by telephone and agreed to approach participants on the list to determine their availability for interview. It was agreed that 6 people would be contacted initially, being selected to include people of a range of ages. The overall number of people actually contacted is unknown to the researcher. However, the researcher was given a list of 5 people who agreed to be interviewed, together with their ages. The researcher successfully contacted 4 of the people by telephone and subsequently interviewed them. However, the 5th could not be reached. Of the 4 participants, one was 65 years, 2 were in their 50's and one was 26. Two of the participants ran support groups for Depression Alliance. The interviews were carried out by telephone as long distances made face to face interviews very difficult. The interviews were not therefore audio taped but notes were taken.

In addition to the participants recruited through the 3 self help groups, a personal contact of the researcher who was suffering from depression agreed to be interviewed. This was carried out face to face, audio taped and transcribed.

## **3.4 Interview Schedule**

As the research with self help groups was an exploratory stage of the project, the interview schedule was designed to allow participants to express their views and opinions in a style which was undirected by the researcher. Respondents were invited to express their views regarding:

1) current and past antidepressant medication taken,

2) positive and negative aspects of taking medication,

3) short and long term expectations of medication,

4) medication in the context of every day life,

5) factors which participants believed to have been important in decision-making regarding taking antidepressant medication,

6) medication versus talk therapy,

7) anything else of importance to them regarding their condition or treatment.

# 3.5 Analysis of data

A qualitative approach to the analysis of the data was used. The transcripts and notes of each individual interview and group meeting were scanned to identify the range of issues and views concerning antidepressant medication expressed within the 3 self help groups. This method of analysis has been described by Patton (1990) as content analysis. The implications of the findings for the main study were then considered. The open nature of the interviews did not allow for a question by question analysis. Therefore the interviews were considered as whole units.

# 3.6 Results

Overall, the preliminary fieldwork data were derived from 2 group meetings and 9 individual interviews. Five of the interviews were performed face to face and the other 4 by telephone. The duration of the individual interviews ranged from 15 to 40 minutes. The group discussions were one and 2 hours in length.

The themes identified are described below. The data obtained from all the individual interviews and group meetings are considered as a cohesive data set.

## 3.6.1 GENERAL VIEWS CONCERNING ANTIDEPRESSANT MEDICATION

A range of views were expressed regarding antidepressant medication. One participant did not wish to take antidepressant medication, due to his perception that his depression was not a medical illness but a process of self development. The majority of participants reported that they would prefer not to be taking medication, although they had taken it because they knew it was necessary. In contrast, one participant stated that she was happy to be taking medication and another said that she took her tablets willingly.

## 3.6.2 MEDICATION BEING TAKEN

The majority of participants reported having taken more than one antidepressant. All

classes of antidepressant medication were represented i.e. tricyclics, SSRIs, monoamine-oxidase inhibitors and newer medication. In addition, one participant reported using herbal medication.

## 3.6.3 DOSAGE

The majority of participants stated the dose of antidepressant medication that they were taking. It became apparent from the analysis that the dosage of medication was adjusted during the treatment process in some cases. The majority of participants were concerned about high dosages being used. One participant on clomipramine spoke of the dose going up and up and up. Another participant stated that she was happier to be taking 20mg Seroxat than 230mg venlafaxine. A third participant reported needing to take 3 lofepramine tablets for there to be any effect and stated that concern over this dosage was one of the reasons for discontinuation. Yet another participant, taking Zisprin, expressed concern about increasing the dose beyond the maximum recommended dose.

# 3.6.4 ISSUES CONCERNING THE PERCEIVED BENEFITS OF ANTIDEPRESSANT MEDICATION

Participants considered depression as a chronic condition. Even those who referred to their medication as a life saver or wonder drug indicated that it was not a cure for the disease. One participant compared being on an antidepressant to being on insulin. Another participant used the analogy of a cloud and said that the medication had made it grey instead of black for her.

Some participants reported that they had not perceived any positive changes after a long time. However, they were still advised to continue with their medication, perhaps with an increase in dosage. One participant reported that it took almost 6 months for the therapy to be changed, despite protestation. In contrast, another participant complained that he had been advised to stop taking his tablets after only 4 weeks and felt that they would not yet have built up their effect. Some participants also discussed the fact that the medication was sometimes very slow to take effect and that a dramatic change was never noticed. Participants were sometimes unsure whether to attribute positive or negative effects to medication or to other causes such as changes in circumstances.

A range of factors contributed to perceived effectiveness. Firstly, some participants reported an improvement in mood. Secondly, participants described the effectiveness of their medication in terms of their everyday functioning. For example, one participant felt that it helped her to go out more and another reported that it enabled her to form relationships. Thirdly, sleep improvement was a benefit which was raised in some interviews.

Participants reported experiencing changes in effectiveness over time. One participant had a positive reaction to Seroxat which only lasted for a short space of time. 'I definitely felt a lift in my mood. ... It only seemed to last for a short time.' Another participant said that she had had a dramatic lift in mood on Prozac but that the treatment stopped working very suddenly. She reported that she crashed, became the lowest that she had ever been and ended up being hospitalised.

Participants also described experiencing changes in effectiveness with different medication. One participant reported that there had been no effect on Lustral but referred to Prothiaden as a life saver. Another noticed no improvement with Efexor but said that her life had completely changed after taking Seroxat. A 3rd participant also stated that Seroxat had been very helpful although no other antidepressant had. Yet another participant said that Marplan was the only drug which seemed to help her.

#### 3.6.5 DIFFICULTIES WITH MEDICATION

# 3.6.5.1 Fear of addiction

Fears of dependency were commonly reported amongst the participants. One participant from the Depression Alliance group, who was a support group leader, reported that many participants in her group were concerned about becoming addicted to their medication. In the Mind support group the majority of the participants were taking benzodiazepines and were very concerned about the addictiveness of psychotropic medication. In general, they did not separate the effects of antidepressants from their benzodiazepine therapy. One participant said in a telephone interview that she knew antidepressants were not supposed to cause dependency. However adding the word, 'supposed' seemed to indicate that she still had some concerns about it. Even where the issue of dependency was not specifically raised, it was evident from terms used by participants that they associated antidepressant medication with social drugs. One participant used the term, 'pill popper'. Another participant said,' I was having about 20, 30 and sleepers.' In describing her views about taking antidepressant medication a 3rd participant said that although she would have preferred not to have taken antidepressant medication 'you just want to pop anything. If coke would be legal you would even take that.'.

A general feeling was expressed by many participants of, 'being drugged' by their tablets. This belief was partly associated with the drowsiness of some medication. Examples of comments which participants made are, 'I don't like to look like a zombie at work.' and 'Something wasn't quite right, I wasn't functioning 100% of the time.'. However, there were also undesirable emotional and cognitive changes when taking the medication. One participant experienced feelings of aggressiveness which made it difficult for him to form relationships. Another reported feeling so high that she had no sense of reality. A third spoke of being unable to listen to music in the same way that she used to. Yet another said that she was unable to make decisions. Participants seemed concerned about taking medication which acted on their central nervous system.

Psychological dependence was mentioned by 2 of the support group co-ordinators. This was described as a feeling of reliance on medication which made people feel as though they did not want to stop taking it.

# 3.6.5.2 Adverse drug reactions

A number of adverse drug reactions were reported in addition to those described in section 3.6.5.1. Some affected the way participants could function in their everyday lives. The most common were sickness and stomach upsets. For example, one participant described being so sick that she had to jump off buses. A range of other adverse drug reactions were also experienced including postural hypotension, slowing of processes, headaches. Participants on tricyclics reported evidence of anti-cholinergic reactions, such as dry mouth and constipation.

In addition, participants reported having fears of longer term effects. In some cases these were effects which the participant had not experienced before, for example, brain cancer. In others it was fear that the adverse drug reactions already experienced maybe irreversible, for example, numbness.

## 3.6.5.3 Stigma

Some participants expressed concerns about stigma. This encompassed an inner sense of shame and a fear of discrimination from others. It was a reason reported by one participant for delaying going to see the doctor. A support group co-ordinator said that she knew of a case where a participant was told she couldn't have a job if she was 'one of those nutters' who took antidepressant medication. Another participant reported that she did not tell her father that she was taking antidepressant medication because he was against medication of any kind. Yet another described being a good actor and covering up his depression. A fourth said that she preferred people not to know. In contrast, one participant said that she felt it was, 'a shame if people like have a stigma with tablets. I've got enough pride to take it.'.

#### 3.6.6 ANTIDEPRESSANTS AS PART OF AN ILLNESS CAREER PROCESS

Different issues arose for respondents at different points in their antidepressant therapy. Participants in an episode of depression wished to gain relief. However other factors, such as fear of relapse, influenced whether participants continued therapy once a degree of recovery took place. It became apparent from the analysis that at the time when the majority of participants first began to take antidepressant medication it was a major issue in their lives. However if they were subsequently able to continue with their 'every day life', it was seen by some participants as a side issue.

#### 3.6.7 EXPERIENCES OF WITHDRAWAL

Participants described their experiences of withdrawing from the medication being taken. In some cases this was much more dramatic than the experience of actually taking the medication. Both positive and negative experiences were reported. In 2 cases participants took the decision to discontinue their medication suddenly. Both these participants reported having experienced bad withdrawal symptoms. In one case this resulted in a hospital admission. The other participant described having such bad trembling that he thought it might be Parkinson's disease. He described an experience of needing to sign a credit form in a bank and thinking that it would not be accepted because his hand was shaking so much. However, he also reported

suddenly feeling alive again after stopping the tablets. Another participant said that it was lovely to feel well again after coming off her medication. She reported that stopping the medication had boosted her up.

#### 3.6.8 DOCTOR-PATIENT RELATIONSHIP

The level of control which participants wished to take over their medication varied between participants and at different times during therapy. Some participants wished to be in control over their medication and were resentful when they felt that doctors did not give them the freedom to do this. For example, one participant reported that she had threatened to change consultants if she was not put on the tablets that she wanted. This viewpoint was particularly prominent in the Mind support group, where participants had taken benzodiazepine medication. Other participants reported making joint decisions with their doctors. One said that her psychiatrist and she had a friendly argument sometimes and that she managed small changes in her therapy herself. She also added that some patients were less in control and ran to the doctor about every little change. She said that they could not deal with their medication. Another participant said that although the doctors gave you information, in the end taking medication was a personal decision. In contrast, one participant reported that she wanted the doctor to make decisions about her therapy and did not want to become too involved. However, she had asked her doctor about Prozac, as someone in the support group had found it very helpful. It became apparent that the level of control which some participants wished to have, changed during the course of therapy. Participants described themselves as feeling very low at the start of treatment and wishing to be completely looked after. 'I would have done anything he said at that point [participant discussing receipt of first prescription]. I was just not coping very well with anything.'. However as they began taking therapy, some participants wished to develop more self control. 'And I wanted to stop taking them myself, rather than a doctor saying, OK, you can stop taking them now.'.

#### 3.6.9 OTHER RELATIONSHIPS

Participants reported that family and friends were involved in the decision-making process regarding antidepressant medication. A range of views were expressed regarding their roles. Firstly, they helped evaluate the effectiveness of the medication. One participant reported that other people had said that he seemed more cheerful on one drug although he hadn't noticed any changes himself. Another stated

that she asked the opinion of those closest to her as to how her tablets were affecting her. Secondly, some participants had family members who were healthcare professionals and relied on their opinions a great deal. Thirdly, family members were used as a 'go between' between healthcare professionals and some participants. For example, one participant's decision to continue with medication was influenced by the fact that her doctor had spoken to her husband and convinced him that she should continue taking the tablets.

## 3.6.10 INFORMATION NEEDS OF PARTICIPANTS

Participants reported using many sources of information to gain knowledge and understanding about their medication. These included patient information leaflets, drug information telephone help lines, medical books, lay books and the Internet.

However, for many participants this information was considered inadequate. Participants reported that they were not given enough information about the purpose of their medication, its adverse reactions and effects of stopping medication.

Participants also said that some of the information which they received was conflicting. One participant had obtained different information from her psychiatrist than from the drug company. Another said that there were so many treatments, people tried to convince you of each of them. She said you end up feeling like a guinea pig because you never knew what was going to work and that although you were given information you never really had the advice you needed.

## 3.6.11 ANTIDEPRESSANT TREATMENT IN THE CONTEXT OF OTHER DRUG TREATMENT

It became apparent from the analysis that participants' views about antidepressant medication were sometimes affected by experiences which they had had on other types of medication. Participants on benzodiazepines were more likely to be concerned about dependency and lack of control.

## 3.6.12 THE PLACE OF DRUG THERAPY IN THE CONTEXT OF OTHER THERAPIES

Participants had different attitudes regarding the helpfulness of using a combination of antidepressant medication and psychological therapy. Some thought that the 2 therapies were complementary to each other. One participant spoke of a combination of the 2 therapies as being important. Another participant said that you needed a balance of both and expressed the opinion that drugs would only work if you believed in them and you wanted to help yourself. Some participants viewed the 2 treatments as having very different roles. One participant stated that drug therapy took her to a stage where psychotherapy could help. Another reported that whereas drugs work on your brain chemistry, talking and listening to music gave you contact with other people. However, some participants had negative views about using the 2 treatments together. Some were concerned that antidepressant medication interfered with counselling as it suppressed normal thought processes, a view particularly expressed by the participants who had taken benzodiazepines. Other participants had negative feelings about talk therapy, expressing the opinion that it could not help them as much as taking drugs. From participants' descriptions it seemed that psychological therapy varied a great deal in its quality which may also have affected participants' views of it. In some interviews, preference was expressed for a specific form of psychological therapy over others.

#### **3.7 Implications for the main study**

From the analysis of the interview data, a number of factors were identified which had implications for the development of the main study.

1) From the analysis of the preliminary interviews, some issues of importance to participants were identified and used to aid in the formation of research objectives for the main study. Firstly, various risks and benefits were associated with taking antidepressant medication. These varied with different medication and dosages that participants had tried. Secondly, the level of involvement that participants wished to have over their own therapy and the amount that they wished to hand over to family, friends and healthcare professionals varied between participants and at different points in their therapy. Thirdly, the majority of participants had used a range of alternative treatments, in conjunction with or in place of antidepressant medication These included herbal remedies, reflexology and talk therapies. Participants' preferences for different therapies partly depended on their beliefs about depression.

2) When considering the sampling frame which was to be used to meet the research objectives of the main study, it was considered that some of the themes which were identified in the preliminary fieldwork may have been particularly prominent in the population used in the preliminary fieldwork. For example, members of self support

groups may have obtained more information about treatment options than other patients with a diagnosis of depression and wished to have more control over their therapy. A less self selecting sample was therefore preferred for the main study.

3) Different issues arose for participants at different points in their antidepressant therapy regarding the effectiveness of their medication, factors of importance in making decisions about their medication and the level of personal control which they wished to have over decisions. This indicated that it would be beneficial to interview patients on more than one occasion, to identify the way in which decisions about therapy changed in the course of time.

4) In comparing the individual interviews to the group meetings, it was found that individuals had greater opportunity to express their personal views when interviewed alone. In the group meetings participation was not completely even. Three participants were interviewed both as part of a group meeting and individually. Different issues were raised at the individual interviews when compared to the group meetings. Each participant had greater opportunity to express their views and they discussed experiences which were more specific to themselves. This was an important consideration when considering possible methods for the main study.

5) Some participants described symptoms resembling anxiety rather than depression. However the researcher did not have access to the participants' medical notes to confirm their diagnoses. In order to obtain a homogenous sample of people suffering from unipolar depression, it was considered advantageous to use diagnosis as one of the criteria for the main study. Access to such information would therefore be needed at the recruitment stage.

6) There were indications that participants taking a combination of medicines which included benzodiazepines had less views to express on antidepressant medication. Views and experiences of antidepressant medication may have been masked by more general views on psychotropic medication. This suggested that it may be beneficial to exclude patients taking benzodiazepines in the main study.

# CHAPTER 4 METHODOLOGY FOR THE MAIN STUDY

# 4.1 Aims and objectives

# 4.1.1 RESEARCH AIM

The overall aim of the main study was to investigate the factors affecting patients' decisions regarding therapy when beginning courses of antidepressant medication. The findings of the study inform the development of the role of healthcare professionals in supporting individuals in their decision-making.

# **4.1.2 RESEARCH OBJECTIVES**

The main study had 5 research objectives:

1) to investigate associations between beliefs about depression and the use of medication for depression with choices about therapy, including preferences for drug therapy or alternative treatments,

2) to investigate the level of involvement which patients wished to have concerning decisions with their medication,

3) to identify factors of importance to patients' decision-making regarding their use of antidepressant medication, including the influences of family, friends and healthcare professionals,

4) to compare the different experiences of patients taking tricyclic antidepressants and those taking newer agents in terms of the way in which patients' perceived symptom alleviation and adverse drug reactions affected their quality of life and subsequent decisions about therapy,

5) to identify variables that distinguished between those patients who continued with drug therapy and those who discontinued.

# **4.2 Development of methodology**

Section 4.2 describes the methodology which was used for the main study and the

rationale for the choice of procedures. Minor modifications were made to the proposed methods during the initial stages of the main study and the reasons for these are also described.

In order to meet the above research objectives, it was necessary to gain an in-depth understanding of the processes by which patients with a diagnosis of depression, made decisions about taking antidepressant medication in the context of their every day lives and to investigate the social and personal factors which affected their perspectives of treatment. It was necessary to go beyond what is known about compliance with antidepressant medication from existing studies and to identify new issues. The use of quantitative methods alone to test existing hypotheses would therefore have been inappropriate. Qualitative procedures and descriptive data were required in order to generate new hypotheses.

With regard to choosing a specific method, observation and diaries would not have provided the data on patients' perspectives needed for the study objectives. Interview data were more appropriate. Two methods were considered: focus groups and individual interviews. There are differences in the data produced by these two methods. Focus groups enable people to discuss issues and form opinions in a natural interactive process. They allow for an exchange of ideas within the group but tend to suppress minority views. A symptom of depression is low self-esteem and it was thought that patients suffering from it may not have the confidence to express views which differ from group opinion. Coyne and Calcaro (1995) conducted focus groups, involving people suffering from depression and noted that participation was uneven amongst the participants, despite efforts of the facilitators to avoid this. Uneven participation amongst participants was also experienced by the researcher during the preliminary fieldwork for this thesis. Mitchell (1996) found that breadth of information was collected in focus groups but that the issues identified were explored in more depth in individual interviews. Group discussions in the preliminary fieldwork of this study allowed the identification of issues of importance to people suffering from depression. The aim of the main study was to research these issues in more depth to gain a greater understanding of the decision-making process regarding the use of antidepressant medication. Therefore, individual interviews were selected in preference to focus groups.

Although a phenomenological approach, rather than a positivist approach, was taken, the use of quantitative instruments was incorporated into the study design in order to complement the qualitative data in the process of generating hypotheses. By approaching the research aim from a different perspective, the use of quantitative instruments added to the overall understanding of factors affecting patients' decisionmaking. Data collected from the quantitative instruments permitted the identification of variables which distinguished between those who continued with their medication and those who discontinued within the respondent group. In addition, the data provided descriptive information about the sample, which helped explain the study's findings. The approach of combining 2 research methods in one study is commonly used to validate or interpret findings and has been referred to as triangulation (Bowling, 1997).

Although support group data were useful for preliminary work, GP practices were selected as the source of recruitment for the main study. Recruitment through general practices would enable a specific diagnosis to be obtained according to ICD-10 criteria (World health Organisation, 1993) and would allow access to medical notes. It would also allow recruitment of a more generaliseable sample than was obtained in the support groups.

#### 4.2.1 RECRUITMENT OF GP PRACTICES

A random sample of GP surgeries would have been desirable, in order to achieve representativeness amongst the participating practices. However, few practices agreed to take part and a random sample was not possible to achieve. The sample therefore consisted of self selecting practices who were the most interested in participating in the research. The researcher then therefore analysed the participating practices to determine whether different types of practice were represented (see section 5.1). The implications for the generalisability of the findings are discussed in section 8.1) The procedures used for recruiting the practices are described below.

Practices were initially selected within Barnet and Camden & Islington Health Authorities. Health authorities were chosen within North London, due to ease of access. Within this geographical area, health authorities with contrasting socioeconomic characteristics were selected. Selection of health authorities was made with the aid of the 1991 Underprivileged Area Scores (UPA) (Jarman 1991). The UPA score is a measure of the deprivation in the health authority and is based on 8 factors. These factors include the numbers of elderly living alone, one parent families, children under 5 years old, unskilled workers (social class 5), unemployed, overcrowded households, persons having changed houses within the last year and persons born in the new commonwealth or Pakistan. The higher the UPA score, the higher the level of deprivation, the mean value being 0. Barnet has an Underprivileged Area Score of -2.07, giving it a rating close to the average. Camden & Islington has an UPA score of 43.43, making it a highly deprived area. No health authorities in North London have a very low deprivation score.

Randomised number tables were initially used to contact practices within Barnet and Camden & Islington health authorities. However, due to a lower than expected response rate, every practice within these 2 Health Authorities was approached and a third Health Authority, Brent & Harrow, was recruited. Brent and Harrow has a UPA score of 6.72, giving it a level of deprivation close to average. Practices were contacted in batches from the 3 health authorities, during the data collection process.

Two different methods were investigated for approaching the practices. Initially a telephone call was made to the practice manager and a contact name obtained to whom a letter could be addressed. Letters were sent to the contacts informing them of the study (see appendix 3) and inviting them to participate. These letters were then followed with a telephone call to discuss the possibilities of the researcher sending further information or meeting face to face to discuss the project. However the initial method used was not found to be practical when the number of surgeries being contacted increased. Therefore the letter was sent directly to the practice manager, asking him/her to contact the researcher if the surgery was interested in participating. If the response rate from any particular batch was zero, further telephone calls were made in an effort to increase it.

Where possible, return visits were made to practices. A period of at least 3 months was allowed between visits in the majority of cases. This was to ensure that patients were not asked to participate twice, as surgery staff were asked to recruit patients who had started courses of antidepressant medication in the last 3 months. A 3 month gap also allowed the researcher to recruit a larger number of patients each time, as more patients would have begun new courses. In one practice the frequency of visits was greater than once every 3 months and patients were recruited who had begun courses of antidepressant medication since the last visit but who had been taking antidepressant medication for less than 3 months.

#### **4.2.2 RECRUITMENT OF PATIENTS**

Patients were recruited from GP surgeries. In order to obtain randomness, every patient who met the eligibility criteria was approached.

GPs were given a screening instrument for identifying suitable patients (see appendix 4). The instrument was based on the inclusion and exclusion criteria (see section 4.2.3). Patient packs were then distributed to eligible patients. The packs consisted of a letter with reply card (see appendix 5), patient information leaflet (see appendix 6) and freepost envelope. Reply cards were addressed to the researcher. During the initial stages of the study 2 methods of distributing the patient packs were used. The first involved supplying packs to doctors, to distribute to patients being initiated on courses of antidepressant medication. With other practices, computerised records were used to identify all patients who had begun courses of antidepressant medication in the last month. A pack was sent to each of these patients by post, with a covering letter from the GP. The latter method was found to be much more effective and robust as there was a greater probability that a pack was sent to every eligible patient. Feedback from doctors using the former method indicated that they only distributed the packs to small numbers of patients who they thought would be interested in participating. The latter method was therefore exclusively used to recruit all the patients in the study. A follow-up letter or phone call was made to all non-responding patients by practice staff. If no reply was received at this stage, the patients were assumed to be non-respondents.

In the early stages of the research, further to 3 patients declining to participate because they were not currently taking medication, the patient letter was altered to include the bold lettered statement, 'We are very interested to hear your views, even if you are not taking or have never taken any medicines.'.

There were minor variations in the procedures used to recruit patients at the different practices. The main differences were in the form of the patient reminder (telephone call or personal letter) and in the number of times the practice was visited (see section 4.2.1). These details varied according to the willingness of the GP and the availability of staff.

# 4.2.3 INCLUSION AND EXCLUSION CRITERIA

The study aimed to recruit a group of patients with unipolar depression as the primary diagnosis, who had recently begun a new course of antidepressant medication. The inclusion and exclusion criteria used in the study reflect this and are listed below.

# 4.2.3.1 Inclusion criteria

Patients between 18 and 65\* years beginning a course of antidepressants with a diagnosis of depression according to the World Health Organisation ICD-10 criteria (1993).

\*Patients over 65 years were not included as there has been found to be co-morbidity with dementia (Puri, 2000).

# 4.2.3.2 Exclusion criteria

The following groups of patients were excluded:

patients with depression secondary to schizophrenia,

patients with an alcohol or drug abuse problem,

patients with manic depression,

patients who have been taking antidepressants for longer than three months.

Other groups of patients were originally excluded from the study but were later included. These groups included patients taking benzodiazepines and patients with depression secondary to physical illness. Patients taking benzodiazepines were originally excluded because it was found, in the preliminary fieldwork, that experiences with these medicines clouded any views on antidepressant medication (see section 2.1.5). However some patients taking benzodiazepines were inadvertently included in the study by the GPs. In one case the patient's views of antidepressant medication were affected by having taken benzodiazepines. It was observed that this interviewee was similar to the participants in the preliminary

fieldwork as she had taken benzodiazepines on a long term basis. However, other interviewees had been taking the benzodiazepines on a short term basis in line with medical guidelines (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000) and distinguished between benzodiazepines and antidepressant medication. These respondents were able to comment specifically on their antidepressant medication and patients taking benzodiazepines were therefore subsequently included in the study. GPs did not exclude patients with depression secondary to physical illness. This was possibly due to the complex co-morbidity of mental and physical illnesses and the difficulty in determining cause and effect. Although respondents with depression secondary to physical illness were sometimes more focused on their physical illness than their depression, they were still able to comment on the factors which affected their decisions about taking antidepressant medication.

#### **4.2.4 TIMING OF INTERVIEWS**

Both the literature review and preliminary fieldwork showed that different issues arise for patients suffering from depression at different points in their treatment. Patients were therefore interviewed on more than one occasion. Patients were initially to be interviewed at one month and 4 months after a first prescription for antidepressant medication. One month was chosen because the treatment is clinically considered to have begun taking affect by this time (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). By 4 months approximately 50% of patients have been found to have stopped taking their antidepressant medication (Maddox et al. 1994; Lin et al. 1995) although this is the recommended minimum treatment time (Paykel and Priest, 1992).

Interview timings were subsequently modified due to difficulties in determining the starting date of medication from GP computerised databases and to practicalities in the time taken to arrange interviews. If the timing of the first interview differed from one month after a first prescription of antidepressant medication, a follow-up interview was still carried out 3 months after the first interview date. The implications of having a range of interview times is discussed in section 8.1.

#### 4.2.5 CONDUCT OF INTERVIEW

At the beginning of the interview, the study was discussed with participants and

consent was obtained (see appendix 7). The interview schedule was then administered (see appendix 8). The interview included both qualitative and quantitative components.

## 4.2.6 INTERVIEW SCHEDULE

# 4.2.6.1 Qualitative component

The qualitative part of the interview schedule was designed to meet the research objectives, which were created from factors identified by the literature review and preliminary fieldwork. It included sections on beliefs about depression and its various treatments, the perceived benefits and risks of different antidepressant medication and dosages, the effect of antidepressant medication on every day life and influences on decisions regarding treatment.

Some minor modifications were made during the study to allow the detailed exploration of themes identified from the original objectives. A list of these modifications are given below.

 The fact that some respondents seemed unaware of the minimum recommended treatment time was identified from the preliminary analysis of earlier interviews.
Following this, in future interviews, respondents were asked about the nature of discussions with their doctor regarding treatment length.

2) The consideration of using complementary medicines was important to many respondents. Therefore its perceived role in comparison to conventional treatment was explored in future interviews.

3) Some respondents reported that either they or a member of their family had previously used antidepressant medication. The interview schedule was modified to investigate the way in which past contact with depression affected decision-making.

In the follow-up interviews, the researcher explored the way in which respondents' medication taking behaviour and their views and experiences of medication had changed over the interval between the 2 interviews. Themes identified in the first interviews were probed further, where the researcher felt that more information could be elicited.

Respondents were asked for their permission to audio tape both interviews to allow verbatim transcription.

## 4.2.6.2 Quantitative component

Three quantitative research instruments were used to meet the research objectives. These were selected to measure the quality of life of respondents, their beliefs about depression and the ways in which respondents assessed specific symptoms. The instruments which were used are reviewed below for their psychometric properties. In addition, where alternative instruments were available for measuring the same concepts, the choice of the instrument selected is discussed.

The Smithkline Beecham Quality Of Life Scale (Stoker et al 1992) was selected to assess quality of life. Quality of life has been defined as the ability to perform and derive satisfaction from life tasks and social roles (Turner, 1994). A quality of life scale was used as the study sought to explore wider perspectives of illness and medication, in order to incorporate its impact on every day life. A quantitative measure of this was used in conjunction with the data collected from the qualitative interviews.

Most quality of life scales for people with mental health problems have been tested in patients with schizophrenia and/or those in hospital. Most measures which have been used in patients with a diagnosis of depression in primary care have been symptom scales, such as the Hamilton Depression Scale (1967) and Beck's Depression Inventory (1961). Other instruments have measured specific aspects of quality of life. Examples are the Social Functioning Scale (Bosc et al. 1997) and the Psychological Well Being Scale (Dupuy, 1984). Some scales have been designed to measure quality of life as a whole in patients who have been prescribed antidepressant therapy: The Sertraline Quality of Life Battery (Turner, 1994), The Quality of Life in Depression Scale (KB) (Dunbar and Stoker, 1992).

The Sertraline Quality of Life Battery (Turner, 1994) consists of 9 separate scales measuring, health perceptions, energy/vitality, cognitive functions, alertness behaviour, work behaviour, home management and social activity, interaction, general life satisfaction and number of bed disability days respectively. In terms of the development of the instrument, it was derived from other health-related quality of

life scales, rather than using patients in its development (Revicki et al. 1992). It does not, therefore, incorporate patients' own ideas about what affects their well being. Revicki et al (1992) have tested the instrument's validity in a sample of patients (n = 28) with major depression who had been stabilised on antidepressant therapy. Pearson's correlation was calculated between scores on the Montgomery Asberg Depression Rating Scale (1979) (a measure of depression severity) and each individual scale of the Sertaline Quality of Life Battery. Correlation coefficients ranged from -0.30 to 0.78. All but the correlation with cognitive function scale were significant. Correlations were moderate rather than excellent, but this may have been due to the fact that the Montogmery Asperg Depression Scale is a symptom scale rather than an alternative quality of life instrument. Revicki et al (1992) have described the instrument as having criterion validity on the basis of these results. Test-retest reliability of the Sertraline Quality of Life Battery was investigated in the same sample of patients with major depression who had been stabilised on antidepressant drug therapy (Revicki et al. 1992). Intraclass correlation coefficients ranged from 0.74 to 0.94. The instrument has also been found to be sensitive to changes over time in a sample of patients beginning courses of antidepressant medication for major depression (n = 12) (Revicki et al. 1992). A low level of burden was found for respondents in both the above samples, in terms of time and difficulty (Revicki et al. 1992). However, the psychometric testing took place in the USA, rather than the UK, and was carried out in a specialist rather than a general care setting. The sample therefore differed from that used in the study presented in this thesis. The researcher was unable to obtain a copy of the instrument.

The Quality of Life in Depression Scale (Hunt and McKenna, 1992a) is based on a single underlying concept of need fulfilment rather than having separate domains. Each item has a choice of 2 responses, true and untrue. The instrument was developed in the UK using a patient population and therefore reflects their concepts and terminology (Hunt and McKenna, 1992a). Excellent internal consistency (correlation coefficient = 0.95), split half reliability (correlation coefficient = 0.93) and test-retest reliability (correlation coefficient = 0.81) have been established in a population of patients with a diagnosis of depression (n = 74) (Mckenna and Hunt, 1992). The instrument also performed well on tests of face, content and construct validity (Mckenna and Hunt, 1992; Hunt and McKenna, 1992a). The latter (n = 70) was assessed by examining the degree of correlation with the General Well Being Index (Hunt and McKenna, 1992b), which is a measure of psychological well being. The correlation coefficient was 0.79. Hunt and McKenna (1992a) noted that some

interviewees found it difficult to define themselves within the 2 categories of true/untrue, which were offered as responses. Although this did not prevent respondents from completing the questionnaire, it is possible that quality of life may be better represented by a continuum of possible responses. In addition, the Quality of Life in Depression Scale was both developed and tested on patients who were under specialist psychiatric care who have been shown to differ from a GP-based population (Klinkman et al. 1997). There is a charge associated with the use of the scale which meant that funding would have been needed to enable its use in the study.

The SKB (Dunbar and Stoker, 1992) consists of 10 domains: psychic well being, physical well being, mood, locus of control, social relationships, work/employment, activities and interests and finance. The domains were developed from a literature review of scales used previously (Dunbar et al. 1992). Each item on the questionnaire has a visual analogue scale consisting of 10 boxes. This allowed for a finer distinction of responses than a dichotomous measure and may therefore have increased the precision. The instrument has been shown to have good internal consistency (correlation coefficients = 0.9-0.92) and test-retest reliability (correlation coefficients = 0.83) in a sample of patients presenting to their GP with major depression or generalized anxiety disorder in the UK (n = 129) (Stoker et al. 1992). Construct validity was assessed in the same sample by examining the relationship between changes in the SKB and corresponding changes in symptomatic status as assessed by the Hamilton Depression Rating Scale (1967). Criterion validity was assessed using the Sickness Impact Profile (De Bruin et al. 1992) and the General Health Questionnaire (Goldberg, 1978) as external criteria. Correlation coefficients ranged from 0.33-0.74 for the Sickness Impact profile and 0.44-0.69 for the General Health Questionnaire (Goldberg, 1978). Although the range of diagnoses of the sample used to carry out the psychometric tests differed slightly from those in the present study, the sample consisted of patients with neurotic disorders in a general practice population and was therefore similar to that being used in the study presented in this thesis.

The SKB (Dunbar and Stoker, 1992) had advantages over the Sertaline Quality of Life Battery (Turner, 1994) and Quality of Life in Depression Scale (Hunt and McKenna, 1992a). Although psychometric tests had been performed for all the 3 instruments, the populations used to test the Sertraline Quality of Life Instrument and The Quality of Life in Depression Scale differed significantly from the population of

patients being used in this study as described above. The SKB was tested in a general practice rather than specialist population and was therefore selected for use in the study. In addition, it was freely available for use.

Two forms of the SKB (Dunbar and Stoker, 1992) are available a pencil and paper version and a computerised version. A high correlation between these 2 versions has been found (correlations coefficient = 0.78-0.93), meaning that the results obtained are almost interchangeable. As the interviews were being conducted in varying locations, it was decided that it would be difficult to administer the computerised version. Therefore the pencil and paper version was used. The SKB has 3 constructs: 'sick self', 'ideal self' and 'self now'. Only the self now construct was used in the study being presented in this thesis, as using all 3 constructs would have been too time consuming.

A quantitative disease specific measure of patients' beliefs about depression was used to investigate associations between these beliefs and treatment decisions. The Jorm et al Questionnaire (1997a; 1997b) has been administered to the general public in Australia (n= 2164) to investigate health beliefs about depression and to investigate their beliefs about various treatments. No formal tests of reliability or validity have been performed. However, a principal components analysis has been performed (Jorm et al. 1997c) to test whether beliefs were organised into coherent systems, that is whether beliefs about the helpfulness of certain interventions tended to re-occur with beliefs about the helpfulness of other related interventions. Three factors were identified: medical interventions, psychological interventions and lifestyle interventions. Three treatment strategy scales were developed from the results of the principal components analysis, using items with factor loadings greater than 0.4. The full original questionnaire was used in the study being presented in this thesis, with one exception. One item on the questionnaire was deleted after piloting the study being presented in this thesis. The deleted item asked about the usefulness of antipsychotics for the treatment of depression. Respondents were uncomfortable and confused with this question. This was not an item which Jorm et al (1997c) found to have high loadings (> 0.4) on any of the 3 factors which they identified.

Two other instruments concerning beliefs about depression were also considered. One was used in a study to measure the beliefs of a sample of the Irish population concerning those suffering from depression (Mckeon and Carrick, 1991). Like the Jorm et al Questionnaire (1997a; 1997b), it was designed for use with the general public. The instrument was not used in the study presented in this thesis as some of the questions were considered inappropriate for patients with a diagnosis of depression such as, 'Would you trust someone suffering from depression to mind children (including your own?)'. Secondly, Priest and Paykel (1996) developed an instrument to measure public attitudes to depression but the researcher was unable to obtain a copy of this.

The Symptoms Interpretation Questionnaire (SIQ) (Robbins and Kirmayer, 1992) was used in this study to explore respondents' perceptions of the causes of specific symptoms, that is their symptom attributions. The instrument consists of 3 scales measuring physical, psychological and lifestyle attributions. Respondents are asked to assess the likelihood of various symptoms being due to physical, psychological and lifestyle causes. This instrument had been used in previous research to investigate whether symptom attributions affected the likelihood of patients being diagnosed with depression. It was used in the study being presented in this thesis to determine whether symptom attributions affected treatment decisions.

Two versions of the instrument are available. The longer of the 2 contains a likert scale for each item and the shorter consists of a forced-choice format. The internal reliability of the longer version has been established in a population of medical and sociology students (n= 233). Cronbach alpha coefficients were calculated for each of the 3 symptom attribution scales and ranged from 0.71-0.86 (Robbins and Kirmayer, 1992). Construct validity has been measured by examining the intercorrelations of each of the 3 the symptom attribution scales with previously developed measures of illness cognition. The psychological scale was significantly correlated with the Private Self Consciousness Scale (Fenigstein et al. 1975), the Private Body Consciousness Scale (Miller et al. 1981), the Whitely Index of Hypochondrias (Pilowsky, 1967), and the Cognitive-Somatic Anxiety Questionnaire (Schwartz et al. 1978). The somatic scale significantly correlated with the Private Body Consciousness Scale (Miller et al. 1981), the Whitely Index of Hypochondrias (Pilowsky, 1967), and the Cognitive-Somatic Anxiety Questionnaire (Schwartz et al. 1978). The Normalising scale significantly correlated with the Private Self Consciousness Scale (Fenigstein et al. 1975), the Private Body Consciousness Scale (Miller et al. 1981), and the somatic scale of the Cognitive-Somatic Anxiety Questionnaire (Schwartz et al. 1978). Although significant, correlations were low, ranging from 0.16 to 0.62. The forced choice format has been shown to have quite low test-retest correlations (0.52-0.6) in a student population (n=140). In addition,

the alpha coefficients of internal consistency were low (0.3-0.6). Low internal consistency limits the ability of the instrument to detect changes over time. As the study aimed to detect changes between 2 different points in time, the longer version was selected in preference to the forced-choice format, due to its higher internal reliability.

The researcher read the questions on the Jorm et al Questionnaire (1997a; 1997b), to respondents, whereas the SKB (Dunbar and Stoker, 1992)and SIQ (Robbins and Kirmayer, 1992) were self administered. The methodology used for administration mirrored that of the instruments' authors.

Sociodemographic details were obtained during the interview. These included the respondents' age, sex, occupation and ethnic group. Ethnic group was classified according to the system used in the 1991 Census. White (Irish) was added because it has been noted that issues concerning this group are often overlooked because they are classified as White (Bracken, 1998). Information regarding respondents' occupations were used to classify patients according to a three class socioeconomic classification (Rose and O'Reilly, 1988).

Originally information regarding prescribed antidepressant medication was to be obtained from respondents' medical records. However, the majority of respondents either brought their medication to the meeting or named it during the interview. As medical records were found to have some inaccuracies (see sections 4.2.4 and. 8.1), self report was used in preference to medical records. The latter were only searched where respondents had not reported the medication that had been prescribed. Where medical records were used, the medication which was documented as being taken at the time of the first interview was recorded.

## 4.2.7 SAMPLE SIZE

A sample size of 60 patients was chosen. This reflected the fact that the study aimed to generate hypotheses rather than test them. A sample size of 60 patients allowed for the inclusion of patients with varying sociodemographic characteristics who had been prescribed different types of antidepressant medication. It also enabled statistical tests to be carried out to examine associations between sociodemographic characteristics and type of prescribed medicine and medication taking behaviour.

# **4.3 Data Collection**

## 4.3.1 OBTAINING ETHICS APPROVAL

Ethical approval was gained from 3 ethics committees: Barnet, Camden & Islington and Brent & Harrow, prior to patients being invited to participate in the study. The approval was subject to minor modifications being made to the patient information leaflet and consent form. For example, it was requested that information regarding the likely duration of the interview was added. Discussions were subsequently undertaken with Barnet and Camden & Islington ethics committees regarding the issue of whether the researcher could contact non-respondents directly but this was not approved.

### 4.3.2 PROCEDURES FOR ARRANGING INTERVIEWS

## 4.3.2.1 First interviews

As described in section 4.2.2, patients sent reply cards directly to the researcher to indicate whether or not they wished to discuss taking part in the study. If patients wished to discuss participating, they also included a contact telephone number on their reply slip. On receiving a positive reply card, the researcher telephoned the patient and asked whether s/he required any further information about the study and arranged to conduct a face to face interview. If patients did not have access to a telephone, the interview arrangements were agreed in writing.

Patients' preferences regarding the timing and locations of interviews were given priority. With regards to the timing, patients had the option of being interviewed outside working hours at evenings or weekends. The interview was carried out at the first opportunity that a mutually agreeable time could be reached. With regards to location, the patient's home address and the researcher's office were offered as options to patients of all participating practices. At practices A, E and F the surgery was also offered as a possible location.

If patients did not attend at the agreed time, they were contacted again by telephone and another interview time arranged. If they could not be reached after several attempts, a letter was sent asking them to contact the researcher if they still wished to take part. If no reply was received, no further contact was made and the patient was assumed to be non-responding.

Following the interview, field notes were recorded regarding contextual information such as the timing and location of the interview. A thank-you letter was sent to the patient. The letter included a reminder that the researcher would contact the patient again after 3 months.

# 4.3.2.2 Follow-up interviews

Three to 4 days, prior to the elapsing of 3 months from the first interview, a letter was sent to the patients informing them that the researcher would be contacting them by telephone to arrange the second interview. Three to 4 days later the patients were telephoned to arrange a second meeting. The options for timings and locations were the same as for the first interviews.

However, in a few cases where the patient was unable to meet for a face to face interview, it was performed over the telephone. The quantitative instruments had to be adapted for telephone usage. Whereas 2 of the measures were designed for self completion, the researcher read the options to the patients. One of these self completion measures, the SKB (Dunbar and Stoker, 1992), had a visual analogue scale which was adapted to asking the participants to select a score between 1 and 10.

Field notes were again recorded for both face to face and telephone interviews. A final thank-you letter was sent after the second interview.

# 4.3.2.3 Non-respondents

There were 4 categories of non-respondents.

1) Patients who sent back a negative reply form.

2) Patient whose original letter was returned by the post office.

3) Patients who did not contact the researcher after a reminder was sent.

4) Patients who sent a positive reply card but who were not interviewed due to having insufficient English or being unavailable to meet the researcher.

If patients did not wish to participate, they were asked to send back a decline form with their reply slip. This asked patients for information on their sex, medication being taken for depression and reasons for not wishing to participate.

## 4.4 Data processing and analysis

The procedures used for the qualitative and quantitative analysis of the data obtained are described below.

# 4.4.1 QUALITATIVE DATA

# 4.4.1.1 Data Processing

The qualitative part of the interviews was transcribed verbatim from the tape recording. Hand written notes were also included in the transcripts where these gave additional information to that which was audio taped. For example, respondents occasionally made further comments after the formal part of the interview had concluded. At other times, respondents' thought processes were stimulated by questions in the quantitative instruments and any extra remarks were written down by the researcher. For those interviews which were not audio taped (see section 5.2.6) all hand written notes were included. However hand written notes were entered in a different style of font on the transcript so that they could be distinguished from the audio taped interviews. The quotations used in this thesis were not taken from hand written records unless they were recorded verbatim.

# 4.4.1.2 Data analysis

Interview data from the first and second interviews were analysed together. The analysis involved coding the information i.e. labels were attached to segments of data with a common theme. In this way, the data were categorised according to meaning and description, as part of a data reduction process. The procedures by which coding were carried out, are described below.

The large amount of data collected during the study meant that a computerised package was required to aid in its management. Non Numerical Unstructured Data Indexing, Searching and Theory Building (NU\*DIST) (1998) was used. This software package is designed to aid in the handling of textual data in qualitative

analysis. It allows the storage and retrieval of processed information.

The interviews were transcribed and analysed on a continuous basis throughout the data collection process. This method was preferred to a single endpoint analysis as it allowed the exploration and testing of developing arguments during continuing data collection. Themes which were pertinent to the research objectives were initially identified from the literature review and preliminary fieldwork. Interviews were then coded into existing categories. New categories and sub categories, i.e. secondary and tertiary nodes, were also developed throughout the process, allowing an index structure to be built. For example, respondents made comments concerning the dosage of their medication and these were classified under the primary node, dosage. This primary node was later divided into a series of secondary nodes such as high dosage, low dosage etc. Stigma was identified as an important theme and initially comments were categorised descriptively. Later in the analytical process a more conceptual framework was developed and additional sub-categories were created to accommodate this. In some cases, themes were categorised as free nodes and later added to the index system. Sociodemographic details, interview type and medication being taken were classified under the node, 'Documents data'.

A number of tools were used to aid in the analytical process. Memos were used to record ideas that occurred to the researcher during the coding process. These were attached either to nodes or documents. In some cases, text searches were carried out. These allowed text to be selected on the basis of words which appeared within the text. For example, the researcher found that a number of interviewees had discussed the use of patient information leaflets and wished to investigate this further. In order to identify the segments of text where this phenomenon was mentioned, 'leaflet,' was searched as a text word. However, the researcher did not rely solely on the text search but also scanned the interviews to determine whether the same concept was referred to using different language.

In addition, summaries were written about each respondents' decision-making concerning their medication, including any changes in their decision-making in the interval between the first and second interviews.

#### 4.4.1.3 Validation

Data collected from qualitative interviews are seen as possessing inherent content

validity as they are guided by the responses of the interviewee rather than following the agenda of the researcher (Smith 1998).

A number of techniques were employed by the researcher during the analytical process to ensure validity at the interpretive stage.

1) The researcher searched the texts for cases which contradicted the main findings. For example, stigma was a prominent theme often discussed in interviews. The researcher therefore searched for examples where interviewees' responses indicated that they did not experience stigma. This has been termed argumentative validation (Smith 1998).

2) The results were searched to find indications of the effect of the researcher and the research process on the results obtained. The effect of non-response bias was also considered, which aided in the interpretation of the results in the context of the research setting.

3) Minor modifications were made to the interview schedule, as described in section 4.2.6.1. Modification of the interview schedule allowed the development and testing of emerging theory, which has been referred to as communicative validation (Smith 1998).

4) The researcher considered the results to determine whether or not the perspectives identified regarding medication were supported by other relevant studies. Where contradictions occurred, the reasons for these were considered. The researcher investigated studies reported in both sociological and medical sources. This has been termed cumulative validation (Smith 1998).

5) Findings from the qualitative data were also considered in conjunction with the quantitative data, rather than being considered from one set of data alone i.e. a triangulation process was used.

# 4.4.2 ANALYSIS OF QUANTITATIVE DATA

Statistical Package for the Social Sciences (SPSS) was used to aid in the management of the quantitative data. Frequency data were generated for all variables. Chi-square and Mann Whitney U tests were used to compare the age,

gender and prescribed medication of the responders and non-respondents of both the first and second interviews.

Prior to the analysis of variables affecting medication taking behaviour, some preliminary investigations were carried out to determine the most appropriate statistical tests to use. Firstly, to determine whether the data were normally distributed, histograms were plotted for each variable. As the histograms showed that the data were not normally distributed, non-parametric tests were used in the analysis. Wilcoxon paired tests were then used to compare participants' responses to the quantitative instruments between the 2 interviews in order to determine whether it would be appropriate to select only one data set for use in the analysis. As these tests demonstrated that there were some differences between the 2 sets of data, they were considered separately in further analysis. Finally, in order to reduce the number of variables on the Jorm et al Questionnaire (1997a; 1997b) which would be used in further analysis, a principal components analysis procedure was carried out on the instrument. This would ease the interpretation of the findings and reduce the number of statistical tests needed, meaning that it would be less likely that associations would be found to be significant by chance. However, as no distinct factors were produced, the variables were each considered separately in subsequent analysis.

Analysis sought to distinguish between those who continued with their medication and those who discontinued. Bivariate tests were used to check for associations between medication taking behaviour and other variables. The variables included sociodemographic variables which were age, gender, ethnic group and social class; variables concerning the treatments used which were drug class, use of herbal remedies and use of talk therapy and variables derived from the 3 quantitative instruments used which were score on the SKB (Dunbar and Stoker, 1992), scores on the psychological, physiological and normalising scales of the SIQ (Robbins and Kirmayer, 1992) and all variables on the Jorm et al Questionnaire (1997a; 1997b). Again, Chi-square and Mann Whitney U tests were used for categorical and interval variables respectively. Where the expected frequencies were too small for chi-square tests to be carried out, categories were combined to increase the expected frequencies. For example very likely and likely categories were combined as one category. As very few associations were found in bivariate analyses, multi-variate analysis was not carried out.

With regards to the instruments used, Cronbach alpha tests were carried out to

determine the internal consistency of the SKB and SIQ. It was not considered appropriate to perform test-retest reliability tests as there was a 3 month interval between the 2 interviews. In addition, the respondents were at the beginning stages of their treatment rather than having been stabilised on therapy. Therefore, changes would have been expected to occur during the period between the interviews. **Section 3-Results** 

# <u>CHAPTER 5</u> <u>RESPONSE RATES AND CHARACTERISTICS OF PARTICIPATING</u> <u>PRACTICES AND PATIENTS</u>

Chapter 5 describes the response rates of practices and patients and discusses the characteristics of the practices and patients who participated. The implications of the response rates on the generalisability of the sample of patients who were recruited, will be discussed in section 8.1. Minor variations in the procedures used in each of the participating practices and information regarding the conduct of the interviews are also reported in chapter 5.

# 5.1 Response rates of practices and practice characteristics

## 5.1.1 Practice response rate

All practices from Barnet, Camden & Islington and Brent & Harrow Health Authorities were invited to participate. Six out of 254 practices took part in the study, making the response rate 2%. Some of the remaining 248 practices gave feedback to indicate the reasons for non-participation. However, messages which could not be traced to a specific surgery were sometimes left on an answer phone, making it difficult to determine the exact numbers of practices declining for each reason.

Some reasons for non-participation found in this study may be general to any health care research. Some practices had a general policy not to take part in research or only became involved in research offering remuneration. These policies were due to staff shortages or a high workload in some cases. Single handed practices were particularly likely to give high workload as a reason for non-participation. Of the practices which were generally willing to participate in research, some were already participating in other projects and therefore chose not to take part. One practice did not have computerised records of patients and was therefore unable to carry out a search for patients beginning courses of antidepressant medication. Some doctors agreed to take part but were subsequently unavailable to discuss the project with the researcher. In one case the interested doctor left the practice before the time that the practice manager had arranged to meet with the researcher. Other doctors met with the researcher but did not subsequently recruit any patients.

In addition to general issues relating to the participation of practices in research,
issues concerning the involvement of patients with a diagnosis of depression were raised. Concerns over confidentiality were expressed by some surgeries. Although procedures were agreed with the ethics committees to ensure confidentiality was not compromised, some surgeries declined on this basis. One doctor also voiced concern about patients being diverted from other activities. If a patient only has a certain level of motivation, she wished this to be channelled into activities such as obtaining counselling rather than participating in research.

#### 5.1.2 CHARACTERISTICS OF PARTICIPATING PRACTICES

To preserve anonymity the 6 participating practices were referred to as A to F. Practices A, B and C were within Barnet Health Authority, D was within Camden & Islington and E and F within Brent & Harrow. The number of doctors working at the practices ranged from 2 to 7. No single handed practices took part. Psychological therapy was available at each of the 6 practices.

Some doctors indicated their reasons for participating in the study. One doctor from practice A identified herself as a researcher and one doctor from practice E showed the researcher a primary care protocol for mental health which she had developed. This protocol included procedures for directly referring patients to other community services, such as stress therapy, rather than to secondary care.

#### 5.1.3 PROCEDURES USED IN THE PARTICIPATING PRACTICES

The methodology used for recruitment of patients were discussed in section 4.2.2. In section 5.1.3, specific details about the procedures used in the individual participating practices are reported.

Practice A was visited 6 times during the study, practices B and C were visited once only, practices D and E were visited 3 times each and practice F was visited twice.

In practices A and C, patients who did not respond to the first invitation were contacted by telephone. In practice A the call was made by the GP and in practice B it was made by the practice administrator. In practices D, E and F, a written reminder was sent. Due to the procedures agreed at practice B, no reminder was sent to patients from this surgery.

### 5.2 Patients' response rates and sample characteristics

Section 5.2 describes the characteristics of the sample of patients who participated in the study. The response rates for each interview are also stated and the socioeconomic characteristics of the respondents and the non-respondents are compared. Respondents and non-respondents are also compared in terms of the medication which was prescribed. As patients were asked to participate in 2 interviews, there was a possibility of declining at 2 different stages. They could decline to participate completely, or participate in the first interview but not the second. There were therefore 2 sets of non-respondents and these are reported separately. Comparison of respondents and non-respondents will identify factors which were associated with the likelihood of patients participating in the 2 interviews.

#### 5.2.1 RESPONSE RATES FOR THE FIRST INTERVIEW

Out of the 171 eligible patients who were invited to participate, 51 successfully completed the first interview, giving a response rate of 30%. Thirty five (69%) of first interview respondents accepted the initial invitation to participate, with the remaining 16 (31%) agreeing after being sent a reminder. The response rate for the first interview therefore increased by 10% on sending a reminder. The number of patients agreeing to participate from each of the 6 practices is shown in table 5.1.

<b>Table 5.1:</b>	Number of patients agreeing to participate from each practice
	(n=171)

Practice	A	В	С	D	Е	F
No. of eligible patients	22	7	5	30	59	48
No. of patients agreeing to participate after receiving first letter	6	2	0	7	9	11
No. of patients agreeing to participate after being sent a reminder	3	n/a*	1	4	5	3

\* no reminders were sent from practice B.

Analysis was performed to determine whether the gender, age and prescribed medication of the eligible patients was similar between practices. Table 5.2 shows the gender of eligible patients at each practice.

	Practice					
Gender	А	В	С	D	Е	F
Male	7	4	1	8	15	10
Female	14	3	4	21	36	11

 Table 5.2:
 Gender of eligible patients at each practice (n=134\*)

\* gender of 37 non-respondents was unknown (see section 5.2.2)

There was a higher ratio of women to men in practice C than in other practices but the numbers were too small to enable the statistical significance of this to be tested.

A Kruskal Wallis test was performed to test for association between age and number of eligible patients per practice. No significant association was found (p = 0.21).

Table 5.3 shows the class of antidepressant medication prescribed for the eligible patients at each practice.

Table 5.3:	Class of antidepressant medication prescribed for the eligible
	patients at each practice (n=89*)

Practice						
Class of antidepressant prescribed	Α	В	С	D	E	F
Tricyclic	3	1	0	1	16	2
SSRI	16	6	1	6	20	16
Venlafaxine	0	0	0	1	0	0

\*Class of antidepressant prescribed was unknown for 75 eligible patients. In addition 7 patients had not been prescribed antidepressant medication (see sections 5.2.2 and 5.2.3).

Patients from practice E were more likely to be taking tricyclic antidepressant than from the other practices. However, as with gender, the numbers were too small to test for statistical significance.

#### 5.2.2 CHARACTERISTICS OF NON-RESPONDENTS OF THE FIRST INTERVIEW

From the 120 patients who did not participate, 28 (23%) sent back negative reply cards, declined by telephone, gave negative responses when contacted by their practice by telephone or had their letters returned by Royal Mail as they had changed their addresses. The reasons for non-participation in the study by these 28 patients are given in Table 5.4.

Reason for non-participation	Number
Unknown	8
Not currently taking medication	7
Insufficient contact details*	5
Too busy	4
Did not wish to sway results* *	2
Insufficient English***	1
Not finding medication effective	1

 Table 5.4:
 Reasons for non-participation in the first interview (n=28)

\* The practice did not have the current correct address.

\*\* One patient had taken homeopathic medication and had found this ineffective but did not want to contribute to negative views about alternative medication. Another was a psychiatrist and stated that her views were therefore skewed. \*\*\* Agreed to participate but was unable to answer any of the interview questions due to insufficient English

No communication was received from the remaining 92 non participating patients. However, 3 practices (A, B and E) gave the researcher details of gender, age and class of antidepressant prescribed for the non-respondents. The researcher obtained details of non-respondents' gender and age from practice C.

Overall, the researcher obtained information about the gender of non-respondents for 83 (69%) patients. Twenty three of these were male and 60 were female. The age of respondents was known for 86 patients. This ranged from19-64, the mean age being 37 and the median 33.

Information concerning the class of antidepressant medication prescribed was obtained for 46 (38%) of the non respondents. Of these 29 had been prescribed SSRIs and 14 had been prescribed tricyclics. Three had been prescribed complementary medicines only.

## 5.2.3 CHARACTERISTICS OF FIRST INTERVIEW RESPONDENTS

Twenty two respondents (43%) were male and 29 (57%) were female. The age of respondents ranged from 19 to 61, the mean age being 41 and the median, 42.

Most respondents in the sample reported their ethnic group as White (Non Irish). The distribution of ethnic groups is shown in table 5.5.

Ethnic Group	Number (%)
White (Non Irish)	40 (78)
White (Irish)	3 (6)
Indian	3 (6)
Asian	3 (6)
Black (African)	2 (4)

 Table 5.5:
 Self reported ethnic group of respondents (n=51)

The respondents were classified according to the 3 class socioeconomic classification (Rose and O'Reilly, 1998). The results are shown in table 5.6. Respondents who were unclassifiable due to student status or insufficient information being obtained are also

shown.

 Table 5.6:
 Socioeconomic class of respondents (n = 51)

Socioeconomic Class	Number (%)
Managerial/professional	21 (41)
Intermediate	9 (18)
Working	12 (23)
Students	3 (6)
Unclassifiable due to insufficient information	6 (12)

Forty seven (92%) of the respondents had been prescribed licensed antidepressant medication in the 3 months prior to the first interview. Of these 36 (77%) had been prescribed SSRIs, 9 (19%) had been prescribed tricyclic antidepressants and one (2%) respondent had been prescribed venlafaxine. Information concerning the class of antidepressant medication prescribed was unavailable for one (2%) respondent, due to the fact that he had changed address and his medical records had been moved. Four respondents had been prescribed complementary medicines only.

Twenty three (45%) respondents reported taking complementary medicines. In 18 cases this was self prescribed and for 5 respondents it was prescribed by a general practitioner. As stated above, 4 of the respondents who had been prescribed herbal or homeopathic medication had not been prescribed other antidepressant medication. The 5<sup>th</sup> had first been prescribed complementary medicine but had found it ineffective and had subsequently changed to licensed antidepressant treatment. All 5 respondents who had been prescribed complementary medicine by a general practitioner had been recruited from practice D. Twenty five (49%) respondents reported that they had not

taken complementary medicines. One respondent had insufficient English to answer questions about the use of complementary therapy and in 2 cases, interviews were carried out before the interview schedule was altered to specifically ask about use of complementary medicines (see section 4.2.6.1).

## 5.2.4 COMPARISON OF RESPONDENTS AND NON-RESPONDENTS FOR THE FIRST INTERVIEW

Information regarding age, gender, and prescribed medication were only available for some non-respondents (see section 5.2.2). Therefore caution is required in the interpretation of data comparing these characteristics of respondents and non-respondents. However, comparisons are made to give some indication of factors associated with the likelihood of patient participation.

Table 5.7 shows the gender of the first interview respondents and non-respondents.

## Table 5.7:Comparison of the gender of respondents and non-respondents for<br/>the first interview (n=134\*)

	Ger	nder
Response to first interview	male (%)	female (%)
Respondents	22 (43)	29 (57)
Non respondents	23 (28)	60 (72)

\* gender of 37 non-respondents was unknown (see section 5.2.1)

A Chi-square test showed that there was no significant difference between the gender of the respondents and non-respondents (p = 0.16).

A Mann Whitney U test showed that there was no significant difference in age between those who participated and those who declined (p = 0.1).

There was a high proportion (41%) of respondents from the managerial/professional social class. A direct comparison with social class data of the public could not be made as The General Household Survey 2000 (Office for National Statistics 2002) used an older classification system than that used in the study being presented in this thesis. However, The General Household Survey 2000 showed, that only 29% of men and 15% of women were professional, employers or managers. The higher proportion of respondents from the managerial/professional social class found in the study being presented in this thesis was unexpected as depression is more common in the lower

social classes (Jenkins et al. 1998; Jenkins et al. 1997). It was not possible to compare the social classes of the respondents and non-respondents directly as information about social class was not collected for the non-respondents. However, the researcher wished to determine whether this finding was due to there being a bias towards the managerial/professional social class in the original sample or to response bias. To aid this, a cross tabulation between practice and social class was created. This helped determine whether the bias towards the managerial/professional social class towards the managerial social class was created. This helped determine whether the bias towards the managerial social social class was only present in the practices in more affluent areas. Table 5.8 shows the results of this cross tabulation.

		Practice				
Social Class	A	В	С	D	E	F
managerial and professional	6	1	1	3	4	6
intermediate	2	1	0	2	1	3
working	1	0	0	2	5	4
student	0	0	0	1	1	1
unclassifiable	0	0	0	3	3	0

 Table 5.8 :
 Social class of respondents from individual practices (n=51)

Table 5.8 shows that the bias towards the managerial/professional social class was present in all but practice E and this was in a less deprived area. However, practices B and C only had very small numbers of patients. Therefore, this interpretation needs to be treated with caution with regards to these 2 practices.

Table 5.9 groups the respondents and non-respondents according to class of antidepressant medication that they were taking.

# Table 5.9:Comparison of the class of antidepressant medication prescribed<br/>for respondents and non-respondents for the first interview (n=89\*)

	Class of	antidepressant medication p	rescribed
Response to first interview	SSRI (%)	tricyclic (%)	venlafaxine (%)
Respondents	36 (78)	9 (20)	1 (2)
Non-respondents	29 (67)	14 (33)	0 (0)

\* Class of antidepressant prescribed was unknown for 75 eligible patients. In addition 7 patients had not been prescribed antidepressant medication (see sections 5.2.1 and 5.2.2).

Table 5.9 shows that SSRIs had been prescribed more frequently for respondents, whereas tricyclics had been prescribed more frequently for non-respondents. A Chi-square test could not be carried out to test the significance of differences between the

medication prescribed for respondents and non-respondents as the expected frequencies were too small. Therefore, the classes of antidepressant medication were reclassified as SSRI and other. A Chi-square test showed that there was no significant difference between the response rates of these groups (p = 0.23).

Therefore no variables were significantly associated with participation in the first interview, although there were indications that those participating in the first interview were more likely to be in the managerial/professional social class.

#### 5.2.5 FOLLOW-UP INTERVIEWS

A second interview was carried out with 44 of the 51 patients who participated in the first interview. Of the remaining 7 patients, 2 were too busy, 2 had moved home with no forwarding address, one was too tired and 2 did not give a reason.

All the respondents who declined to take part in the second interview were female, and classified themselves as having an ethnic group of white. Three of the second interview-decliners were from the managerial/professional class, 2 from the intermediate class, 2 were working class and one was a student. All had been prescribed SSRIs. Chi-square tests, to test the statistical significance of differences between the respondents and non-respondents were inappropriate as the expected frequencies were too low.

The age of respondents who took part in the second interview ranged from 21 to 60 years, the mean age being 42 and the median 44. A Mann Whitney U test showed that age was significantly related to whether or not a second interview was carried out, with older patients being more likely to participate (p=0.03).

Of the 44 respondents who participated in both the first and second interviews, 18 respondents (40%) had taken their prescribed medication continually throughout the research period. Seven respondents (16%) had taken their medication for the recommended treatment time of 4 to 6 months (Paykel and Priest, 1992) after which they had stopped taking it. Thirteen respondents (30%) had begun to take their medication but had discontinued within 4 months. Five (12%) of respondents had taken their medication intermittently and one respondent (2%) had not taken any medication.

Of the seven patients who had taken their medication for 4-6 months before

discontinuing it, in 3 cases the doctor had been involved in the decision to discontinue treatment. In one case the doctor had recommended discontinuation of treatment as he felt that it was no longer necessary and in the other 2 cases the decision had been made jointly during discussions about the respondent's progress. In 4 cases the doctor had not been involved in the decision to discontinue treatment after 4-6 months.

Out of the 13 patients who discontinued treatment before 4 months, in one case the doctor had recommended discontinuation of treatment as he thought that it was no longer necessary and in another case a new doctor had felt that psychological therapy would be a more appropriate treatment. In the former case the medication prescribed had been homeopathic and the 4 to 6 month minimum recommended treatment time did not apply. Eleven respondents had made the decision to discontinue before 4 to 6 months alone.

Of the 7 respondents who took part in the first interview but not the second, 4 were continuing with treatment at the time of the first interview, 2 had decided to discontinue before the recommended treatment time of 4 to 6 months and one had not taken any medication.

Of the 44 respondents who participated in both the first and second interviews, 26 respondents (59%) reported that they had engaged in some form of psychological therapy in addition to medication. Fifteen (34%) respondents stated that they had never had psychological therapy. Two respondents (5%) did not have sufficient English to answer questions regarding the use of psychological therapy and the issue was not raised with one respondent (2%).

Of the 7 respondents who took part in the first interview but not the second, 5 reported having had some form of professional psychological therapy, and 2 stated that they had never had psychological therapy.

For those who participated in both the first and second interviews, the median number of days between the 2 interviews was 111.5. The follow-up period ranged from 91 to 230 days.

### 5.2.6 CONDUCT OF INTERVIEWS

Eighteen first interviews were carried out in general practice surgeries, 16 in

respondents' homes, 14 in the researcher's place of work and 3 in the respondent's place of work. The latter was not originally suggested as a location by the researcher for confidentiality reasons but was requested by these respondents.

Seventeen follow-up interviews were carried out in respondents' homes, 12 in general practice surgeries, 10 in the researcher's place of work, 2 in the respondent's place of work and 3 by telephone. In one of the latter interviews only a short qualitative interview, concentrating on key issues which had been identified in the first interview, was performed and no quantitative instruments were administered, due to the respondent having very little time available. Where interviews were carried out by telephone, the qualitative part could not be audio taped. In addition, one patient requested that the follow-up interview was not audio taped. In these cases, notes were taken.

Where interviews were carried out at home, there were often interruptions due to telephone calls and other family members entering the room. These affected the flow of the interaction, particularly where they took place during the qualitative part of the interview. In 2 home interviews, the patient's partner was present at one of the 2 meetings. Only the patient's own perspectives were used in the analysis, in line with the original objectives.

Where interviews were carried out at the respondent's place of work, 2 took place in a private office. However, in one case the office was more open and there was another person present working along the corridor. Although he was not visible the researcher was aware of his presence during the interview.

The duration of the first interviews ranged from 25 to 180 minutes, the mean duration being 58 minutes and the median 55 minutes. One second interview was of very short duration (under 5 minutes) due to the respondent having very little time available. The duration of the remaining 43 second interviews ranged from 20 minutes to 195 minutes, the mean duration being 38 minutes and the median 30 minutes. In one case the interview data were collected on 2 occasions in both interviews due to the respondent becoming fatigued. The qualitative component and the Jorm et al Questionnaire (1997a;1997b) were completed on the first occasion and the SKB (Dunbar et al. 1992) and SIQ (Robbins and Kirmayer, 1992) on the second.

## <u>CHAPTER 6</u> <u>Respondents' perspectives of taking antidepressant</u> <u>MEDICATION</u>

Chapter 6 presents respondents' perceptions of their treatment. Data from the first and second interviews are initially considered together. The chapter opens by discussing the initial stages in the treatment process and then continues by describing respondents' views and experiences of the positive and negative aspects of taking antidepressant medication. Issues relating to the level of control which respondents wished to have over decision-making during the course of treatment are then reported. Respondents' perceptions of taking different drugs and dosages are also described and the role of medication is considered in relation to that of other treatments. Changes which occurred to respondents' perspectives and decision-making regarding their medication, between the 2 interviews, are then discussed. Finally, the insight which the data from both interviews gave into how the researcher and research process affected the validity of the results is reported.

### 6.1 Factors associated with the decision to seek professional help

Section 6.1 considers the initial stages in the treatment process. Respondents were asked about their reasons for seeking medical help for the first time during their illness experience and about their expectations of the initial consultation. The analysis of the interview data sought to determine the extent to which respondents' help-seeking behaviour fitted Zola's theory of non-physiological patterns of triggers (Zola, 1973). Where aspects of respondents help-seeking behaviour had not previously been identified by Zola, an earlier paper (Mechanic, 1968) was examined to investigate whether this helped to explain the study findings.

#### 6.1.1 TIMING OF THE DECISION IN THE ILLNESS CAREER PROCESS

Using qualitative methods, previous researchers have identified the stages which patients experienced during episodes of depression (Karp, 1994; Hagerty et al. 1997). Such studies have reported that respondents experienced many of the symptoms of depression before recognising the severity of their condition. At some point they realise that 'something is really wrong' and reach a 'crisis point' at which they seek medical help. It is at the 'crisis point' that medication is prescribed. The majority of respondents in the study being presented in this thesis described a similar process. They experienced symptoms of depression such as tiredness, loss of appetite and weepiness but did not realise that these were due to a clinical condition.

[Until recently] I've always thought it's just a bad week or just a bad month and I've always been stressed out and I didn't know that taking medication would actually help and I've not really thought of it as being depressed. Respondent 529, lines 364-369

I think that's the nature of the illness that you've got no concept of how you are until just one day you just feel that you just can't cope anymore, you just, it just all goes to pieces.

Respondent 531, lines 1698-1703

A number of factors were found to influence patients' decisions to seek medical help at a particular point in their illness. Zola (1973) identified 5 non-physiological triggers that caused patients in a general practice population to seek medical advice at a particular point in their illness (see section 2.3.1). He found that the relative importance of different triggers altered with different populations of patients. The reasons which interviewees gave for seeking help in the study being presented in this thesis were compared with Zola's triggers to determine to what extent the findings agreed. Some of the reasons respondents gave for seeking help in this study corresponded to Zola's triggers.

Firstly, some interviewees reported that interference with vocational or physical activity triggered the decision to seek help.

And it was getting worse and worse. It wasn't just a matter of a couple of hours a day and you can't do that when you've got a young family. And the other thing I couldn't do, I couldn't face going out sometimes. Respondent 013, lines 423-428

When you've got a job you've got to do and lots of other things going on in your life, you've got to get some of it [the depression] out of the way, if you like. Respondent 409, lines 50-53

Secondly, for other respondents, perceived interference with social or personal relationships triggered the decision.

Um, I couldn't go on the way that I was feeling. And it definitely wasn't doing my marriage any favours. And it wasn't doing the kids any favours. So I had to speak to somebody. It got to the stage where this isn't me, it definitely is not me. And so it was either leave it for another 3 or 4 months and my marriage to be totally in the bin or go.

Respondent 503, lines 306-320

Thirdly, some interviewees were sanctioned to seek help by others. There was an explicit recommendation that respondents sought medical help, in the majority of cases where sanctioning was reported.

Um it wasn't really my decision to be fair. I was in a situation where I think, for a long period of time maybe, it's very difficult to pinpoint the time on these things but possibly anything between eighteen months, a year, I was getting progressively worse. ... My parents who I wasn't living with but saw, you know, saw fairly regularly saw a change in me and were getting increasingly more worried about me. Um, and in the end, um, as I was, you know, not going to work. As I was not able to go to work, basically my parents made me go to the doctors.

Respondent 532, lines 99-122

However, sanctioning was more implicit in some cases. Respondents were not directly advised to seek medical help but sought a medical consultation based on others' realisations that something was wrong.

A few people, before I started, noticed I was down which is unusually (sic), I've had 30 years of disguising it. But when they started to notice [it] obviously shows how bad it was.

Respondent 529, lines 325-334

Although interference with vocational or social activity or sanctioning were the triggers which were most commonly identified in the analysis, Zola's other 2 triggers were found to be relevant to some interviewees. Temporalising symptoms, that is symptoms that persisted for longer than would be considered normal, triggered some respondents to seek help. Zola found that patients had specific ideas about how long symptoms should be expected to last. The respondents in this study, however, did not mention specific times.

It took me a long time to go because I thought I'd snap out of it. But when it didn't go, I thought maybe I needed just a helping hand to give me a push. Respondent 427, lines 55-58

In other cases, an interpersonal crisis in patients lives triggered them to seek medical help.

So it sort of started bringing the problem back again when he got really ill ... and that's why I needed something to help me through it. Respondent 528, lines 48-52

However, on one occasion an interpersonal crisis prevented one interviewee from seeking further medical help. The respondent described how her circumstances changed again in the course of her treatment, making it difficult for her to concentrate on her own recovery.

Priorities changed, I wasn't number one in my mind. You know. I think it would have been simpler if life had been going on as it is now, when I started taking them. [Respondent whose father died, shortly after she began treatment]. Respondent 528, lines 733-738

Although Zola's triggers were found to influence help-seeking behaviour, his theory needed modification for the sample of patients in this study. Zola claimed that symptoms were important but that it was not a worsening of these that caused the patient to seek help. Rather symptoms remained constant but their social implications changed. Although Zola's triggers could be identified in the interview data, they were accompanied by a perceived worsening of symptoms, as is illustrated in the quotes earlier in this section. The reason for the difference between Zola's study and the study being presented in this thesis may be that Zola investigated a general sample of patients attending medical surgeries or clinics for a new problem whereas patients newly diagnosed with depression were specifically researched in this study. The nature of depression may mean that decline in social functioning is associated with a worsening of symptoms.

In addition, Zola's triggers did not account for all the factors influencing help-seeking behaviour that were identified in the analysis. Zola did not take differing perspectives of illness into account when examining help-seeking behaviour. Interviewees in the study presented in this thesis had a range of perceptions regarding their illness which influenced their help-seeking behaviour. Some interviewees perceived their illness as being physical, rather than emotional and therefore sought help for a condition other than depression.

I thought I was anaemic because I was really tired and I had that once before ages ago and because I was really tired I had a blood test and it all came out then.

Respondent 530, lines 162-166

I never thought it was depression, it was just because I was getting the funny feeling here in my leg and my arm was hurting, so I was worried that it's something to do with my heart.

Respondent 424, lines 193-197

I didn't actually speak to him about being depressed, I spoke to him about my migraines and he, like, asked me how it was affecting everything else. ... And every time he'd ask that I'd end up crying my eyes out with a box of tissues. And he picked up on it, I didn't even know that I was feeling depressed. He picked up on it and he spoke to me about um putting me on antidepressants. Respondent 529, lines 63-74

In some cases, the physical illness was reported as being the primary focus during

consultations, rather than depression.

We discussed more about irritable bowel syndrome and the operation than depression.

Respondent 535, lines 155-157

Another interviewee reported that he perceived his symptoms as being close to schizophrenia, which caused him to delay seeking medical advice.

The whole problem was that if I thought it was just depression, I probably would have gone to the doctors a long time ago. But, um, I literally, because I have a habit of seeing things and hearing things, I just nailed it down to um, schizophrenia. So eh, that's, you think of it as just a personal sin. Respondent 501, lines 211-218

Respondents' perceptions of their symptoms were influenced by previous experiences of depression. Some interviewees who had had previous episodes of depression reported that they sought help earlier because they realised that these symptoms were signs of a more serious condition developing.

And it's not the first time I've suffered from depression, so I know the symptoms and I know like, the reasons why I feel the way I do. And I just don't like it to get out of hand.

Respondent 332, lines 41-45

I could feel signs, things coming back that I didn't like and I thought well I'm not going to let it go too far because I would hate to go back into that situation. Respondent 431, lines 105-112

Mechanic (1968) identified recognisability of symptoms as one of the variables affecting general help-seeking behaviour (see section 2.3.1). In the study being presented in this thesis, the recognisability was based on previous experience of the illness.

In contrast, Hagerty et al(1997) found that respondents suffering from repeated depressive episodes denied early symptoms of it. However, she also found that as the episode progressed respondents could identify symptoms which signified the onset of an acute attack. It was at this point that they sought help. Therefore, although there was an initial delay in seeking help in Hagerty's study, past memories of depressive episodes still influenced respondents' help-seeking behaviour.

Zola (1973) discussed the social consequences of symptoms but did not consider their perceived effect on fatality. Mechanic (1968), however, identified perceived

seriousness of the symptoms as one of the variables affecting help-seeking behaviour (see section 2.3.1). Some respondents in this study reported that they sought help because they thought they were at risk of suicide.

I was sort of literally within days of killing myself, um, so I went to my GP. Respondent 438, lines 114-117

Therefore, although Zola's triggers helped explain some of the help-seeking behaviour observed in this study, findings from other theories had to be incorporated in order to account for other aspects of it.

#### 6.1.2 INITIAL EXPECTATIONS OF CONSULTATIONS AND TREATMENT

There were a range of views regarding the expected outcomes of the initial consultation with the general practitioner. As has been found in a previous study (Karp, 1993), the decision to seek professional help was not necessarily analogous with the decision to take antidepressant medication. Rather seeking a consultation, being prescribed antidepressant medication, having it dispensed and actually taking it were all separate parts of the decision-making process. When asked about their expectations of the initial consultation, some respondents reported that they had anticipated medication. However, 3 interviewees reported that they simply wanted counselling or a listening ear.

Eh, just, I just wanted to speak to someone about it, someone who could understand what I was going through because these things are, kind of, things that I cannot speak to my husband about.

Respondent 308, lines 152-157

Other respondents reported seeking confirmation of their status as being unwell. They wanted a definite diagnosis along with the knowledge that treatment was available.

Um, I just, I think I went to the doctor more for some sort of reassurance. ... Somebody to tell me your problem is this. You know, you'll get better. Respondent 405, lines 68-75

One respondent wanted a medical exemption certificate.

Well my first expectation actually was to get some time off work. Respondent 302, lines 514-515 This indicated that she sought entry into the sick role (Parsons, 1951), becoming temporarily exempt from social obligations while taking steps to becoming well. However, entry into the sick role for patients with a diagnosis of depression may be more complex than for patients with other conditions as indicated by the fact that one interviewee had found that his health insurance was invalid for depression, unless he had been seen by a psychiatrist. A specialist rather than general practitioner diagnosis was required.

Other respondents saw the general practitioner as a source of potential help but were unclear as to what to expect from the initial consultation.

Eh, I don't think, I don't really know. I just wanted something to make me better and to stop the crying and to stop me being miserable. Respondent 318, lines 191-195

Um, to be fair I didn't really have any, I think I can say fairly certainly that I didn't have really any expectation about going to the doctor um, at the time, because I was possibly too ill to have any expectation. Respondent 532, lines 153-158

When doctors suggested, in the consultation, that respondents take medication there were a range of views regarding its usage. Some respondents reported that it took time before they wished to try pharmacotherapy.

I'd turned them down before, the time when he actually prescribed them, the 6 weeks before he said do you want them and I said no, I didn't want them ... but because things were getting so bad at the time, the next time I saw him that's when I said yes, I would have them.

Respondent 528, lines 826-836

Medication was thus perceived as a last resort when other measures had failed.

I just wasn't keen on it. But it's just when I realised talking to myself wasn't going to do it [that I took medication].

Respondent 303, lines 108-111

Some respondents were not currently taking medication, but expressed a feeling of reassurance that the option was available if their condition deteriorated.

I think it's useful to know that there is something there if I just feel I can't cope at all.

Respondent 302, lines 307-309

Where respondents took the decision to take medication, some reported that they were hoping for a miracle cure.

But you know, you read about antidepressants and you hear about them. You think that's going to change everything.

Respondent 406, lines 205-207

However, others stated that they simply wanted to return to normal life and functioning.

I'm not looking for something to help me make my life improve. Only the standard of my life that I'm used to. Respondent 106, lines 279-281

Obtaining a miracle cure and returning to normal functioning may, in fact, be part of the same perspective. Returning to normal life and functioning for a person with a diagnosis of depression may be felt as a miracle.

## Expectations regarding length of antidepressant treatment

This section describes respondents' initial expectations regarding the length of time for which they would be taking antidepressant medication.

The majority of respondents began with the perspective that their medication would be a short term treatment or did not give it much thought.

I never thought that I should take them long term. I just thought, just to get me through that little [terrible time]. That's how I view them. Just to get me through that little terrible time. [Respondent who had taken medication on several occasions but never for longer than two months]. Respondent 301, lines 1012-1016

Um, I don't know, I haven't really thought about it, maybe, either until things pick up in general or until, I can notice it, they are taking some sort of positive effect. My mind's so busy with my other problems, I haven't got time for anything else.

Respondent 332, lines 425-430

It became apparent from the analysis that some respondents' expectations, regarding treatment time, were linked to doctors' own beliefs or to the information which they gave to patients at the initial consultation. Some interviewees reported that length of treatment was not discussed at the beginning of treatment. They were simply given a month's supply and told to return when necessary. This led to respondents being

unaware of clinical guidelines.

I had no idea. Um, I thought maybe a couple of months or something. I didn't know eh what to expect.

Respondent 429b, lines 187-189

It is conceivable that doctors had discussed treatment time with some of the respondents but that they did not remember this, as recall of this time was low (see section 6.7.6).

Other respondents reported being given clear information about the recommended treatment length and were therefore expecting to be taking their medication for a longer time.

He thinks it reduces the chance of a relapse if you stay on medication for 6 months or somewhere around that period. Um, and it was always his intention to keep me on medication for that period and he made that clear from the outset.

Respondent 532, lines 670-677

However, in some cases, it became evident that doctors had suggested a treatment length which was shorter than that recommended in the treatment guidelines.

He say maximum, it might take about 6 months, one month to 6 months. Respondent 424, lines 397-398

In contrast to the majority of cases, one interviewee did not share the same opinion of the doctor regarding treatment length. She had had previous experience of taking antidepressant medication and expressed concern that the length of treatment recommended by her doctor would be insufficient.

She said you need 2 or 3 months at least and that concerned me because I thought is that enough? Um, because I didn't want her to suddenly say right I'm not going to give it you anymore and for me to get my depression. Respondent 013, lines 241-246

Respondents' initial expectations of treatment impacted on later decision-making in some cases as illustrated in the example below.

They were good actually, they did the trick. He said I could have some more [if I went back to him] but you know, I thought I'd get on with it now. [Respondent who discontinued treatment after one month]. Respondent 526, lines 158-161 Similarly, other interviewees reported discontinuing their medication before the recommended treatment time as they felt it was no longer necessary.

I just didn't feel like I should continue taking it, feeling so well. Respondent 301, lines 869-870

Other studies have also shown that patients discontinued medication because they felt better (Maddox et al. 1994; Lin et al. 1995). However, analysis of the data being presented in this thesis indicated that discontinuing due to feeling better was associated with respondents' initial views of wishing to take the medication for as short a time as possible.

To conclude, interviewees were at 'crisis point' at the time when they sought help. The identification of the need to seek help at this time was influenced by a number of different factors, some of which were the same as the triggers identified by Zola. Although some respondents had expected a prescription for antidepressant medication, other interviewees reported that they had consulted the general practitioner to obtain a diagnosis or for a referral for counselling When medication was prescribed, the majority of respondents viewed it as a short term measure.

## 6.2 Respondents' perceptions of the positive and negative aspects of taking antidepressant medication and the impact of these on decision-making

Section 6.2 discusses the themes which have been identified, from the analysis of the transcripts of interviews, regarding the role of medication in the context of respondents' illness and every day life. Some general observations regarding factors associated with respondents' medication taking behaviour are first made. Respondents' perceptions of the positive and negative aspects of treatment and the impact of these on decision-making are then described.

Two approaches to medication taking behaviour have been discussed in the literature. Medication taking behaviour has been discussed in terms of patients' ability to remember to take their medication correctly (Mcgavock, 1996). However, more recently, it has been analysed in the context of patients' beliefs about their illness and medication (Donovan and Blake, 1992; Adams et al. 1997; Conrad, 1985; Britten, 1994; Morgan and Watkins, 1988). In the majority of cases in the study being presented in this thesis respondents' medication taking behaviour resulted from deliberate decision-making, arising from interviewees' feelings and experiences concerning their medication. Unintentional non-compliance was only mentioned in 2 cases. Even in these cases, the role of treatment in interviewees' lives may have been associated with medication taking behaviour. Depression was not the major focus in either respondent's life at the time when they reported forgetting to take their medication. One of the respondents was more focussed on her physical condition than her depression and the other one perceived that the reason he forgot to take his medication was that he was feeling better.

Um, I forget to take it every now and then, usually by a day. Um, I think that's a good sign. If I forget to take it I'm not thinking every morning I must have it, help me out.

Respondent 405, lines 126-128

The remainder of section 6.2 will therefore discuss perspectives of treatment associated with deliberate decision-making. Interviewees reported that their feelings about taking antidepressant medication were influenced by their attitudes to taking medication in general. In the majority of cases attitudes to taking medicines in general were predominantly negative.

My basic thoughts on medicines are if you can get by without them, so much the better. Respondent 505, lines 430-432

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However, respondents reported that they were willing to take medication if they perceived it as being necessary. This view towards medication has also been found in another study concerning patients' perspectives of medication (Britten, 1994). Britten (Britten, 1994) noted that in a general practice population, a strong theme emerging from analysis of interview data was that patients preferred not to take medication if possible.

On the other hand, one interviewee, in the study being presented in this thesis, was positive about using measures, such as medication, to improve health.

To be honest, I'll try anything new, if it's something for my health, I'll try it. You haven't lost anything. So um that was my reasoning [in deciding take antidepressant medication].

Respondent 529, lines 526-529

However, many specific factors relating to antidepressant medication influenced interviewees' decisions, beyond their feelings about medication in general, as will be discussed within sections 6.2.1 and 6.2.2.

## 6.2.1 RESPONDENTS' PERCEPTIONS OF THE POSITIVE ASPECTS OF ANTIDEPRESSANT MEDICATION USE

Section 6.2.1 describes the role of medication in the process of recovering from depression. Associations between interviewees' perspectives of the benefits of their treatment and their medication taking behaviour are discussed, where appropriate.

## 6.2.1.1 Role of medication

Two different stages were identified in the interview data, where benefits of medication were noticeable. Firstly, making the decision to take antidepressant medication gave some respondents a different perspective of their illness. It helped some of these interviewees to feel that they were taking control of their disease. These respondents can be thought of as having an internal health locus of control (Wallston et al. 1978) i.e. they perceived a relationship between their own actions and expected outcomes.

I would know that I was taking steps to do something about it, not to just keep going and it would go on affecting me. I wanted to actually change the situation and it was one way I felt I was able to do it. Respondent 015, lines 184-189 For another interviewee, making the decision to take antidepressant medication provided a means of hope that recovery from his condition was possible.

I was clinging onto that one hope and I wanted, I wanted it to work. Respondent 101, lines 366-368

Secondly, there were a range of views regarding the benefits of medication once it had begun to take effect. However, no respondents regarded antidepressant medication as being a miracle cure.

You think it's going to be a guarantee to make you happy all the time but it's not. Respondent 428, lines 519-521

None of the interviewees reported that antidepressant medication had produced feelings of euphoria. A lack of this type of effect was explicitly mentioned by some respondents.

I didn't get the high that everyone says you get on you know, there was no, none of that.

Respondent 319, lines 298-300

Some interviewees viewed the lack of an euphoric effect as an advantage.

It doesn't make me irresponsible, like you know eating magic mushrooms. Respondent 106, lines 392-396

Although medication was not regarded as being a miracle cure, it was perceived as aiding the return to normal life and functioning by the majority of respondents.

Basically, the basic thing is I feel a lot more stable. I feel I can cope. ... I'm able to have some kind of normasy (sic) anyway. Respondent 501, lines 1045-1052

I think it's coming back. I think I can see things more clearly. I'm back to the way I should be. I can enjoy myself.

Respondent 015, lines 607-610

In the majority of cases, returning to normal functioning was perceived as the ability to fulfill social roles. Interviewees reported being able to carry out activities which their illness had prevented them from doing, for example returning to work or having improved relationships with family or friends.

I can actually go shopping in the store that I want now. You know, so they are helping me like that. [Respondent who had previously avoided places where she would meet people she knew].

Respondent 503, lines 538-540

With work, yeah, it definitely helps being able to know that I'm going to be able to get up in the morning. [Respondent who had been unable to work at some points during her illness].

Respondent 435, line 157

Um, well I go out more and socialise and meet up with friends. Whereas when the anxiety was at its worst there wasn't any such inclination to do that. So that's a positive step in itself.

Respondent 438b, lines 60-64

One aspect of improved social relationships was that some interviewees believed that the lives of those closest to them were better as a result of respondents' treatment.

It's the snappiness [that's gone]. It's made her life better because we're back how we always used to be.

Respondent 106, lines 723-725

I think it's made me nicer to live with than I was.

Respondent 409, lines 223-224

One respondent reported being concerned about coming off her medication in case her friends could not cope with her relapsing.

So your brain sort of says well hang on a minute if you're cutting it down then you know, what if I'm not better and all that started creeping in. Do you know what I mean? What if I go back to how I was ... can my friends stand it? I doubt it.

Respondent 319, lines 307-314

The feeling of normality for one interviewee was being able to feel sad. He reported that his medication removed the physical and psychotic features of his illness. This respondent was of the view that his diagnosis may have been schizophrenia rather than depression.

It's not really [that] I'm incoherent or my mind's wandering. I just feel depressed, almost tearful, so to speak. Um, I actually quite like the feeling. [Laughter]. It's a lot better than everything else I've gone through so, it's a lot better. It's actually quite calming in some way, I'm not sure why. But it's calming in certain respects.

Respondent 501, lines 296-306

Some respondents reported that medication also relieved the physical symptoms

associated with depression.

It helps my blood pressure settle down, as well as the blood pressure tablets. I don't know, I suppose being depressed puts your blood pressure up. Respondent 506, lines 260-264

Kleinman and Cohen (1991) noted that advertisements from drug companies encouraged patients to take antidepressant medication in order to meet the demands made of them by society. Returning to normal functioning was an important role of the medication for the interviewees in the study. Similarly Conrad (1985) found that the most important reason for taking anticonvulsants was to lead a normal life. However, in Conrad's study it was the reactions of others to seizures which otherwise prevented interviewees from leading a normal life whereas in the study being presented in this thesis it was also the symptoms of depression themselves. The difference in the findings is possibly due to distinctions between the course of depression and epilepsy. Symptoms of depression are constant rather than occasional and may therefore have a more direct association with functioning than epilepsy.

## 6.2.1.2 Process of recovery

The majority of interviewees regarded the return of normal functioning as a gradual process, where fluctuations occurred. The gradual process took place whether respondents were being treated with antidepressant medication or complementary therapy (see section 6.5.1.1).

It's carried me forward. It's been slow. Respondent 001, lines 199-200

I wouldn't say that the medication or anything really had a dramatic effect. Um, you can almost draw a graph where things get better, then a bit worse, then a bit better, then a bit worse but things generally, the general trend is getting better.

Respondent 532, lines 284-290

Some respondents reported being disappointed when there had been an initial fast improvement and then their progress had slowed down or they had experienced a period of relapse.

I think the first week, I don't know whether it was all psychological but [ I thought] yes, I['ve] got these tablets. Yes I'm going to be absolutely fine. And I was, I perked up an awful lot and that was ok. And that was 2 weeks and then I hit like a stalemate and I went down hill again.

Respondent 503, lines 364-371

One interviewee had been extremely satisfied with his treatment at the time of the first interview. However in the second interview he described how he had become slightly disillusioned with the medication.

And I thought well that was it, this is like my magic pill. And then I started having problems at the end of November, beginning of um December and then I started getting bouts again.

Respondent 501, lines 19-23

These periods of relapse experienced during the treatment process, might have been predicted to lead to discontinuation of therapy in some cases. However the latter 2 interviewees persisted with their medication despite periods of relapse and found that the upwards trend continued. In addition, 2 interviewees described how a relapse had influenced their decision to proceed with treatment as it had increased their perceptions of their susceptibility to the illness.

Especially now. I mean before, when I was first on them, when I got the benefits from it, to start with I thought I didn't actually need it because I know that I can actually feel good. I can do it on my own without the medication but now I'm starting to get used to it I realise that I do need it. Respondent 529, lines 260-268

This finding may have been influenced by the possibility that those who participated in the study were more positive about antidepressant medication than those who declined (see section 6.7).

## Exceptions to the slow recovering process

There were some exceptions to the slow recovering process. A minority of respondents described experiencing more sudden improvements. One interviewee reported a difference between changing medication and beginning a completely new course.

Um, the effect was quite, quite quick and quite dramatic [when I started taking the new tablets]. I mean within, within the space of a few days of taking them, I mean I know they take a while to work. Um, but I think because I was on ... something already I think they worked a lot quicker. Um, but within the space of a few days I, my mood had almost lifted. Um, I was feeling more like my old self. Um, but eh, I mean it didn't suddenly transform me. I'm not saying that but um, but it left me feeling better than I had done for a long time, so I think, I think the new medication that I'm on is helping. Respondent 532, lines 392-410

In addition, although some interviewees had taken their medication for a shorter period of time than is recommended in the treatment guidelines (see section 5.2.5), a few of these respondents still found them effective.

Um, it's a pick me up, like you'd drink a glass of orange juice to give you a burst of energy.

Respondent 106, lines 258-260

It got me out of the cycle of panicking. ... The way I see it, it was there for a purpose and it fulfilled it.

Respondent 015, lines 222-223 236-238

### 6.2.1.3 Extent of recovery

Even in the course of time, the medication was often perceived as having some effectiveness, but not alleviating the depression entirely.

As I say, I still feel depressed but not depressed enough to stop me sleeping and this sort of thing. I get more relaxed.

Respondent 506, lines 199-201

Um, I think that on sort of entering this sort of depressive state um, you get this sort of great dive into this endless pit you can't really see your way out of it and I think the tablets just sort of clip the bottom off the trough and don't allow you to go any further down.

Respondent 504, lines 180-187

Some respondents commented that complete recovery was not possible as medication could not change the life circumstances that had they viewed as having caused depression. (As reported in chapter 7, the majority of respondents believed that depression was caused by factors in the immediate social environment such as bereavement, day to days problems and traumatic events).

It doesn't help in the long run because the problems are still there, they don't go away.

Respondent 332, 161-163

However, other respondents reported that their medication had helped them to cope with the stressful situations in their life.

I noticed in myself that ... although it was a tough thing I had to deal with again, that I dealt with it a lot better than I had done in the first place. Respondent 428b lines 322-326

Respondents' associations between taking medication and coping with stress impacted on medication taking behaviour. Some interviewees stated that their need to continue with treatment would depend on how long their present circumstances continued.

But I think for me, having to do this Master's, I need to stay on it until I finish. Respondent 403, lines 242-244

I still need them at least until I find out if I've got a job or somewhere to live, you know.

Respondent 506, lines 270-272

Another interviewee reported that he reduced the dosage of his medication intermittently, whenever he was at a distance from his work.

I just reduced the [dosage], I just missed out alternate days, like that, with no [work], lulling by the swimming pool in the South of France, I felt that was kind of a safe, stress free situation.

Respondent 016, lines 539-544

Some interviewees found it difficult to talk in terms of their degree of recovery because they felt that after an episode of depression, permanent psychological changes had taken place. These respondents expressed the view that they would never return to what had previously been their perceived normal condition. Some respondents perceived this as a negative aspect of depression.

I think it helps you to be more yourself. I think you can never be who you were before. I don't think I'll ever go back to being the same me. Respondent 530, lines 328-332

However, others were not sure that it was negative and simply thought of it as different.

I think I've got a very different view of life now. ... [than I had before I became depressed] I don't think I'm going to feel a lot better than I'm feeling now. It's certainly different. I'm being more conscious [of my needs] and ... I don't want to return to that state [of being depressed].

Respondent 504b, lines 246-248 290-294

Coyne and Calcaro (1998) found that the experience of depression continued to affect the way in which sufferers structured their lives even after recovery had occurred. The latter 2 quotes indicate that this applied to some of the interviewees in the study presented in this thesis. However this finding was not applicable to all the respondents. Some interviewees perceived that their recovery was near to completion and that their illness did not continue to affect them.

#### 6.2.1.4 Attributions of benefits

A recurring theme was that medication on its own was not a cure but helped in conjunction with other factors (see section 6.5).

Part of taking the medication, um, is that I realise that medication on its own ... won't help me. I've got to help myself as well.

Respondent 405, lines 66-68

The majority of respondents were unsure of the exact contribution of medication in aiding their recovery.

And I think yes the medication has helped um, but it's difficult to determine quite how much it's helped when you've had a circumstance change as well. Respondent 532, lines 262-266

Some respondents were of the view that this uncertainty was due to the fact that the chronic nature of the treatment process made it difficult to build an association between cause and effect.

Um, it's difficult to say [what's caused the improvement] really. It's um, it's a very intangible sort of improvement. I mean it's not noticeable day by day but eh, viewed over a, sort of, longer term you notice sort of differences. ... so I don't know what it [is], I mean the medication's part of a factor. Respondent 438, lines 70-75

I'm not really aware of them. They're not, sort of, like a headache tablet, you know, you take it and it solves the problem.

Respondent 504, lines 134-137

When you're having a good day and you wake up and it's like ok, let's face the world, that's when you think well I don't need them. You know if you're having a good day you don't associate the 2 together. You don't [think] that maybe the reason that you are feeling as good as you do feel is because of the tablets that you took yesterday and to keep you on an even keel, you should take it today and you take it tomorrow.

Respondent 503, lines 712-726

In order to know the precise effect of the medication, respondents would have needed to have been able to differentiate between their status when taking or refraining from medication. This was reported as being difficult as respondents could not have both taken and refrained from treatment.

If I didn't take it, what would have happened? So it's very difficult for me to judge its effect on me.

Respondent 101, lines 997-999

However, some interviewees reported that they had developed ways of assessing differences in their well being. For example, one interviewee built an association between cause and effect by writing a diary of how she felt in order to assess whether or not the treatment was helping.

Um, I kept a record of the problems I was getting because I've got an incredibly bad memory for time and so I won't be able to remember, I can't now remember exactly how I was feeling then. But I didn't want to feel like that and I wanted to be able to see if I was coping better or not.

Respondent 015b, lines 159-169

Other interviewees reported that they would evaluate the situation after discontinuing the medication.

Now whether that it is because of the medication or it's because I've got back to work and everybody's been supportive. Again I won't know that until [name of doctor] says right, that's it, we don't need to give you any more, see how it goes.

Respondent 524, lines 1609-1605

One interviewee reported that discontinuing the medication as a test may be necessary. This aspect of medication taking behaviour has also been described by other authors (Conrad, 1985; Karp, 1993).

You won't really know when you are feeling better. I think you actually have to come off it to see ... whether it's going to work or not. Respondent 403, lines 225-230 However, a more common reaction to the uncertainty of how much the medication was helping, was to continue with treatment. This was due to fears of relapsing on stopping the medication.

It could be again because of [the] medicine, or because I'm taking things easy ... So I don't know exactly why. I just want to carry on with [the] medicine in case.

Respondent 424, lines 429-436

Nevertheless, some interviewees reported that they felt confident in the security that they could go back to taking medication if they needed to. One respondent kept the medication in case of need for future use.

If [my life] goes through a down would I cope or not? And also although I don't use them, I still actually have the pills, which gives me a good feeling. Respondent 015, lines 289-291

Models of health behaviours discussed by Demyttenaere (1997) suggest that a lack of tight association between using treatment and positive outcome leads to noncompliance. However, respondents in the study being presented in this thesis continued with medication despite being uncertain about the effectiveness of medication. This finding may have been influenced by the fact that the sample was biased towards patients who were more positive about taking antidepressant medication (see section 6.7). However, it may also show that the picture of compliance is more complex than models of health behaviour show. Demyttenaere (1997) did not discuss evidence of the application of these models to populations of patients with a diagnosis of depression.

## 6.2.1.5 Exceptions to the effectiveness of antidepressant medication

As would have been expected, some respondents considered their tablets to be ineffective. In some cases this was reported as being resolved by changing the medication or dosage (see section 6.4). However this was not always the case.

So far, I'd say they weren't doing anything whatsoever. To me it's just like taking, eating a sweet. I haven't felt anything really even since I've upped [the dosage].

Respondent 441, lines 102-106

Three interviewees reported that they had not taken their medication for long enough for an effect to have been built up.

So I don't know whether they would have helped me or not as I say I've never got far enough into them to know.

Respondent 528, lines 117-120

One respondent stated that it took 10 weeks until the medication had any effects.

I think they have taken 10 weeks and I think they've just recently kicked in because um, last week I noticed an elevation in spirits, you know. Respondent 504, lines 282-287

In 2 other cases, interviewees reported that they found their medication effective initially but the improvement only lasted a short period of time. In contrast to the respondents mentioned in section 6.2.1.2, this lack of effect was not due to a temporary relapse during the recovery process.

I think it gave me energy for a limited time, the first 2 or 3 months. And then after about 3 months I started sleeping a lot again. And after Christmas it got bad, I was sleeping so much that I had to do something. Respondent 013, lines 901-906

Two interviewees found that medication had helped them with a past episode of depression but reported that they were less effective on this occasion.

But this time, I don't know, I just didn't feel. Maybe because I was feeling better. I just, I didn't feel it helped me to sleep, like it did the other time. Respondent 301, lines 319-322

However, although some interviewees reported that their medication had been ineffective, it did not appear to be a major influence on patients' decisions regarding their medication. Lack of effectiveness was only given as a reason for discontinuing medication in 2 (4%) cases. It was not reported as the sole factor, influencing the decision to stop therapy, by either of these respondents. In contrast, other studies have shown that 15% (Maddox et al. 1994) to 17% (Lin et al. 1995) of patients discontinued antidepressant medication due to the fact that they felt their medication was not working. There were several possible reasons for the difference seen in these findings. Firstly, the type of data collected differed between the studies. Previous research (Maddox et al. 1994; Lin et al. 1995) used quantitative questionnaires to ascertain patients' self reported reasons for discontinuing treatment. The responses given were not, therefore, in the context of patients' experiences. It is possible that lack of efficacy was only one factor in the whole process. For example, in the study being presented in this thesis, respondents felt that their medication wasn't working due to the fact that they experienced adverse drug reactions which were perceived as

worsening the symptoms of their disease state (see section.6.2.2.3). In previous research (Maddox et al. 1994; Lin et al. 1995), patients may have reported lack of efficacy as a reason for discontinuation if they considered adverse drug reactions as worsening their disease state. Secondly, the samples may have differed between the study being presented in this thesis and previous research (Maddox et al. 1994; Lin et al. 1995). None of the 3 samples can be considered to have been generalisable, due to the sampling methods used in previous research (Maddox et al. 1994; Lin et al. 1995) and the response rate achieved in the study being presented in this thesis. Patients who discontinued due to lack of effectiveness may have been less likely to take part in the study being presented in this thesis. There were indications that patients only participated in the interview when a degree of recovery had taken place (see section 6.7.2).

Overall, respondents perceived medication as having benefits but did not consider it as an easy solution. Despite the fact that several factors in respondents' accounts of their experiences may have been expected to encourage discontinuation of treatment, respondents in this study did not report these as reasons for stopping medication. Moreover, periods of relapse during treatment, encouraged some respondents to continue with treatment (as cited in section 6.2.1.2).

# 6.2.2 RESPONDENTS' PERCEPTIONS OF THE NEGATIVE ASPECTS OF ANTIDEPRESSANT MEDICATION

Throughout the interview data, perceptions were identified that described negative aspects of drug treatment. Section 6.2.2 discusses each of these negative aspects in turn. These include stigma, dependency, adverse drug reactions, interactions, contra-indications and expense.

## 6.2.2.1 Stigma

Feelings of stigma were associated with taking antidepressant medication. Section 6.2.2.1 will describe these feelings followed by mechanisms by which respondents dealt with this stigma. Finally, views which appeared to contradict the main findings will be considered. Two theoretical approaches were incorporated into the study findings, Goffman's theory of spoiled identity (1964) and Scambler and Hopkins perspectives of 'felt' and 'enacted' stigma (Scambler and Hopkins, 1986).

In agreement with other findings, (Priest et al. 1996; Crisp et al. 2000; Coyne and Calarco, 1995; Karp, 1994; Schreiber, 1996) the majority of interviewees in this study experienced some degree of stigma towards their condition or treatment. The issue was addressed in the interview schedule by the question 'How do you feel about other people knowing that you take your medication?'. However the issue was raised frequently by participants in other parts of the interview, both preceding and following this question. The comments were made during discussions about the use of medication.

## Stigma and depression

In this study, the stigma that respondents associated with being depressed may be interpreted as 'felt' stigma (Scambler and Hopkins, 1986) in the majority of cases. 'Felt' stigma refers principally to the fear of discrimination on the basis of perceived unacceptability or inferiority, as opposed to actual instances of discrimination. A recurring theme was that depression was an illness that was misunderstood by society.

I think there's quite, quite a stigma attached, attached to depression. Um, I think for people that understand what's going on, I don't think there's a problem, but I think the majority of people, you know, generally speaking, don't really understand much about the illness.

Respondent 532, lines 492-499

I mean as far as advice from other people goes, it's very strange how people see depression. Um, I think there's this sort of feeling, snap out of it. And it's just not like that, you know. And I think that's how I was reading colleagues at work. And um, yeah, it's not really like that.

#### Respondent 504, lines 438-444

I wanted to go and see a psychiatrist at the time and my partner was very much against it because he thought it was a kind of mission that I wasn't right in the head, sort of thing.

Respondent 302, lines 457-461

Fears of discrimination by employers were reported by 3 respondents.

And if you've had a nervous breakdown you'll find it very difficult to get another teaching job. You're labelled for life as some sort of freak. That's what I think.

Respondent 014, lines 663-667

The respondents who expressed concern about discrimination by employers all worked in education. One such respondent had worked in both education and free lance production and distinguished between the 2 professions in terms of fears of discrimination.

I mean, in production no one gives a D! Because most people in their life time at some point or another have probably taken sort of Prozac or something like that but in education I'd have a real trouble getting a full time job having taken antidepressants, looking after 16 to 19 year olds you know, young adults. Respondent 319, lines 443-452

'Felt' stigma also encompasses a feeling of shame (Scambler and Hopkins, 1986). Many interviewees described having the feeling that they were, at least in part, responsible for their illness. These respondents perceived that their health status was a consequence of their own actions and therefore under personal control. Wallston et al (1978) described this as an internal health locus of control orientation.

You know, I do see it as a, like a failure. You know why can't I cope? Other people cope.

Respondent 409, lines 174-176

It was not something that you would say was just happening to me. It's something that I must have contributed to. It must be something about me and I don't like that.

Respondent 015b, lines 266-270

However, there were also some reported instances of 'enacted' stigma (Scambler and

Hopkins, 1986), i.e. actual experiences of discrimination.

They didn't respect my judgement of anything when I was taking the medication. Respondent 312, lines 515-517

#### Stigma and antidepressant medication

From the interview data, 2 ways were identified in which antidepressant medication was associated with 'felt' and 'enacted' stigma. Firstly, taking antidepressant medication was perceived as labelling the respondent as being depressed and thereby conveyed the associated stigma of the disease. The stigma attached to the medication was therefore intertwined with that of depression.

And it's not so much I'm, I'm worried about, I'm concerned about them finding out that I'm on medication, it's the fact that I'm more worried about them finding out more about my illness. ... But I think the 2 are quite strongly linked anyway, so obviously you try and possibly slightly cover up the fact that you're on medication. So um, I think one leads to the other really. Respondent 532, lines 500-504

The receipt of a first prescription for antidepressant medication was perceived to produce a change of identity which was difficult for respondents to accept.

And when I came out I did feel quite odd because she gave me a prescription. I couldn't. I suddenly felt like I fell into a bracket of a type of people, emotionally in my head. Which is quite a strange feeling really because ... I'm not like I thought I was and now I'm a bit different. Respondent 428, lines 167-174

Some respondents reported finding it difficult to reconcile receiving the prescription with their previous self identity.

So I couldn't, first of all I could not believe that I was on, I was feeling like this, I mean I needed Prozac. That was a big culture shock for me. Respondent 101, lines 280-283

Similarly, Karp (1994; 1993) found that respondents suffering from depression had an initially strong negative reaction to taking medication as it was one of the factors confirming their status as that of being chronically ill rather than just merely troubled. Goffman (1964) described 2 groups of people, 'normals' and 'stigmatised'. While Goffman did not dwell on the means by which people acquired the identity of being stigmatised, the mentally ill respondents that he discussed had all been
institutionalised at some point in time. It is implied that having been institutionalised labelled them as mentally ill. However, the interviewees in this study were living within a community setting, very few having ever been hospitalised for their condition. Thus the only label of mental illness for them was the fact that they were taking antidepressant medication. Evidence was found, in the interview data, that being prescribed antidepressant medication changed respondents' statuses from 'normal' to 'stigmatised'. Similarly, Conrad (1985) noted, in his study of people suffering from epilepsy, that where respondents were seizure free, taking anti-epileptic medication was the only factor confirming their status as 'epileptic'. The medication itself thus represented the stigma of epilepsy. The stigma could be both 'felt' and/or 'enacted'.

Secondly, taking antidepressant medication carried an additional stigma, beyond that of depression. There were indications that this stigma was connected to the view that psychotropic medication would affect cognitive functions. This type of stigma was based on actual discriminatory remarks by others and was therefore 'enacted' stigma.

He had a very bad reaction to the fact I was diagnosed with depression and even more so when I told him I was taking medication. Respondent 312, lines 436-439

Um, when I first started to feel as if I wanted to go and see the doctor all [name of husband] said to me was he's going to put you on tablets that are going to make you into an idiot. I think most people think immediately you know, you're going to be drugged up to the eye balls, that's what most people think. Respondent 503, lines 896-904

# Stigmatising factors associated with medication

A number of factors were perceived to contribute to the stigma associated with taking antidepressant medication. These factors included being of a younger age, the changing attitudes that people had acquired towards antidepressant medication over time, having a relative with bipolar depression, the social environment of the interviewee and previous use of psychotropic medication. Each of these factors was only raised by a small minority of interviewees.

One interviewee, who had taken the medication on a past occasion 5 or 6 years previously, expressed the view that the stigma had increased in recent years.

The very negative image I think [that there is] now in the press, ... I don't know if I'm correct in that but my perception is ... that people have got a more negative image towards taking it.

Respondent 013, lines 772-786

From the interview data, it was identified that being of a younger age was a stigmatising factor for some respondents.

I mean I suppose my family would feel that why are you going on antidepressants? You are young. From an age point of view you're in a situation where you don't need to go [on them].. Respondent 009, lines 647-651

One respondent described how her doctor held the view that she did not approve of taking antidepressant medication at such a young age.

And she didn't want to put me on any medication. She said she don't believe in it. I'm too young to be on it.

Respondent 005, lines 570-573

Two interviewees had relatives with manic depression and they reported that this increased their own feelings of stigma towards taking antidepressant medication. They were concerned that by taking the same medication as their relatives, they were associating themselves with the same condition. In one case the stigma was 'enacted' but in the other it was the respondent's own associations which were important.

Well, I have to say my sister's manic depressive ... Um, and I really didn't want to take an antidepressant because of my sister. I didn't want to. ... I worry about not sleeping because that's also a symptom of my sister. But I know, I mean I do know, now, sitting here being intelligent, that I'm not having the same symptoms as my sister, but it worries me. Respondent 303, lines 88-90

409-414

From the interview data, it can therefore be suggested that bipolar depression had more stigma associated with it than unipolar depression. However there were indications that clear distinctions were not always made between the 2 types of depression, possibly due to the fact that the same medication was used.

Previous research has identified that ethnicity is an important determinant in the way in which mental illness is viewed (Smaje, 1995). Similarly, in the study presented in this thesis some respondents indicated that their ethnicity contributed to the stigma which they felt. [I was] unhappy to be on it because [in] the culture we come from, we're Sri Lankans, any behaviour like this, they will suppose we're mad. Respondent 101, lines 270-276

However, in this study it was not only respondents' ethnic groups but also the social environment in which they existed within those groups which were important. It was considered as more acceptable to be taking antidepressant medication in some social environments than others. An example of this has been cited earlier (in section 4.2.2.1) with relation to different vocations. In addition, there was an indication that there was less stigma attached to taking antidepressant medication in prison. One interviewee had taken antidepressant medication in a prison on a previous occasion. In response to being asked how she had felt about other people knowing she took medication she said:

Um, well in that kind of environment a lot of people are. In a place like that it's administered so easily anyway without a second thought. Respondent 332, lines 279-296

Long term past use of benzodiazepines in this study was associated with fears of adverse drug reactions from psychotropic medications (see section 6.2.2.3). In addition, one interviewee reported having strong feelings against taking antidepressant medication which were not related to any particular adverse drug reaction that she had experienced with benzodiazepines, but to a general feeling that she did not want to return to the stage of her life where she had needed them.

So I've got these little bench marks through my life, thinking well I won't go back to there, I can't be back like that, I can't be. ... It's as though I've gone one step forward and massive amounts back.

Respondent 528, lines 356-359

#### Interviewees' responses to stigma

Respondents reported using various mechanisms of dealing with stigma. These included rejecting medication, disassociation of medication from a label, passing, sharing experiences with others and challenging the views of others. All but the last of these mechanisms were used as a response to 'felt' stigma. However, the last was used as a response to 'enacted' stigma, i.e. as a way of overcoming actual instances of discrimination.

## **REJECTING MEDICATION**

During analysis of interview data, stigma was found to be associated with medication taking behaviour. By resisting medication, respondents were avoiding the label of depression and its associated stigma.

I didn't want to go on them. I didn't want to go on them because you think of people with clinical depression.

Respondent 001, lines 147-149

It has been noted that 'felt' stigma encompassed a fear of shame and that respondents described having the feeling that they had a degree of responsibility for their illness. Some interviewees indicated that taking medication was an admission of loss of personal control. This was one of the reasons given for its avoidance.

[The doctor] gave me antidepressants and I thought I'm not going to take [them]. I don't need it, I'm going to sort myself out. Respondent 403, lines 63-66

He offered me tablets for depression or for anxiety and I wouldn't take them because I thought it was weak.

Respondent 525, lines 119-122

In these cases, an internal locus of control was associated with respondents not taking their medication. This finding conflicts with results reported in section 6.2.1. This is discussed further in section 8.3.

DISASSOCIATION OF MEDICATION FROM LABEL

Goffman (1964) argued that stigmatised individuals identified others in their group who were worse than themselves as a means of coping with stigma. Comments from some interviewees, in the study being presented in this thesis, indicated that although they had taken antidepressant medication, they did not perceive themselves as being severely depressed.

Mine's sort of more of a stress depression than anything. I mean people that are sort of deeply depressed, are depressed all the time and they can't control, they don't even know how to control it. But, um, every now and then I just get um, very down.

Respondent 106, lines 67-73 In some cases the fact that interviewees were using this belief as a means of coping with stigma was explicit from their remarks. I don't know whether I can call it depression. May be I make it, maybe I'm thinking it's depression and it's not as bad ... When you hear of people suicidal and they're really in a bad way, maybe I'm just not that bad. That's what I'm trying to think.

Respondent 301, lines 237-244

Respondents were therefore able to disassociate their medication from the disease of depression.

Um, I'm not sure if what I've been taking is for depression, I mean it's very hard to define depression. I always find it a very negative term. I don't like being labelled as depressed.

Respondent 013, lines 39-43

Similarly, Williams and Healy (2001) found that maintaining a level of uncertainty of the identity of their illness, helped new referrals to a Community Mental Health Team, to maintain hope and avoid a socially unacceptable identity. Dowell and Hudson (1997) demonstrated that the barriers to accepting medication for general conditions could be overcome by considering the medication as trivial and therefore not a sign of illness.

This phenomenon of separating medication from having a disease can also be seen by the fact that some interviewees in the study being presented in this thesis preferred benzodiazepines as they could be taken on a when required basis.

I was able to, um, just take it occasionally, instead of taking it continuously. Respondent 427, lines 94-97

Interviewees expressing a preference for benzodiazepines had had them prescribed recently and had only taken them short term. Similarly Adams et al (1997) found that some people suffering from asthma reported taking reliever rather than preventative medication. The authors of the study found that taking occasional rather than regular medication signified dealing with a problem rather than admitting to having a condition. It is possible that some interviewees in the study being presented in this thesis favoured taking occasional sleeping tablets over taking antidepressant medication because they felt that this did not label them as being depressed.

# PASSING

Another way in which interviewees reported responding to stigma was by attempting to conceal the fact that they were depressed from others.

When I'm with people but I'm generally, even when I didn't feel well with it at all, I still tried to put on a brave face. I always did that. No-one ever suspects that I was suffering from anything.

Respondent 431b, lines 344-340

This has been identified by Goffman (1964) as the mechanism of passing (see section 2.3.3).

Some interviewees reported that they were selective about who they told that they were taking antidepressant medication, entrusting the information to some close family or friends.

It's something I might discuss with close relatives, but I don't particularly want to. I don't see it as a, you know, dinner party conversation. Respondent 016, lines 466-470

Others told no-one at all. Two respondents remarked that although they had not told anyone they felt that others probably realised. Goffman has identified that those who conceal information, are often unsure what others know about them.

Maybe they can [tell], I mean people aren't stupid. They probably realise that it's caused by depression, also. But I say it's for sleep. Respondent 501, lines 670-673

Goffman (1964) noted that the possibility of passing was dependent on the visibility of the condition. Although he did not discuss the health status of the mentally ill interviewees in his study, it is implied through his commentary that their condition would have obvious signs to indicate to others that they were unwell. The respondents in this study had less visible signs of mental illness than those which Goffman discussed.

You haven't got a green light on your head that's telling people you're a depressive. Respondent 531, lines 1794-1797

However, antidepressant medication was sometimes seen as making the condition visible. Thus it had the possibility of moving respondents from being discreditable to being discredited. Interviewees reported hiding their medication to prevent disclosing their illness.

I covered his tablets if people came into the house. He'd just leave them by the phone where everyone could see. [Respondent whose husband also took antidepressant medication].

Respondent 013b, lines 319-325

However, this was not always possible if there were other visible signs that respondents were taking antidepressant medication. One interviewee described how not consuming alcohol interfered with the normal flow of social interaction, causing him difficulties.

But in those terms and things like going out, particularly around Christmas and going to the pub and it said, my packet said, don't drink ... so I had to keep coming up with excuses why I wasn't doing it. And some people I would, I felt like telling but I don't know, there's a bit of a stigma around taking or being like that. So I decided to say I was on antibiotics and that just made it worse because people would ask me lots of questions about what was wrong with me. Respondent 428, lines 416-429

He reported that not consuming alcohol then probably caused him to be 'discovered'.

I think other people just know because I'm, they just assume that I am but they haven't said to me because of my pathetic excuse about antibiotics didn't and generally, I think you know they just put 2 and 2 together really, I think. Respondent 428, lines 458-463

A fundamental concept in Goffman's work was the great difficulties stigmatised individuals experienced in interacting with 'normals' (Goffman, 1964). People with depression characteristically experience problems with socialising with others. Taking medication and acquiring the associated stigma may worsen this symptom. In the study being presented in this thesis, the difficulties in social interactions relating to stigma, which were expressed by respondents, were caused by fears of discrimination, rather than actual discrimination, i.e. 'felt', rather than 'enacted' stigma. Scambler and Hopkins (1986) found that it was 'felt' rather than 'enacted' stigma which caused respondents suffering from epilepsy, to experience unhappiness and self doubt. The study being presented in this thesis shows that this finding can also be extended to a sample of people with a diagnosis of depression.

SHARING EXPERIENCES WITH OTHERS WITH A DIAGNOSIS OF DEPRESSION

Some interviewees reported that the stigma of taking antidepressant medication was reduced after finding others with a similar experience.

She knew how fed up I was getting because she was in a similar situation with work and she said, volunteered the information then and I must admit I felt a bit more comfortable about it. Um, oh it's not the end of the world you know, it's not that bad. I mean it helped her, it should help me.

Respondent 528, lines 889-897

This finding is supported by those of Kendler (1995) who found that individuals with relatives who had previously sought treatment for depression were more likely to seek medical help. Kendler suggested that one of the reasons for this may be a reduction in the associated stigma. The above finding suggests a mechanism by which this takes effect. Family members would have been an accessible group of people to share experiences with.

However, it can be deduced that respondents were unlikely to meet others taking antidepressant medication, due to the general attempt to conceal the condition. This is illustrated by the remarks of one interviewee.

I can't imagine any of my family took that. I don't know. I don't really [know]. Maybe they keep it secret as well. Respondent 005, lines 453-455

The Internet was mentioned as a source of contacts.

It was good to know so many people were on Prozac. Otherwise you could feel you were a bit strange, thinking you were the only one on it. [Respondent using Internet].

Respondent 414b, lines 41-45

Similarly, Goffman (1964) noted that stigmatised individuals may find support from others in the same group. However, he spoke of this support as a means of being shown how to cope with stigma by using 'tricks of the trade'. In contrast, in this study, its function was to provide an indication to interviewees of how common it was to take antidepressant medication, thereby reducing or removing 'felt stigma'. The respondents in this study lived within the community and possibly had greater opportunity to be perceived (and to perceive themselves) as normal than Goffman's patients who had been institutionalised.

CHALLENGING THE VIEWS OF OTHERS

Rogers and Baffalo (1974) argued that people may use individual or group strategies to reject a label. One respondent identified challenging the views of others as a way

of dealing with discriminatory remarks made by others.

I sort of say well you don't understand. I ask them have you ever had depression and they say I've felt a bit irritable once or twice. So I say you don't sort of understand how it feels to be really depressed and stuff like that. Respondent 403, lines 503-513

Another interviewee went beyond their own individual mechanisms of coping with stigma to the fact the issue should be addressed by society.

Well I think there's a certain stigma, to you know, being on antidepressants and I think it needs to be addressed and if it could be addressed by drug companies or by the medical profession generally. I mean typical, on the television you have programmes like Peak Practice, a doctor's wife was suffering from depression and it's as though you're some sort of freak, you know. Respondent 014, lines 500-510

Goffman's (1964) theories on coping with stigma are very important when considering the interviewees' responses to stigma, particularly in relation to passing and the difficulties that this sometimes caused in social interactions. Goffman also discussed finding others with the same stigmatising attribute and identifying others worse in the stigmatised group as mechanisms for dealing with stigma. This thesis further demonstrates how all these mechanisms related to views and behaviour concerning antidepressant medication.

# Views representing lack of stigma attached to antidepressant medication

A small proportion of interviewees reported being completely open about the fact that they took medication. There were a range of reasons reported for this openness. Some respondents were of the opinion that mental illnesses were equitable with physical illnesses and should not be stigmatised.

Um, I don't think anything about it. I think if people have kidney problems, I think it's the same kind of thing.

Respondent 015, lines 367-370

I didn't mind because I really believe that mental illness is like any other physical illness and it should be treated in the same way and people who are suffering from it should be treated in the same way. And I don't see depression as such a big deal. I mean it's not schizophrenia or something. And even that, why should anyone be ostracised for it, for something. You wouldn't ostracise someone who had cancer.

Respondent 312, lines 460-470

However, some respondents stated that family and close friends did not always share the view that there was no shame in having a mental illness.

Um, well actually I didn't think there was a problem with it but people around me had a very big problem with me taking this medication. My family wanted me to hide the fact, like there was something wrong. And I just thought it was like taking any other medication, like taking my vitamins or something. Respondent 312, lines 423-430

Goffman (1964) reported, however, that disclosing a condition to others may lead to increased support with select individuals. Some interviewees in this study commented that taking antidepressant medication labelled them as depressed but that this was, in part, a positive experience as it legitimised their feelings and behaviour and meant that they gained support from social contacts and healthcare professionals. Symptoms of depression may, in themselves, cause difficulties in social relationships but medication may legitimise these problems.

I was just so glad that he could tell me you're not an idiot and there are things that you can take and you will get better.

Respondent 503, lines 978-982

I suppose it was a bit of a worry at first, I thought people might be talking about me, she's going nuts already, kind of thing. [Laughter] But um in some ways it's nicer to tell people because then they realise how bad things have been and you can get a bit more support. ... So when I said that I was taking antidepressants. So they realise how bad it is and then I get a lot more support from them. Respondent 529, lines 189-197

One respondent in this study commented that she resented the fact that she needed to take medication for others to recognise her as depressed.

Um, I'm not saying that's a good thing because I think people should be able to accept you being low and not have to have tablets to prove it. Respondent 531, lines 1254-1257

One interviewee felt that although she took antidepressant medication her circumstances legitimised this.

I've been through a H! of a lot over the last 2 months so I think people would understand.

Respondent 332, lines 360-361

There is possibly less stigma attached to taking antidepressant medication where it explicitly fits into a respondent's life story. Williams and Healy (2001) found that

where an external factor was thought to be severe enough to cause the level of depression which the interviewee had, they did not explicitly internalise the illness.

Another view was that nobody else would be that interested in personal affairs, one way or the other.

Because I made a joke or 2 about Prozac. Um, just for laugh, sort of thing. Um, but I mean, everyone's concerned about themselves, they're not really interested in anyone else.

Respondent 007, lines 915-917

However, in the majority of the cases described in this section, there was some indication of stigma. For example, respondent 529 still had some initial concern of what others might think. Other respondents reported having feelings of stigma during other parts of the interview. Therefore even where respondents expressed a view of lack of stigma, it became apparent from the analysis that this feeling was incomplete in the majority of cases.

# LONG TERM ADJUSTMENT

Although the study aimed to recruit patients beginning courses of antidepressant medication, some people were included who had been taking medication on a long term basis. In contrast to respondents who rejected medication, there were indications that these interviewees had adjusted and integrated this into their daily lives.

That in itself holds no um, fear for me, stigma attached to it ... It's something that you do automatically like getting up in the morning and brushing your teeth or whatever.

Respondent 438, lines 232-236

From the interview data, it was identified that at later points in treatment, respondents had expectations of continuing with their treatment for longer periods of time, which also suggested they may have adjusted to medication being part of their lives. For example, one respondent said at the first interview, that she wished to take her medication as a short term measure to get over a crisis but by the second interview she had been taking it for over 6 months and was still planning to continue. Similarly, Karp (1993) found that, in time, medication taking became a part of daily reality.

In agreement with previous research (Priest et al. 1996; Crisp et al. 2000; Coyne and

Calarco, 1995; Karp, 1994; Schreiber, 1996), Section 6.2.2.1 demonstrates that there was a stigma attached to depression, for the interviewees in this study. Goffman (1964) discussed the plight of the mentally ill in relation to stigma. However, he discussed a group of individuals who had been in asylums at a time when the mentally ill were institutionalised. In contrast, the respondents in this study were living 'ordinary' lives within the community. Thus it may be perceived that it was medication that had the largest role in distinguishing them from others. It had the potential to change respondents' statuses from normal to stigmatised and from discreditable to discredited.

The results of this study extend the findings of Scambler and Hopkins (1986) who demonstrated that it was 'felt' rather than 'enacted' stigma which caused respondents with a diagnosis of epilepsy the most difficulties. In the study presented in this thesis it was 'felt' stigma which had greater prominence in influencing attitudes towards taking antidepressant medication, rather than actual experiences of discrimination.

With regards to medication use, 4 respondents explicitly stated that they were reluctant to begin treatment, due to the associated stigma. In addition to this, the general importance given to stigma by the interviewees in the study, and the contribution of antidepressant medication to this, implies that it was a factor which generally influenced respondents' decisions about taking antidepressant medication.

# 6.2.2.2 Dependency

Interviewees' beliefs about the addictiveness of antidepressant medication and the subsequent effect on the choices they made about therapy are discussed in section 6.2.2.2. Both physical and psychological aspects of dependency are considered. The findings are considered in relation to previous research about lay views on the addictiveness of medication, with particular reference to studies which have researched antidepressant medication.

In 2 cross sectional surveys of the general public, it was found that between 74% (Paykel et al. 1998) (n= 2003) and 78% (Priest et al. 1996) (n= 2006) of the general population of Great Britain believed that antidepressants were addictive. In the study being presented in this thesis, fears of dependency were expressed by interviewees, when they were asked if they had any concerns about their antidepressant medication. These were categorised into physical and psychological dependency.

# Physical dependency

Dependency was described as what may be interpreted as a physical addiction to the tablets by some interviewees. It emerged from analysing the interview data that there were fears of tolerance building up.

And I wondered whether, whether the medication had the same, whether, whether you'd need a stronger dose if you kept going on for longer and longer. Do you see? Because maybe your physiology might build up a resistance to it. So I was wondering about that, whether after a while, you might get um, it might be having less and less effect because your body gets more and more used to it.

Respondent 428b, lines 447-457

Analysis of interview data indicated that fears of physical dependency were partly associated with the general concern about the addictiveness of medicines that has been noted by the Royal Pharmaceutical Society of Great Britain (RPSGB and Merck Sharp & Dohme, 1997).

Because what if I get down again and then, you know, then I, the resistance builds up and you end up going higher and higher. I mean I don't know if that happens or it's just my perception of it. But it works that way with antibiotics and stuff like that so I presume that, you know, your body can get immune to it eventually.

Respondent 319b, lines 79-88

The only other thing I'm worried about is do they become addictive? I take them as a matter of routine in the morning. Are you going to end up relying on it? The same with my blood pressure [tablets].

Respondent 506b, lines 326-331

However, there was also specific concern about the addictiveness of antidepressant medication, derived from the general publicity associated with them.

[I was concerned whether these were] addictive, because there's been so much bad publicity hasn't there about all these terrible tablets. Respondent 531, lines 1019-1021

Priest et al (1996) have suggested that people may extrapolate from what they have heard about the addictiveness of benzodiazepine tranquillisers. Some of the comments made by respondents in this study agreed with that hypothesis. Either interviewees did not distinguish between tranquillisers and antidepressant medication or they were concerned that antidepressant medication may have the same effects.

I'm 45 so I've heard a lot of things about you know people taking different tranquillisers and what have you and being addicted to them. So I was just concerned that they may be addictive.

Respondent 504, lines 227-232

In hindsight, of course, people realised that these antidepressants were over prescribed. ... People would pop them all over the place, all the time and they'd get a lift. You know, going in to a meeting, they'd have some and they'd cheer up immediately. But, of course, the effect wore off and um, you ended up being worse, so that was discredited. So I was mindful, as I think many people are, of the risk that the drugs promised more than they deliver. And moreover you became dependent on them. In other words, you needed, the dose needed to be bigger and bigger all the time. ... So I didn't want to repeat that.

Respondent 016, lines 610-625

Nervous. Nervous because I didn't want to take something which I could end up relying on because you hear a lot of stories, mainly with sleeping pills but also with antidepressants.

Respondent 015, lines 146-150

Bonn (1998) has previously identified that withdrawal reactions occurring on stopping medication may be regarded as evidence of addictiveness. Comments from some respondents in this study, indicated that they viewed such reactions in this way.

I mean you do kind of get almost addicted to it. I mean they wean you off them.

Respondent 319, lines 631-633

#### RESPONSES TO FEARS OF PHYSICAL DEPENDENCY

As with stigma, fears of dependency, affected interviewees' medication taking behaviour. In Maddox's study (1994) of 46 patients who had begun courses of antidepressant medication in the previous 12 weeks, fears of dependency were one of the reasons given for discontinuing medication after a mean duration of 8 weeks treatment. In the study being presented in this thesis, fears of dependency affected decision-making at different stages of treatment. Some respondents expressed reluctance to begin medication.

But I refrain myself because of this concern or not a concern but um this uncertainty that is in my mind that if I take the tablet, will I become addicted to it. Will it really help me or will it cause me more problems later on in life? Because I may become dependent on something, which I really don't want to do.

Respondent 009, lines 666-674

And I thought well I don't want to get reliant on something like that. ... well obviously you couldn't be on them for the rest of your life, so somewhere along the line you'd have to come off them and I would be worried about what the side effects would be coming off them. So I thought if I don't go on them in the first place, I won't get this problem.

Respondent 505, lines 275-296

Other respondents gave fears of addiction as a reason for discontinuing treatment.

And anyway I was kind of scared I'd get stuck on it so I thought I'll come off it now.

Respondent 015, lines 196-198

Interviewees often reported that doctors reassured them that their medication was not addictive. This was successful to an extent but the majority of respondents stated that reassurance did not alleviate their concerns entirely.

And, in a way, um, when he, when he assured me that they were not um, addictive I sort of thought well, um, ok let's go with it. ... Well I've been told you can't become dependent, ok but there's, there's always that little niggle of this is a chemical that's you know, this is an alien substance being introduced. Respondent 531, lines 1017-1023 2007-2010 I don't feel that I should take medication. Because I have a feeling that you become addicted to this, although the GP did advise me that these are [a] very mild form and you won't get addicted to them.

Respondent 009b, lines 349-352

I asked my GP. She assured me that the drug I'm having is not of that kind. It doesn't build up. It doesn't have, so now I'm not [an expert] about medicine, so I found that reassuring. I hope it's true, I assume it's true. I don't feel any, I don't feel it building up in me.

Respondent 016, lines 663-672

# Psychological dependency

Fears of becoming dependent on medication went beyond physical addiction to what Lader (1979) termed psychological dependency (see section 2.3.2). He defined psychological dependence as the need the patient experiences for the psychological effects of the drug, either through craving the changes in mood produced by the medication or by taking the medication to starve off symptoms of withdrawal. He noted that patients who were psychologically dependent on medication had an intense need to secure supply. Comments from respondents showed some agreement with Lader's definition. Firstly, respondents were concerned about relying on medication to solve their problems instead of finding their own solutions (see section 6.2.2.1).

It's not something I want to be dependent on. I hope to be able to sort things out.

Respondent 015b, lines 130-132

It had to be me and I couldn't depend on them the whole time. Respondent 503, lines 26-28

But I want to feel, I want to feel I'm going to get better and be able to live without it and just cope with those moments when everybody feels low from time to time, in a normal way, without having to be, have something falsely keeping me at a reasonable level.

Respondent 531, lines 2026-2033

One interviewee felt that if he took the medication once he would be much more likely to rely on it again another time.

But also if I got over that boundary perhaps 18 months later I felt for whatever reason again a little bit down, I think it would be much easier to go along [and take antidepressant medication]. I think I'd fight the battle less ... I mean [name of doctor] has assured me that these are not addictive, I'm sure he's right. But it's addictive from the point of view that once you start taking them, it's easier the next time.

Respondent 525, lines 707-713, 1074-1079

Secondly, respondents perceived that they were dependent on taking the medication because of fears of relapse.

I worry about the feeling of relying on it. Um, I'm a bit worried that if I come off it I'm going to feel depressed again ... Um, I'm sort of worried that I might have to need it long term.

Respondent 403, lines 579 - 584

I think that, I think you do depend on them and you think you don't want to feel like you did before. I think it's psychological, you think if you stop taking it then you will feel like that.

Respondent 530, lines 412 - 416

Respondents' perceptions did not fully meet the criteria of Lader's (1979) definition of psychological dependency, as there were no concerns about developing a craving for the drug such that there would be an intense need to secure supply. This may be due to the fact that antidepressant medication was perceived as having gradual effects, as opposed to causing immediate gratification (see section 6.2.1.2). However, respondents expressed concern about relying on the medication to produce changes in mood and this accounted for some of the fears of dependency reported by respondents in the study.

Fears of a similar type of dependency have been reported by respondents suffering from epilepsy (Conrad, 1985). Conrad (1985) also noted that where respondents felt dependent on their medication, as a result of family members coaxing them to take it, they altered their medication taking behaviour as a way of regaining control. In the study being presented in this thesis, a respondent stated that she was unsure of the reason she had decided to stop taking her antidepressant medication but said that everyone was bothering her at home at the time and due to family circumstances she was not allowed to go out. In the context of the whole interview, it appeared as though she stopped taking her medication as she felt that that was one way in which she could regain control, when others were trying to dominate her. Unlike Conrad's study, the control that others were exerting was not in relation to her medication. Nevertheless, the control being imposed by others affected her medication taking behaviour.

Overall section 6.2.2.2 shows that both the psychological and physical factors of addiction were of concern to respondents taking antidepressant medication.

So yeah, it's both. It's the medicine being addictive and me being addicted to taking it as a solution.

Respondent 530, lines 143-147

In all interviews where respondents raised the issue of dependency, concerns about becoming reliant on medication were reported. Such concerns about dependency were one of the factors which respondents considered when making decisions about taking antidepressant medication.

## 6.2.2.3 Adverse drug reactions

The impact of adverse drug reactions on respondents' lives and on their medication taking behaviour will be described in section 6.2.2.3. The findings will be discussed with reference to other relevant studies, which have investigated people's perceptions of medication or compliance with antidepressant medication. Throughout the section, the term adverse drug reaction is used when describing respondents' reports of unwanted effects, although the term side effects is used verbatim in quotations. Respondents' comments concerning adverse drug reactions were classified into fears of adverse drug reactions and experienced adverse drug reactions.

## Fears of adverse drug reactions

Some respondents stated that they had had initial concerns regarding adverse drug reactions, which they anticipated may occur, after first being prescribed antidepressant medication. These fears then lessoned when these reactions did not develop.

I think sometimes you worry when you take things that it's going to affect your concentration or um, certain things but I just find my reaction, everything is exactly the same.

Respondent 431b, lines 224-229

In addition, some respondents expressed concern that their medication may have caused unseen adverse drug reactions of which they were unaware.

Well it's more of a fear really. I don't know because I was wondering whether it was going to slow my metabolism or heart rate down or whether it had any kind of effects.

Respondent 428b, lines 53-57

Such fears of unknown reactions were associated with previous benzodiazepine use in some cases. One respondent had experienced severe adverse drug reactions with diazepam in the past and also reported that her mother had developed leukaemia after using amphetamines for dieting, that were later withdrawn. She was of the view that at some point in the future something negative would be discovered about antidepressant medication.

I don't know how or when or what will be wrong with it but I'm sure something will come up.

Respondent 022, lines 150-152

## Experienced adverse drug reactions

Respondents were asked if they had experienced any adverse drug reactions with their antidepressant medication and whether these had affected anything they did or would like to have done. The extent and severity of adverse drug reactions varied between the respondents in the study. Four respondents reported that they had not experienced any adverse drug reactions at all. However the remaining respondents who had taken licensed antidepressant medication had experienced adverse drug reactions at some point in their treatment. Respondents perceived some of the adverse drug reactions that they experienced as being minor or as having little impact on their every day functioning.

No, ... sort of like an itch you can't scratch, you know [respondent being asked whether dry mouth affected his every day functioning]. Respondent 106, lines 343-344

Such reactions included mild nausea, constipation, dry mouth, dry skin, minor headaches, sweating or slight loss of appetite.

It wasn't like a real headache. It was just like a funny sensation. A muzzy feeling in my head. It wasn't like the usual headache. Respondent 301, lines 529-533

Respondents often reported adjusting to these more minor adverse drug reactions by making simple lifestyle changes or altering the medication schedule slightly.

It's when I wake up in the morning that I'm really thirsty so I just have to drink a lot of water. Or sometimes I wake up in the night and drink some water. I've sort of adjusted like that really.

Respondent 428, lines 355-360

My stomach. I'd actually be physically sick . So now I take it at lunch time. Respondent 503, lines 686-687

One respondent reported that his medication made him feel tired. However he saw this as a positive step in his life as it made him rest more, thereby reducing his anxiety.

However, those adverse drug reactions that were considered more serious were reported to have had more dramatic effects on respondents' lives. They included more severe nausea, tiredness, lethargy, insomnia, difficulties with sexual relationships, dizziness, pulling sensations, weight gain, blurred vision and wheezing. There were a range of ways in which these reactions impacted on respondents.

Some respondents reported that the impact of adverse drug reactions was noticeable at work, college and when carrying out general day to day activities.

As I say I'm slower, I'm not getting through as much work. Respondent 409, lines 205-207

I'd rather have the depression than what I was feeling with the medication .... Everything was difficult. I couldn't think straight. I couldn't think things through properly. Even reading the newspaper was hard work. I had to go back and re read the paragraph.

Respondent 427, lines 93-96 126-130

I didn't feel totally safe. Eh, I was always a bit concerned that, I would, that the giddiness which I was able to control [in other aspects of my life] might just impair my driving.

Respondent 007, lines 585-589

This reduction in day to day functioning affected respondents' perspectives of the role of their medication in the context of their illness, in some cases. Demeyttenaere (1997) suggested patients may attribute symptoms of adverse drug reactions to the illness, leading patients to conclude that the medication is making them more unwell. There is evidence that some respondents in this study perceived adverse drug reactions in this way. Depression is associated with a decrease in every day functioning and with low mood. Where adverse drug reactions of the medication reduced this further, they were viewed as worsening the disease state.

The medication did make my symptoms worse ... because I couldn't cope with my normal life and I had all the stress of trying to finish off my dissertation when I couldn't get out of bed.

Respondent 312, lines 386-393

It did, it, it took over when I ate, what I ate, when I left home. First thing in the mornings I wasn't sick because I hadn't taken the tablet. But I have problems in the morning so um, by the time that settled down, the tablets had kicked in and I was feeling sick again.

Respondent 303, lines 195-203

They make me, it's hard to describe, how they, they seem to bring me down instead of lifting my frame of mind. [Respondent experiencing headaches]. Respondent 406b, lines 75-79

Another perceived impact of adverse drug reactions was a direct effect on

respondents' emotions. Some interviewees described experiencing symptoms of anxiety or aggressiveness.

Um, I don't know it's like, just felt a little bit sort of like hyperactive, like the adrenaline's rushing through your legs like you're going to have a fight or something eeeh and it just felt like that all the time.

Respondent 429b, lines 38-43

It was unbelievable and that depressed me more because I was never like that. I never looked at, I never wanted to look at a negative side of people. [Respondent experiencing aggressive feelings].

Respondent 101, lines 750-756

In addition, some adverse drug reactions were described as being very frightening for respondents.

That really scared and frightened me especially when I'd stand up and not be able to see for half a minute.

Respondent 312, lines 265-268

I found it gave you a strange kind of sensation that your brain was not moving in time with your head, if that makes any sense and I found that disconcerting. Respondent 331b, lines 78-86

RESPONSES TO EXPERIENCING SEVERE ADVERSE DRUG REACTIONS

The response to these more severe adverse drug reactions differed from that of the minor ones. It became apparent from the analysis that it was not possible to adjust to them by making simple lifestyle changes. Respondents reported dealing with them in a number of other ways.

In some cases respondents' comments indicated that tolerance to these more serious adverse drug reactions was built up.

For the first few days I couldn't sleep. I'd go to bed and I'd just be awake. I'd drive myself mad because I couldn't get any sleep at all. Um, I think it was worth it, that was going on for a few days.

Respondent 529, lines 132-137

However, other respondents reported finding the adverse drug reactions so debilitating that they were unable to persist with taking the medication whilst waiting for tolerance to built up. Eh, well if I took them, you know, I was constantly in the toilet and I had blurred vision, a bit awkward when you're driving... and they did say it would take probably a week to get over the side effects but I didn't want to wait a week. [Laughter]. It was quite nasty, yeah.

Respondent 505, 99-113

Respondents often reported discontinuing their medication as a response to severe adverse drug reactions.

And I just felt quite uneasy when I was having these persistent headaches. I couldn't really do much and I didn't, you know feel that I could continue with it.

Respondent 009b, lines 123-126

Um, it was just a huge effort to do anything. At which point I was beginning to think maybe I've got too much of this.

Respondent 015, lines 194-196

One respondent resolved the adverse drug reaction by discontinuing with his medication on a short term basis.

Um, I stopped taking the medication for 2 days because I just wasn't getting any sleep whatsoever and the nightmares stopped and I started taking the medication again and they haven't come back, touch wood. Respondent 504b, lines 52-57

Another response was for respondents to return to their doctor, who changed the class of antidepressant medication rather than stopping treatment completely.

I used to start to panic a little bit which I think might have been down to the medication but when I changed to the second drug then that went. Respondent 429, lines 257-268

The finding that the experience of severe adverse drug reactions affects medication taking behaviour in respondents with a diagnosis of depression has also been demonstrated by Lin et al(1995) who showed that patients' experiences of severe adverse drug reactions was a significant predictor of early discontinuation of antidepressant therapy. Furthermore, previous research has shown that psychological adverse drug reactions in respondents suffering from bipolar disorder (Demyttenaere, 1997) or adverse drug reactions affecting social functioning in respondents suffering from epilepsy (Conrad, 1985) were more likely to result in alteration of medication taking behaviour than those affecting body functioning. The response to experiencing adverse drug reactions reported by the respondents of the study being presented in this thesis show that the findings of these studies (Lin et al. 1995; Demyttenaere, 1997; Conrad, 1985) can also be extended to respondents with a diagnosis of unipolar depression. Psychological adverse drug reactions or those affecting social functioning often resulted in discontinuation of therapy. Similarly Zola (1973) found that it was respondents' social circumstances which triggered them to seek medical help for a condition rather than their actual symptoms. This may also be applied to interviewees' responses to adverse drug reactions. It became apparent from the analysis of interview data that it was the effect of the medication on respondents' day to day functioning which was important for decisions made about antidepressant treatment.

Response to adverse drug reactions was associated with other negative aspects of medication use. In the psychodynamic literature (Book, 1987), it was suggested that, at times, when patients reported discontinuing medication because of adverse drug reactions they may actually have been projecting other fears about their medication onto the adverse drug reactions. One respondent in the study presented in this thesis reported that experiencing adverse drug reactions strengthened her negative feelings towards taking antidepressant medication.

I already had the feeling there but once I took them and had those side effects I thought, well that made me think more and more, I can't take them. Respondent 528, lines 484 - 488

Similarly, in Karp's study (1993) of a snowball sample of 20 people, respondents who were never fully committed to a biological view of their difficulties, found it easy to discontinue their medication as a result of experiencing adverse drug reactions. It is possible that in the study being presented in this thesis, respondents' communication about medication focussed on the physical rather than social aspects of therapy making doctors unaware of the true origins of patients' views.

Experiencing adverse drug reactions increased the stigma associated with taking medication in some cases. Goffman (1964) noted that stigmatised individuals may try to identify themselves as normal but be reminded of their true status by certain events e.g. a respondent with a physical deformity looking in the mirror. In the study being presented in this thesis, one respondent noted that experiencing adverse drug reactions from their medication could act as one such reminder.

Yes, no matter what I did just walking or getting up from the chair. It was there the giddiness. It was always reminding me that I was taking the tranquillisers. Respondent 007, lines 497-501

In this case the medication was viewed as a continual reminder, rather than an occasional one.

Adverse drug reactions were also another means of making the illness more visible in some cases, causing tensions in social interactions, because of fear of discovery.

I had kind of shaky hands. I've always had kind of quite shaky hands but I was getting to the stage where I couldn't eat properly. And I'd be sat with someone who didn't know there was anything wrong with me and I couldn't pick up my [cutlery].

Respondent 428, lines 319 - 324

#### ATTRIBUTION OF ADVERSE REACTIONS

As with positive effects, respondents were sometimes unsure whether to attribute any negative reactions they were experiencing to the medication or not.

I thought [it] was because of the antidepressant. And eh, but since I've stopped them and I've reduced the dosage of the Lipitor, I still get headaches, I had one yesterday, but it's not as bad as before. So I can't really be absolutely positive that it is to do with the antidepressants or the Lipitor tablets but I know for a fact that the headaches have reduced and it's not as common as it was before. Respondent 009b, lines 319-327

Um, whether it's the tablets or whether it's the time of the year [Respondent experiencing constipation].

Respondent 531, lines 1140-1141

However, overall adverse drug reactions were perceived as one of the negative aspects of taking antidepressant medication. The vast majority of respondents had experienced adverse drug reactions but the importance of them, in terms of their impact on respondents' illness, lives and medication taking behaviour varied. The relative weighting given to adverse drug reactions, in relation to other factors, when respondents made decisions about taking antidepressant medication was influenced by their perceptions of the importance of such reactions in the context of their illness and every day lives.

# 6.2.2.4 Less frequently mentioned negative factors

A number of other concerns about taking antidepressant medication were reported as being possible influences on decisions made about pharmacotherapy, including interactions, contraindications and expense, which are described in section 6.2.2.4.

# Interactions and contraindications

Some respondents indicated that concerns regarding interactions with alcohol or other medication were a factor in decision-making. Again, there was a range of perspectives identified in the analysis, regarding the associations of these concerns with the decisions which were made.

Some respondents reported that refraining from alcohol had a negative impact on respondents' lifestyles but this was not always a major influence on their decisions.

The other thing is I like a little glass of wine at night. I only have one glass but I don't like taking any alcohol when I'm on amitryptiline as well. I think a lot of people on antidepressants think you can't have a drink. But that's not it really, I could do without the drink. It's just that I enjoy it.

Respondent 014b, lines 309-323

However, some respondents considered missing a dose of medication because they had recently consumed alcohol or other medication.

Sometimes when I've been out and I've had something to drink or something and I think maybe I shouldn't take it. That's only in the sense that I risk, that I'm worried about what the effect might be.

Respondent 428b, lines 389-349

Um and you, particularly if you take lots of other stuff at the time, if you're taking lots of pain killers, you kind of think oh G-d, maybe I shouldn't take any more pills of any kind today. The trouble with that is you start having withdrawal symptoms from not taking antidepressants so it's actually better to take them. [I'm going] on the assumption that they're not going to clash with the pain killers because they're presumably doing different things to different parts of your anatomy. [Respondent who had occasionally skipped doses because of fears of interactions with other medication].

Respondent 331b, lines 190-205

In other cases, fears of interactions with other medication caused respondents to stop taking their medication altogether.

I stopped because I know [it's dangerous] to mix um, these tablets, because it's different medicines.

Respondent 201, lines 359-362

Two respondents were concerned about taking antidepressant medication in pregnancy. One lady was planning another baby in the future and expressed concern about whether a discontinuation period would be needed before conceiving. Another had taken benzodiazepines and tricylic antidepressant medication while pregnant, in the past and was of the view that this had affected her son.

So there's a lot of guilt that I took these antidepressants, 6 a day. It must have really harmed my son.

Respondent 415, lines 467-468

# Expense

The cost of licensed antidepressant medication was only raised by one respondent. He had many financial worries which he spoke of throughout the interview. On the expense of medication he said:

But um, whether I would take them if I had to pay for them is another thing because I couldn't afford to pay for them. But being unemployed, I can get them free at the moment, you know, so that's another thing in it, the cost of medicines these days.

Respondent 506, lines 292 - 298

Many of the negative aspects of therapy which have been identified as affecting decisions about its use in section 6.2.2 may also be expected to affect respondents' initial help-seeking behaviour. It may be suggested that concerns over stigma, dependency and adverse drug reactions would prevent some people from seeking help from their general practitioner and obtaining a prescription for antidepressant medication. It is also possible that such concerns would lead to somatisisation of symptoms. It may be therefore be hypothesised that concerns regarding stigma, dependency and adverse drug reactions could therefore contribute to the under recognition of depression as well as to early discontinuation of treatment.

# 6.2.3 OVERALL EFFECTS OF RESPONDENTS' PERCEPTIONS OF THERAPY ON DECISION-MAKING

In section 6.2.3, conclusions are drawn about the overall effects of the different factors of therapy on decision-making. Similar findings were observed to those of Conrad's (1985) study concerning the perceptions of anticonvulsant medication for respondents with epilepsy. Reasons for the similarities between the 2 studies will be considered further in chapter 8.

Overall, neither the positive nor negative aspects of therapy individually influenced respondents' decision-making. Rather the risks and benefits were weighed against each other.

Well I think all medicines have side effects. Um, but when the thing that they're helping you with is better than the side effect you continue with the medicine.

Respondent 015b, lines 123-127

Decision-making was therefore a complex process. Respondents could not be divided into those who were positive about antidepressant medication and those who were negative. Only 2 respondents expressed particularly negative views about taking antidepressant medication. The remaining 49 respondents identified both positive and negative aspects of medication. They assessed their circumstances at a particular point in time and made a decision as to whether or not it would be beneficial to take their medication.

So, at the moment, as far as I'm concerned I'd prefer to carry on taking them. They seem to be doing me a lot more good than it's doing me harm. Respondent 506, lines 595-598

Conrad (1985) used the results of a qualitative study to examine the meaning of medication for those with epilepsy and produced some similar findings to this study. In both samples respondents took medication in order to enable them to lead a normal life. However, taking medication was perceived to label respondents as having the disease. In addition respondents perceived that they were psychologically dependent on medication and reported being unsure of whether they had recovered.

The response of the respondents to the negative aspects of taking medication, in both studies was sometimes to change their medication taking behaviour. However, the respondents in Conrad's study typically responded by what has been termed as partial

non-compliance (McGavock, 1996) (eg lowering dosage, stopping for short period of time) whereas those in the study being presented in this thesis were most likely to discontinue their medication completely (see section 5.2.5).

The reason for the difference between responses to the negative aspects of medication seen in the 2 studies, may be due to the fact that anticonvulsant medication was perceived as being more essential to those with epilepsy than antidepressant medication was to those with a diagnosis of depression. The contrast between one respondent's perception of the importance of antidepressant medication in comparison to the importance of medication for her other chronic conditions is illustrated below.

I stopped because I thought I didn't need it. I was having so many drugs with so many side effects that I just thought well I don't need the amitriptyline. Respondent 014, lines 768-772

As has been discussed in section 6.1.2 respondents in the study being presented in this thesis perceived antidepressant medication as a short term measure. Two respondents directly contrasted depression with other chronic conditions in terms of the length of treatment.

Yes, it's not the same kind of illness as having a like um, blood disorder or something like that. It's something that should pass. Respondent 015, lines 137-140

Additional evidence of respondents' viewing antidepressant medication as less essential than other medication can be gained from the actions that they reported taking in association with concerns about drug interactions. In these instances respondents only spoke of considering discontinuation of the antidepressant medication and not the medication taken for other conditions.

# 6.3 The level of involvement which respondents wished to have concerning decisions with their medication

During the interviews, respondents were asked how different people had influenced decisions about their treatment. Respondents were also asked about the involvement that they had personally had in making decisions about their treatment. Factors affecting the balance of internal and external control were identified from the analysis of the data and will be discussed in section 6.3. The level of internal control which interviewees wished to take over their therapy varied between respondents and at different points of time during treatment. The external person most frequently reported to influence therapy was the doctor. However, family, friends, counsellors and pharmacists were also identified as having an impact on decisions.

# **6.3.1 DOCTOR-PATIENT RELATIONSHIPS**

Charles et al (1999) have developed a conceptual framework of different decisionmaking approaches within the medical encounter. They have identified 3 different models of doctor-patient relationships with varying levels of patient involvement. These are the paternalistic, informed and shared models. The data collected from the study being presented in this thesis are discussed in relation to each of these models.

# 6.3.1.1 Paternalistic model

It became apparent from the analysis that some interviewees in this study were part of a relationship where the physicians had the dominant role in decision-making.

I said how long are you going to put me on these? He says until I tell you to come off them and that was it. Respondent 524 lines 1073-1075

Respondent 524, lines 1073-1075

Many interviewees gave passive reports of following doctor's instructions. This has been identified as the paternalistic model (Charles et al. 1999). Respondents often expressed satisfaction with this type of relationship. A recurring theme was that of trust and faith in the medical profession in general or in a particular doctor, and of compliance with their instructions. I never asked the doctor [why he changed my tablets] because I have full faith in him. So I don't question him at all. He's a very good doctor in fact. I'm very lucky to have [a] GP like him.

Respondent 424, lines 518-520

Although this paternalistic type of relationship fits the functionalist model, identified by Parsons (1951), to a large extent, there were indications that in the study being presented in this thesis, doctors went beyond the biomedical approach to address social concerns of the patient.

We talked about the job, if the worst happens what I'm going to do, what he could which was great you know support coming from an avenue I didn't expect, which was wonderful.

Respondent 504, lines 656-661

The fact that doctors addressed such wider concerns may be due to the psychological and social factors associated with depression. The finding may therefore be more likely to be generalisable to patients suffering from depression than other conditions.

Interviewees expressed various reasons for wishing to be involved in a paternalistic style of relationship. Firstly, respondents expressed the view that they lacked personal knowledge and therefore wished the doctor to take charge.

I haven't really made any decisions at all. Eh, I'm not a practitioner, I sort of don't claim to be an expert. Respondent 438, lines 427-431

Secondly, respondents were of the view that they had been too unwell to make their own decisions at the start of treatment and that they therefore relinquished control to the doctor. It may be suggested that this reason for wishing the doctor to take control would be particularly applicable to patients with a diagnosis of depression. Depression is characterised by an inability to make decisions and interviewees sought help at crisis point in the majority of cases, as described in section 6.1.1.

For the first time in my life, I was more than willing to put myself in the hands of a doctor, um, so low was I.

Respondent 531, lines 995-1000

#### 6.3.1.2 Informed model

Although some respondents had a paternalistic relationship with their general practitioners, other interviewees reported being in control of their treatment

themselves.

So it was my decision. So I wasn't influenced by the doctor or the counsellor. It was a decision I felt like I had to make so I was fully prepared. Respondent 326, lines 523-527

Charles et al (1999) identified an informed model whereby the patient takes full responsibility for making the decision and the doctor's role is only to provide information. One interviewee in the study being presented in this thesis had a preference for this type of relationship.

Um, I really sort of. I firmly believe that doctors shouldn't willy nilly hand out [antidepressant medication]. ... Rather I would think, have some sort of leaflet and just say that you know, this is what you have, this is the treatment you have and you go away and think about it and you make the decision. Respondent 403, lines 700-710.

However, for other respondents, the doctor's role was not even to provide information but simply to prescribe medication. Some interviewees reported that they had made the decision and the doctor then prescribed.

Um, I would say it would be a hundred per cent involved. Um, like I say with the first drug I was taking, I didn't like it. It wasn't working. It was causing lots of problems. So I said I didn't like that one. I wanted something else and he prescribed something else. [Respondent on being asked level of own control]. Respondent 429, lines 434-440

There was not really any [other] option open to her ... because I was going again about depression, and I'd already been and had this healing thing with another doctor and I said to her that it didn't do anything for me and um, she said to me about counselling and I said no I've had years of counselling and I don't need, it's not something I really need because I understand everything, it's not like I need to talk about it because I can talk about it you know, so that was the only option [to prescribe antidepressant medication].

Respondent 332, lines 456-468

Therefore, 'patient-centred model' was considered to be a more appropriate terminology than 'informed model' for the data being presented in this thesis and is the term which will subsequently be used.

Charles et al (1999) noted that physicians may find it difficult to accept a relationship where they have no role in the discussion or recommendation of treatment. In this study, it became apparent from the analysis that the actual decision to operate a patient-centred style was taken by the patient. Indeed, it is possible that physicians would have viewed the interactions differently to support their need for participation in decision-making. Sleath et al (1997) showed that patients initiated prescribing decisions more often that doctors admitted it.

From the analysis of the interview data, it was identified that even where respondents did not have complete control within the consultation, they made treatment decisions outside of it. These decisions included discontinuation of medication or other alterations to treatment, such as adjustment of dosage.

Some respondents expressed dissatisfaction with the level of control doctors allowed them and discussed the steps they could take to alter this. For example, if interviewees felt that the level of information they were given was insufficient they searched other sources.

Um, I tried speaking to the GP when he prescribed it for me about what sort of side effects to expect and that sort of thing and he wasn't really very forthcoming on that. A friend of mine looked it up on the Internet and gave me the side effects of ... the main one.

Respondent 429, lines 359-365

Another interviewee reported that he would have changed doctors if he had not been prescribed the medication which he wanted.

# Factors associated with preference for a patient-centred model

Some respondents differentiated between the level of control they wanted in decisions about antidepressant treatment and their general decision-making about medication.

I'm not a know it all who thinks they know better than the doctor. ... The diabetes tablets I take ... I'm a straight forward person but on that issue [taking antidepressant medication], I feel very strongly.

Respondent 022, lines 71-241

These respondents indicated that their preference for taking internal control, over decisions about antidepressant medication, was associated with strong feelings against psychotropic medication which had resulted from past experiences with benzodiazepines.

From analysing the interview data, it emerged that during the course of treatment, some interviewees moved from being involved in a paternalistic doctor-patient relationship to being part of a more patient-centred model. Various factors were associated with respondents taking greater autonomy over therapy as the treatment

process continued.

Firstly, as respondents' symptoms began to improve they took a greater role in decision-making.

I'd try anything. The doctor said Prozac so I'd take Prozac ... There was no question, there was no question in my mind whether to take it. If you say it's going to help [Respondent recalling start of treatment]. Respondent 101, lines 333-340

The respondent then dramatically improved while taking a religious holiday, resulting in him taking control over his own treatment.

But the decision, something told me in Jerusalem, stop taking Prozac. For some reason. My sister had given me so many articles on that you shouldn't stop it immediately, it can recur and this and that. And I said I'm going to do this with my faith. So that's the way it's happened. Respondent 101, lines 513-520

The results of Sleath et al's study (1997) also indicated that patients with a diagnosis of depression wished to take a more active role further ahead in the treatment process. They found that patients with a diagnosis of depression were more likely to initiate the repeat prescribing of psychotropic medication than the first prescription for a new medicine. Unlike the respondent quoted above, the majority of respondents reported that recovery was a more gradual process (see section 6.2.1). The possibility may therefore be suggested that some respondents took control over treatment more gradually and did not notice the change in autonomy.

Secondly, in cases where interviewees had previously been happy to follow their doctors' instructions, some respondents indicated that the occurrence of an adverse drug reaction encouraged them to take control.

Um, I didn't, I didn't want to do anything. I felt not guilty, I suppose but I felt as though I should have, eh, spoken to [name of doctor] before I did it [skipped 2 doses of medication] but I was just so tired. [Respondent who experienced nightmares during treatment].

Respondent 504b, lines 68-72

In one case, however, the interviewee's preferred style of consultation moved in the opposite direction after an adverse drug reaction occurred.

I should have left it up to him and said I'm not sleeping that well. Instead of going in and demanding something like I did, I want Prozac [Respondent whose insomnia worsened after taking Prozac]. Respondent 301, lines 1244-1247

## 6.3.1.3 Shared decision-making model

The paternalistic and patient-centred models can be seen as 2 ends of a spectrum. However many doctor-patient relationships may be seen as being somewhere in between these 2 extremes (Charles et al. 1999). In the study being presented in this thesis, some interviewees reported discussing their treatment options with their doctors. This type of doctor-patient relationship has been identified as a shared decision-making model (Charles et al. 1999). Respondents used phrases such as 'we decided that-' when discussing treatment decisions. In addition, one interviewee reported that doctors asked how she felt about different aspects of treatment.

The doctor ... went through it quite a lot with me before I actually, before he actually prescribed them. We spoke about it a couple of times and he said well what do you think about it and stuff like that. Respondent 529, lines 212-217

Interview data demonstrated that some interviewees and doctors negotiated the discontinuation of treatment together.

I had discussed with him about coming off them and he worked out a programme of reducing the dosage every week, which worked pretty well. Respondent 429, lines 148-151

The shared decision style of consultation was perceived favourably by some interviewees.

So, the world has opened up and you are more in control and you can, you can now have a rational discussion with your doctor. Respondent 531, lines 1411-1414

From analysing the interview data, indications were found that even where interviewees reported taking full control over treatment, some identified that doctors had a part in the decision-making process, as they controlled prescribing.

It's like, I just went in and said can I have some Prozac [Name of doctor]. I thought, G-d, he won't give me any again.

Respondent 301, lines 288-290

Some interviewees reported that they went into the consultation asking for sleeping tablets but were prescribed antidepressant medication.

I went to [name of doctor] he wouldn't give me sleeping tablets which is fine. He offered me tablets for depression or ... anxiety and I wouldn't take them. Respondent 525, lines 117-121

Therefore doctors always had the power to make the final decision about whether or not to prescribe medication and respondents had ultimate control over whether or not to take it. It could be argued, therefore that both respondents and doctors always had roles in decision-making about medication. What varied, however, was the extent to which decisions were shared during the consultation. Barry et al (2000) interviewed a sample of general practice patients prior to and after consultations and recorded the consultations themselves. They found that patients often had unvoiced agendas in consultations. The lack of discussion of items of importance to patients, adversely affected outcomes. Barry et al's results demonstrated that although patients' concerns and needs were not openly discussed with the doctor, they still affected patients' decisions.

It may be concluded that the models of different decision-making approaches which were identified by Charles et al (1999) could be applied to the interviewees' data presented in this thesis. However, a modification to the framework is needed. Charles et al (1999) identified an informed model, in which the physician gives information to the patient and allows him/her to make the decision. However, in some cases in the study being presented in this thesis respondents perceived the doctor's role as merely being the gateway to obtaining medication. Therefore the Charles et al's informed model did not cover all aspects of the patient-centred model identified from the data being presented in this thesis.

# 6.3.2 ROLE OF PHARMACISTS

Pharmacists were rarely raised as having a role in influencing decisions about antidepressant treatment. Two interviewees reported that pharmacists had been a source of information about St John's Wort. Two other respondents reported that a pharmacist had given them information about their prescribed antidepressant therapy. One of the pharmacists encouraged the respondent to take the medication by normalising the behaviour (see section 6.2.2.1).
The pharmacist said so many people take them and it's unbelievable that you know, the number of people that take antidepressants. Respondent 009, lines 507-510

However the other interviewee was told to only take it for a short time as it was addictive!

One interviewee reported that he had an excellent relationship with his pharmacist and often discussed his medication with him. However on being probed specifically about discussions with his pharmacist regarding his antidepressant therapy, he reported that very little exchange had taken place.

Therefore it may be concluded that the pharmacists' role was perceived as being very limited with regards to influencing decision-making about antidepressant therapy.

#### 6.3.3 ROLES OF FAMILY AND FRIENDS

Charles et al (1999) have noted that patients may decide to share decision-making with persons other than or in addition to their doctor. From the data presented in this thesis, family and friends were identified as having various roles in decision-making. Firstly, as has been reported earlier, social contacts often initially encouraged respondents to seek help (see section 6.1.1). Secondly, some respondents reported that close family attended appointments to provide support or gain a deeper understanding of the illness and treatment process. From analysing the interview data, it emerged that the spouse had different roles in the doctor-patient relationship. Comments made by some interviewees indicated that the spouse acted as an intermediary between the doctor and patient.

But I wanted [name of wife] to be there anyway because I again, probably when I bottle things up and don't say anything but I didn't know what was happening, I just didn't know. I thought is it just stress and I just didn't know what it was. So every time I went down to doctors [name of wife] came down ... just as a comfort factor and just in case I didn't say what I wanted to say. Respondent 524 lines 642-649

However, other comments indicated that the doctor acted as an intermediary between the patient and spouse. My husband came last time to see [name of doctor] because it's all well and good telling him that this is what I have. But they still have no conception of [what it actually is] and a lot of people, especially [name of husband] thought the way probably I did at the beginning that I'd take a few tablets, you should be fine.

Respondent 503, lines 404-415

Thirdly, respondents also identified family and friends as sources of information. Where these contacts had also suffered from depression they were able to give information about their own experiences to the respondents.

People who have suffered from depression are the best people to talk to ... they said it's not going to be, it's not steady, there are ups and down ... You'll feel great, a couple of days later there'll be another drop. At the beginning that was difficult because um, every time I thought every time I had to go back into a slump again I thought this is not working, what's the use? But then, knowing that other people are doing that, waiting to come round again. If you speak to people who've been through that, it's a lot of help.

Respondent 429, lines 397-413

In other cases, social contacts searched lay and medical sources of information such as the Internet and patient information leaflets to inform respondents.

My fiance's been very active in trying to find out information about the illness and support groups and counsellors.

Respondent 101, lines 517-519

Some interviewees reported asking relatives or friends who were healthcare professionals for medical input.

What I did is I took an opportunity to discuss it with a friend of mine who is a doctor himself. We were together when we were studying at colleges and universities. So he's a general practitioner. I rang him and I said look I've got these tablets and ... he's the one who explained a little bit more about beta blockers and antidepressants.

Respondent 009, lines 572-581

Fourthly, interviewees reported that family and friends acted as a general source of encouragement to them to continue their treatment.

I mean my wife sort of nudged me, you know, take your tablet, a few times so it just provokes you to, you know, follow it up. Respondent 504b, lines 324-328

One way in which social contacts were reported to encourage respondents was to observe positive changes in interviewees, thereby helping to give them knowledge that they were recovering.

The people around me at work said - you don't let things worry you as much they say. Other people feedback to me, you know ... And [Name of wife] and that and even my children ...So that's how I'll know. Respondent 106, lines 292-305

In contrast, some interviewees reported that they found that others were against them taking medication (see section 6.2.2.1). However, there were no examples of interviewees deciding not to take medication as a result of the opinions of others. Several possible explanations may be suggested for this. There are indications from the data that interviewees did not follow the advice of some social contacts as they felt that those advising them not to take the medication had little understanding of their situation and were unable to offer any alternative sources of help.

Mainly people didn't want me to take it but I ended up taking the. ... Because I felt really bad, I had to take them because they [people advising me not to take it] weren't making me feel any better.

Respondent 530, lines 491-495

In addition, another possible hypothesis is that people who had been influenced against taking antidepressant medication had consequently not sought medical advice and therefore not have been diagnosed with depression. They would, therefore not have been eligible to participate in the study. In one case, a respondent's husband was initially unsupportive of her taking medication but changed his views after seeing improvement.

He's done a full turn about. A major, major turn about. I think he's happy that I went because his life is an awful lot easier [respondent whose husband had not wanted her to seek medical advice].

Respondent 503, lines 931-934

The possibility therefore arises that family and friends influenced people suffering from depression against taking medication before seeking help and obtaining treatment. Respondents were most easily influenced before recovery had begun (see section 6.3.1.2.

#### 6.3.4 ROLE OF COUNSELLORS

Some interviewees reported that counsellors felt that being involved in decisionmaking about antidepressant therapy was distinct from their role. Yeah I did speak to her [about how long I needed to take the medication for] and she said um, that ... she wouldn't herself determine whether or not I needed to take the medication and she said I should ask the doctor really. Respondent 428, lines 167-173

However, on some occasions counsellors were reported to sanction interviewees to seek medical advice alongside their treatment, which resulted in a the respondent obtaining a prescription for antidepressant medication.

Well I went to counselling and they suggested that I go to the doctor. You know, we're doing so much for you but we feel that you need this extra help. Respondent 106, lines 597-600

Therefore, although counsellors were not directly involved in decision-making about antidepressant therapy, they influenced the process of obtaining treatment in some cases.

#### 6.3.5 INFORMATION

In Charles et al's conceptual framework of doctor-patient relationships (1999) it has been identified that the patient needs to gain information in order to make decisions. The above discussion has identified that doctors, family and friends were all reported as sources of information. Interviewees' needs regarding information are considered further below.

#### 6.3.5.1 Role of patient information leaflets

Patient information leaflets were often reported as being a source of knowledge. The most common information that respondents reported extracting from them was that regarding adverse drug reactions. A range of perspectives regarding the helpfulness of this information was reported. Some respondents stated that they had been concerned about adverse drug reactions as a result of reading the leaflets.

I worried about what it would do to me because I read the instructions and it's saying you get all these side effects.

Respondent 005, lines 236-240

Two interviewees reported making a deliberate decision not to read the leaflets to prevent this concern.

No. I didn't read about the side effects because it would just make me panic. The first set of tablets, I read the side effects and I got scared of taking them. Respondent 530, lines 444-448

However, other respondents reported that they had felt less worried when adverse drug reactions had occurred because they had known what to attribute them to.

I mean the first couple of weeks I felt a lot worse. I must admit. I felt the panicky thing got worse ... but I knew this was going to happen because I knew it said so when I was reading the leaflet about it. It said, you know, for a period of time you could actually get worse symptoms from it. Respondent 431, lines 304-311

Other information which was reported to be gained from the leaflets included contraindications and dosages.

Two interviewees stated that they were unhappy with using patient information leaflets because they were produced by pharmaceutical manufacturers and were therefore perceived as potentially biased.

Leaflets are sometimes dished out, publicity leaflets, propaganda from the um, pharmaceutical companies, which I find not in the least bit interesting or helpful ... they're just totally unreliable.

Respondent 016, lines 681-688

The interview data were explored to determine whether there were patterns of perceived reliability of different sources of information. However, no such patterns were found.

#### 6.3.5.2 Common unmet information needs

Respondents were asked whether there was any information they would like to have had, that they had not received. Some interviewees reported that they had obtained all the information they needed. However others commented that they would have benefited from being given more information. Both the type of information given and the timing of it were important. Again, the most common unmet information need concerned adverse drug reactions. Where respondents discussed this in more detail, they reported they would have liked more information about the adverse drug reactions which might be expected to occur with the medication. I think I would have liked more information to be told about the side effects because I really wasn't told that, certainly there was one in particular that I was put on and a very high number of people who go on it have side effects from it. Respondent 001, lines 538-544

It became apparent from the analysis that when healthcare professionals told respondents that there would be few adverse drug reactions, interviewees' responses to subsequently experiencing them were affected. Comments from respondents implied that if medication which was supposed to have few adverse reactions still caused problems, there would be no benefit in changing to a different tablet.

When I talked to the pharmacist he said to me that... they've got very very few side effects and I was quite surprised that they were having side effects ... so I just decided that I'm not um going to take them. [Respondent who had changed treatment several times due to adverse drug reactions but who, on this occasion, discontinued treatment completely].

Respondent 009b, lines 169-175

The other information which some interviewees reported was lacking, was a greater knowledge of the role of medication in recovery from depression. It has been noted that some respondents were expecting a miracle cure (see section 6.1.2) They were therefore unprepared for the reality of the recovery process (as described in section 6.2.1.2).

I'd like to know what effects does it have? Because I thought there'd be a drastic change. You know I'd be like a new person, so I'd like to know a bit more about that. Just what it does to you.

Respondent 005, lines 735-742

Some respondents had difficulty recalling the information that the doctor had given them at the time of diagnosis. One interviewee explicitly described his recollection of this.

At the time when I spoke to my doctor, the first time before she put me on to the medicine, I'm sure she might have said to me how it's going to affect me but I felt so kind of upset and confused ... I couldn't really take in what she was saying, if she did say anything. So it was all a bit of a blur really after a point. Respondent 428, lines 597-605

This finding implies that subsequent reinforcement of information may be particularly important. This issue will be discussed further in section 8.2.

To conclude, preferences for control over decision-making varied between respondents and at different stages of therapy. Both healthcare professionals and social contacts contributed to the decisions that interviewees made about their treatment. The most commonly reported unmet information need regarding medication was the adverse drug reactions which might be expected to occur. The specifics of this information was not reported.

# 6.4 Respondents' perspectives of taking different classes of antidepressant medication and different dosages

#### 6.4.1 Classes of antidepressant medication

Some interviewees reported using different antidepressant agents over time. Only one interviewee stated that he had been taking the same medication long term. Some respondents reported having had to try a number of different medicines and dosages before reaching the optimum one.

I mean I think it's quite hard to find the right drug. My experience and I think that of my GP is it's hard to find the right medicines for the individual. So I have tried 2 or 3 before arriving at what I think is the right one for me and moreover the dosage which is appropriate.

Respondent 016, lines 94-105

Similarly, Karp (1993) noted that respondents often entered a process of trial and error, when trying to find the right medication. This experimentation had serious consequences for one interviewee in the study being presented in this thesis who was unable to hold down a job until the right medication was found.

### 6.4.2 Dosage

It became apparent from the analysis that interviewees were generally happier when they felt that the dosage they were taking was at the low end of the spectrum of recommended doses.

The maximum you can go up to is 50mg. So if I've been prescribed a 10mg, to me [this] means that it's something very small, you don't have to worry about it.

Respondent 009, lines 598-602

Similarly, in a qualitative study of general practice patients (n=29), Dowell and Hudson (1997) found that the higher the dosage of the medication, the greater was the reluctance to take it, giving the finding cumulative validity.

However, there was an exception to this preference for lower dosages in the study being presented in this thesis. One interviewee who had been treated in both primary and secondary care and expressed the view that the dosages used in primary care were too low. I've never been convinced that antidepressants on the relatively low doses that I've been taking have any great effect.

Respondent 331, lines 273-277

Nevertheless, he also expressed concern about having once been prescribed a drug above the maximum dosage which suggests he preferred dosages near the maximum but within the recommended range.

Another interviewee expressed concern about being prescribed a dosage which was far below the minimum recommended dose.

I'm supposed to take one at night and on the leaflet it says if you take one at night it's supposed to be 150 to 175mg and if you take them in the daytime it's supposed to be 3x25g (sic) or 50g (sic) per day. And I'm taking one 25g (sic) at night and that's it. So I think it's either been written up wrong or I don't know, maybe the pharmacy's got it wrong or something because I don't think it's right. [Respondent taking tricyclic antidepressant]. Respondent 332, lines 309-318

At the follow-up interview this respondent reported that she had subsequently. discontinued her medication as she felt it would have no effects at such a low dosage. The effectiveness of tricyclic antidepressants at such low dosages is unknown. Interview data from the study being presented in this thesis indicated that the gap between recommendations and practice has the potential to influence decision-making regarding antidepressant medication.

Medication or dosage were reported as being changed as a result of the experience of side effects or the reaching of a plateau in the recovery process. Dosages were also gradually reduced on withdrawing the medication. However, the experience of adverse drug reactions caused some respondents to discontinue their medication completely, rather than trying a different drug (see section 6.2.2.3).

#### 6.5 The role of medication in the context of other treatments

As discussed in section 6.2.1.4, interviewees considered medication as only one factor in the recovery process. Section 6.5 describes strategies which were used to overcome depression, alongside conventional pharmacotherapy, including complementary therapy, psychological therapy, external support and additional coping strategies which respondents identified. Respondents' views of each of these strategies in comparison to licensed antidepressant medication will be discussed.

#### 6.5.1 COMPLEMENTARY THERAPY

A range of complementary therapies was reported as being used by interviewees, including St John's Wort, herbal sleep aiding remedies, homeopathy, vitamin supplements, aromotherapy, healing, alcohol and acupuncture. In the majority of cases complementary medicines were self prescribed. However, some interviewees had had prescriptions issued by their general practitioner or by alternative practitioners.

A variety of opinions were expressed concerning the use of complementary therapies. Discussions took place with many interviewees regarding their treatment preferences. Others had not considered using alternative remedies and did not discuss them at any length.

#### 6.5.1.1 Comparison to licensed antidepressant medication

As one of the inclusion criteria for the study was to have been prescribed antidepressant medication, most interviewees who had used complementary therapies had used them in conjunction with prescribed medication and were able to compare the 2 directly. Others had only used alternative remedies, making their means of comparison speculative. The latter group of interviewees fell into 2 categories, those who had not been prescribed licensed antidepressant therapy and those who had chosen not to take it.

#### General attitudes towards treatment

Respondents often described complementary therapies as being more natural than licensed antidepressant medication and as being less likely to cause dependence.

And it was a very natural process where[as] I think Prozac is very man made. Respondent 326, lines 125-126

They seemed a non addictive alternative way, being natural, one thinks it's ok. Respondent 525, lines 402-404

This view has also been expressed in other studies relating to patients' perceptions of medicines (Donovan and Blake, 1992; Morgan, 1993).

However, one interviewee expressed concern about becoming psychologically dependent on complementary medicines in the same way that other respondents were concerned about becoming reliant on licensed antidepressant medication (see section 6.2.2.2).

But I don't want to get myself used to it too much. I want to be able to do it by myself, not depending on something to do it. Respondent 308, lines 370-373

In addition, some interviewees were aware of the lack of medical evidence supporting the use of complementary therapy.

Um, I think they are of some value. I think there are medicines around that we've probably ignored for a long time. So, yeah, they are of some value but I think the companies have got a long way to research, rather than leave it to some guy in a shop around the corner. [Respondent who had not used complementary therapy].

Respondent 504, lines 623-633

Lack of medical evidence caused scepticism about the usefulness of alternative remedies. Two interviewees reported that they did not wish to use complementary therapy as they felt that it would only help those who had personal beliefs in its effectiveness.

I don't think enough's known about some of it. I wouldn't trust it. I don't think I'd have enough faith in it for it to do me any good. I think you've got to trust what you're taking to do you some good to take it. Do you know what I mean? Um, so, to me it's not, it's a bit nonsensical. I know it's becoming very acceptable these days, even some GPs do homeopathy as well but to me, I suppose because I've worked in a pharmaceutical company for so long. [Laughter]. I just don't see the point in it.

Respondent 528, lines 934-947

#### <u>Benefits</u>

Interviewees expressed a range of views regarding the benefits of complementary

medicines, when compared to those of licensed antidepressant medication. Some interviewees perceived complementary medicines as having been more effective than licenced antidepressant medication.

And the extreme fatigue and sleeping, overpowering sleepiness has gone, which I was [still] getting while I was on the Prozac. And so that, so I would say it's very successful.

Respondent 013b, lines 145-149

I could say that it's the first medication that really has had any positive effect on me.

Respondent 302, lines 351-353

However, even for the interviewees with these positive feelings towards complementary therapy, many of the same issues arose as have been discussed concerning the effectiveness of licensed antidepressant medication. Miracle cures were not reported.

Um, I was on a more even keel and it definitely did help with the anxiety but I still did feel depressed quite often.

Respondent 312b, lines 154-156

In addition, 2 respondents reported that they were unsure as to whether the benefits they had noticed could be attributed to the complementary therapy they were using.

I think they helped. I say I think because it could have been that it was natural that I would come out of it anyway.

Respondent 427, lines 214-216

Furthermore, the recovery process after taking alternative remedies, was generally regarded as being slow.

It was quite gradual as well ... I'd say it's taken about 6 months. Respondent 326, lines 97-102

There was, however, one exception to this where homeopathic remedies were perceived as working faster than licensed antidepressant medication.

They've worked faster than the stuff that I was on before. It's worked, you know, it seems to have got into my system. But maybe, it might because it's liquid rather than in a tablet form.

Respondent 319, lines 162-167

Although some interviewees perceived complementary medicines as being more effective than licensed antidepressant medication, in other cases licensed antidepressant medication was perceived as being the main therapy and the complementary therapy was an adjuvant to this.

No, I think the drug treatment's the bit that got me out of it and I think it's [aromotherapy] just a way to pamper yourself, enjoy yourself and lie in a bath of oil.

Respondent 015, lines 595-599

Some of these interviewees described complementary therapies as effective, but simply as placebos.

I'm a great believer in rescue remedy. ... I'm quite sure it's all in the mind actually. It doesn't matter. Respondent 409, lines 365-371

In addition, some respondents reported that they had found that alternative remedies were ineffective compared with conventional antidepressant medication.

I have experimented with these things from organic food shops but they don't seem to have the smallest effects. I've tried acupuncture, it made things worse. So um, I'm disposed to believe that conventional medicines, pharmaceutical products are the best.

Respondent 016, lines 412-419

Well ,I thought, why am I taking those? They're not really doing anything for me anyway. ... So, I thought, well I'll get off them and I'll take St John's Wort, which is just a herbal thing and of course they didn't do nothing either. I just got gradually ... worse and worse over the next month or 2. [Respondent who had tried both and eventually settled on licensed antidepressant medication]. Respondent 406, lines 458-469

One interviewee was very angry with a GP who had only prescribed homeopathic remedies, which she was finding ineffective.

#### Adverse drug reactions

Three respondents perceived complementary therapy as having less adverse drug reactions than antidepressant medication.

I'd actually go back to her to get more complementary medicine rather than straight medicine actually, because I hadn't had any side effects at all. Respondent 319, lines 250-253 However, 3 respondents mentioned that they had had some adverse drug reactions with complementary medicine.

I did have masses and masses of gunge coming out of my nose shortly after I'd taken it.

Respondent 013, lines 447-449

In addition, one interviewee complained that his family did not like the strong smell when an infusion he was using, was being boiled. Two interviewees reported having anticipatory concerns over potential adverse drug reactions and expressed the need for a knowledge base.

I'm not quite sure about herbal remedies because I think most drugs are actually herbal and I think if you don't know what you're doing you take overdoses and have side effects of those as well. You just aren't qualified to know that. Respondent 015, lines 571-580

Such views may result from the increasing publicity associated with the potential dangers of St John's Wort, tempering the general view that complementary medicines are safe.

One of the latter interviewees had used herbal therapies for other conditions but described having more fear over using them for depression.

Now I'm always a bit, I'm a bit bothered about the brain you know and I sort of think to myself well suppose this isn't quite right? Um, should I take it? So I haven't bothered.

Respondent 531, lines 1592-1601

She therefore chose to take only licensed antidepressant medication.

#### Interactions

There has been recent concern over interactions that can occur between St John's Wort and other medication (Yue et al. 2000; Ruschitzka et al. 2000; Piscitelli et al. 2000; Ernst, 1999). In interviews carried out since this problem was highlighted, some respondents were concerned about taking licenced antidepressant medication in conjunction with St John's Wort. In all cases this led interviewees to choose the prescribed licensed antidepressant medication over the herbal remedy, rather than vice versa.

I haven't actually [taken any herbal or homeopathic remedies] because ... I saw something in the newspaper about taking some kind of herbs, or whatever it is they make them out of, in conjunction with medication and there can be a detrimental effect. But I didn't read the whole article but I just thought it might be, I don't know whether I should mix the 2.

Respondent 428, lines 376-385

#### <u>Stigma</u>

Three interviewees reported that an advantage of using complementary therapy, when compared to taking antidepressant medication, was that there was no stigma attached to it. This view was further supported by another interviewee who declined to take licensed antidepressant medication due to feelings of stigma but occasionally took St John's Wort. The reasons for the lack of stigma attached to taking complementary therapies were not always explicitly stated but there were indications that it was partly because they could be obtained without receiving a formal diagnosis of depression. They were therefore a resource used for coping with every day life, rather than being indicative of a medical condition.

It was sort of a joke. You know at work we were going, yeah, tipping it back. I know it sounds funny but we was mucking about with it. We just thought it was. Because it said on the bottle for stress and at work, you know, you get all stressed and we were going 'get me some, we'll take it.' ... I showed my mum because it's different to Prozac. [Laughter]. Because when you show her that it's just something from the Boots. And it's not. You didn't need to go and see anyone to say I need [it] because I'm depressed. [Respondent who had not told family or workmates that she was taking Prozac].

Respondent 005, lines 387-394 427-435

#### **Compliance**

Despite the perception of lower risks being involved, 3 interviewees said that they were less compliant with their complementary medicines than their licensed antidepressant medication. Again, interviewees indicated they were unsure of the reason for this.

I keep forgetting to take them. Then I don't forget to take Prozac but I forget to take them. It's really strange.

Respondent 005b, lines 472-475

However, on being prompted, one respondent suggested that a possible reason for being less compliant with complementary medicine was that her licensed antidepressant medication was in a calendar pack. It may be hypothesised that interviewees were less compliant with complementary medicines as they were self prescribed and a medical regime was not being followed. Being prescribed licensed antidepressant medication was a traumatic event for respondents as it labelled them as suffering from depression (as described in section 6.2.2.1). As there was no label of stigma attached to complementary medicines, the decision to take them may have been less dramatic and it may therefore have had a lower level of focus in interviewees' minds.

#### Expense and availability

Two interviewees identified expense as a reason for not taking homeopathic medication.

She prescribed all these drop things to get from the homeopathic place and I never went and got them because I'm on income support anyway and I couldn't afford to go and get them anyway.

Respondent 332, lines 81-87

Both these respondents were exempt from prescription charges.

Connected to expense, interviewees suggested that complementary therapy should be more readily available through the NHS.

It does concern me, you know, the way alternatives aren't looked into [on the NHS].

Respondent 013b, lines 486-487

#### 6.5.2 PSYCHOLOGICAL THERAPY

The term 'talk therapy' was used when asking respondents about their views on psychological treatments (when compared to antidepressant medication). However, in this thesis 'talk therapy' is replaced with 'psychological therapy' with the exception of verbatim quotations.

Thirty one interviewees had received professional psychological therapy in addition to their antidepressant medication.

Some respondents reported that the 2 treatments complemented each other, there being a range of views regarding the way in which this worked. Taking medication was perceived to aid psychological therapy by allowing the respondent to feel more

relaxed and open, in some cases. For another interviewee, psychological therapy was perceived to reduce the feelings of stigma that he had towards taking antidepressant medication by identifying that there were reasons for his depression. Other interviewees reported that the 2 treatments fulfilled different roles.

No, the counselling was more just because I needed somebody to talk to who had to sit there and listen to it and I did sort of learn from those experiences but it wasn't dealing with my anxiety at all. Um, these pills were far more specific, I think to get over the claustrophobia.

Respondent 007, lines 1151-1159

For example, some interviewees reported that one therapy dealt with the symptoms of depression whereas the other dealt with the underlying cause. Depending on interviewees' perceptions of the cause of their depression, some respondents perceived that the psychological therapy dealt with the underlying cause and the medication with the symptoms or vice versa. Where interviewees were of the opinion that the cause of their depression was psychological they felt that psychological therapy could address it, while medication could relieve their symptoms. However, when interviewees viewed their depression as having an underlying biological cause, they reported that medication could deal with it and that although psychological therapy helped, it did not deal with the underlying problem. Two interviewees were of the view that although psychological therapy had helped, without medication they would not have reached the stage that they were now at.

I don't think I could have done it without you know, the medication which I had. I think that really put me on the final push and gave me the boost I needed really.

Respondent 106, lines 165-169

#### 6.5.2.1 Disadvantages of psychological therapy

Interviewees' perceptions of the negative aspects of taking antidepressant medication have been discussed in section 6.2.2. Respondents also identified several problems with psychological therapy. Firstly, respondents described experiences of feeling abandoned at the end of a session.

I've had a lot of different counselling for different reasons and every time it's like everything gets opened out, dragged up and then your counselling like is finished and you have to leave and you have to deal with all that. Respondent 332, lines 522-528

Secondly, some interviewees reported being sceptical about the powers of talking to

someone to solve their problems, particularly where the psychological therapy was non-directive.

They are just there to listen. But they can't advise you. They can't say anything to you. ... They can't give you any professional advice or make a decision for you, basically.

Respondent 009, lines 765-769

Thirdly, it became apparent from the analysis that psychological dependency was an issue associated with psychological therapy, although it was less frequently raised in association with this than antidepressant medication.

You can get hooked on that as much as you can on the drug. You just transfer it.

Respondent 015, lines 658-661

I think people can take that as a kind of a crutch once they get involved in it and there's no end of it. No time of actually saying, well that's it. You see it in America where people are seeing a therapist for 30 years. I didn't want that, thank-you.

Respondent 015b, lines 103-109

Finally, 2 interviewees reported that their therapist tried to trace their current situation back to difficulties in sexual relationships where there was no indication of this. These interviewees both came from the same surgery and no respondents recruited from other surgeries expressed concern about this. Therefore it is likely that this view was related to one specific therapist rather than being a generalisable finding.

### 6.5.2.2 Treatment preferences between pharmacotherapy and psychological therapy

When discussing preferences for treatment, respondents differed as to which therapy was preferred. Some interviewees stated that they would prefer psychological therapy.

I think counselling would sort of let me get out of my emotions, instead of getting these, eh antidepressants and suppressing, antidepressants suppress your emotions.

Respondent 415, lines 865-871

In contrast, other interviewees reported that they favoured medication over psychological therapy.

I wanted to take the Prozac because I thought that would do more good than the counselling. I didn't know that counselling would get me out of the dips because I do feel it's physical rather than purely emotional. Respondent 013, lines 1219-1228

A reason given for preferring pharmacotherapy by one interviewee was that he already had experience of taking medication for other conditions whereas he had no experience of psychological therapy.

Medication I've been on, I've been a diabetic for 3 years now, 4 years, 3 years. Medication I can take ... talking to someone, I don't know because I've never had to, had to experience it before.

Respondent 524, lines 1526-1540

However, preferences for each treatment were represented by both respondents who reported having experienced psychological therapy and those who did not.

A randomised controlled trial with patient preference arms (preference group n = 220) showed that patients preferred counselling for mild depression and antidepressant medication for more severe depression (Chilvers et al. 2001). One respondent in the study being presented in this thesis, however, suggested that she felt that receiving psychological therapy was indicated for more severe depression than antidepressant medication, which shows that not all patients share this view.

In fact, I would say she were worse than me, well she had to have counselling. [Respondent who had taken medication but had had no counselling]. Respondent 526, lines 611-612

#### 6.5.2.3 Availability

A long waiting time for psychological services in primary care was raised by some interviewees.

Counselling's not always there when you need it. It's like with the depression, you know, you need someone to do something now. Respondent 013, lines 1197-1204

In comparison, evidence from interview data demonstrated that antidepressant medication was more readily available.

In contrast to the results in this section, which showed that medication can be considered favourably alongside psychological therapy, other studies (Kendrick, 1996; The Mental Health Foundation, 1998) have shown that psychological therapy is greatly preferred to medication. The difference could be due to the fact that respondents in the study being presented in this thesis already had experience of using antidepressant medication, whereas other studies have generally either researched the general public or patients who have not yet received treatment. This suggests that patients' more favourable attitudes to medication are associated with medication use. Jorm et al, (2000) found that those who had sought help for depression were more likely to believe that medical treatments were effective than those who had not. In addition, Rogers and Pilgrim (1993) found that 69% of psychiatric patients were of the opinion that antidepressant medication was helpful, whereas Priest et al (1996) found that only 16% of the general public thought that they would be helpful. Another factor which may have been associated with the more favourable attitudes expressed towards antidepressant medication in the study being presented in this thesis, is that patients who were more positive about their medication may have been more likely to participate (see section 8.1.2).

#### 6.5.3 EXTERNAL SUPPORT

In additional to professional psychological therapy, family, friends and healthcare professionals were cited as a means of support for some interviewees.

I think the extended family helped me tremendously, tremendously, because we rely on each other. And they would call me all the time. Respondent 101, lines 300-307

Informal support was sometimes described as counselling. One interviewee stated that this support was as important to recovery as taking antidepressant medication.

The turn around was really down to um, as much, [name of doctor]'s support, knowledge and just being a decent bloke really [as] the medication. I mean the medication is obviously doing something now but um, I'm not sure that, that on its own would have been enough.

Respondent 504b lines 340-347

However, respondents often had limited access to this level of help. With regards to family and friends, some interviewees reported that they had no-one to turn to. Others stated that they did not find them a source of help. In some cases, this was partly connected to the stigmatising nature of the illness (see section 6.2.2.1). In other cases, family and friends were not perceived to be informed enough to possess the knowledge that there was anything wrong.

Some respondents who reported having good relationships with their doctors still expressed concern about taking up too much of the doctor's time. Doctors were sometimes able to reassure respondents on this point.

GPs [are] quite important, I think. If he's just got that time of day, he says to me if you want to just pop along and have a chat, do so, that's quite reassuring. I hate to waste his time.

Respondent 525, lines 767-772

However, some interviewees were of the view that doctors gave out prescriptions for antidepressant medication as it was a quicker option.

And I hate, it's so sad that they just dump on you these things because they don't have the time. They just prescribe to you these things. Respondent 415, lines 1094-1097

#### 6.5.4 COPING STRATEGIES

Interviewees were asked if they had any additional coping strategies for managing their illness. The most frequent response was taking up more exercise or going to the gym. Others reported going to creative classes, such as art or cake decorating, enjoying nature, reading, cooking, listening to music and generally keeping busy and getting out and about more. However, respondents noted that coping strategies could not always be employed when depression was at its worst.

I play the piano for a while and that stops me getting angry or stressed out but then yeah, it's worked before but then this time round it seems to be a lot worse and because my creativity has dried out, I wouldn't couldn't think of, anything to play. [Laughter]. Or I couldn't really be bothered to get up and play the piano because I didn't feel like it, even though I knew it might help. Respondent 529, lines 392-404

Coping strategies would possibly therefore help when medication had already begun to take effect and some degree of recovery had taken place.

Some respondents reported carrying out a form of self counselling or stress management which they used in conjunction with other treatment.

I talk to myself and I mean I make myself a list of pros and cons of things. That's something I have. I get a pen and a paper and I write down a list of things and I write down pros and cons of everything for me. Respondent 308, lines 738-744 To conclude, when respondents made decisions about treatment for depression, medication was considered alongside other strategies.

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### <u>6.6 Changes to respondents' decisions about treatment for depression between</u> <u>first and second interviews</u>

Changes to respondents' views and experiences of medication were explored in the second interviews. Respondents' perspectives of their medication had changed in some cases. For example, one interviewee reported that he had less positive views towards his medication than he had had in the first interview (see section 6.2.1). In a number of other cases, respondents reported improvement between the 2 interviews.

Um, yeah I know there's a definite sign of improvement, I'm not so irritable, I don't get so upset. Um, as I say it's getting better. [Respondent at first interview].

Respondent 318, lines 135-138

On being asked at the second interview if there had been any changes in the interval between the 2 interviews, she then said:

Oh yeah I'd say I was a lot better. I'm still on the same medication. Respondent 318, lines 24-25

In addition, changes to respondent's medication taking behaviour, between the 2 interviews, were examined. It became apparent that some respondents had changed their decisions about taking antidepressant medication between the 2 interviews. For example, one respondent had both begun taking antidepressant medication (due to worsening of symptoms-see section 6.1.1) and stopped taking the medication (due to adverse drug reactions-section 6.2.2.3), in the period between the 2 interviews. In some cases, interviewees had begun to have counselling, in addition to their antidepressant medication and discussed the use of drug treatment in conjunction with talk therapy in the second interview (see section 6.5).

The value of data gained in the  $2^{nd}$  interviews will be discussed further in section 8.1.4.

#### 6.7 Interaction of research, researcher and participants

In section 6.7, observations regarding the interaction between the researcher, the participants and the research process are reported. Respondents sometimes made direct remarks concerning such issues, in the recorded section of the interview. However, comments made outside the formal interview and recorded in the field notes have also been included in the analysis. The implications of the interactions between the researcher, respondents and research process, on the validity of the study, will be discussed in section 8.1.

#### 6.7.1 REASONS FOR PARTICIPATION

Factors influencing patients' participation in the study were identified from the interviews. Firstly, some people had a general desire to be helpful.

I mean I'm only doing this to help you out, otherwise I wouldn't be, you know, doing it. Respondent 320b, lines 230-232

This desire to be helpful was sometimes associated with respondents' own involvement in studying or research, or that of their family. One interviewee stated that she was happy to help because her son was a student. Two respondents in the study were academic researchers themselves and it is possible that they were more motivated to take part in research than the general population.

The desire to help with the research was reported to be influenced by a 'good' doctorpatient relationship and a desire to help the GP, in some cases.

Because it was [name of doctor] I thought yeah, I'll do it. Respondent 504, lines 390-391

Secondly, some respondents reported feeling that it would be beneficial to talk to someone about their experiences.

Even though with [name of doctor] I said should I talk to someone? He said well not yet, see how you go. Then your letter arrived and ... I thought maybe another set of ears might you know, might be a help or whatever. Respondent 524, lines 555-559

Some respondents reported to the researcher at the second interview that they had

found the first interview very helpful in terms of clarifying their thought processes, even though they had not begun with any expectation of benefiting from talking through their experiences.

Thirdly, there were indications that respondents may have felt that they would gain from having the opportunity to discuss medical issues with the researcher. One respondent asked during a telephone call, in which arrangements for the interview were arranged, whether he would be given the opportunity to ask questions about his medication, to which the interviewer replied that questions would be answered at the end of the interview.

Fourthly, another respondent stated she had participated in order to voice her strongly felt opinions against antidepressant medication.

So that's why I really wanted to talk and to say that these antidepressants aren't good. Or you know, I mean, I often feel the doctors, just to get you out of their surgery, they prescribe these things.

Respondent 415, lines 814-817

Fifthly, another respondent was unemployed and spoke of being very bored and always happy for the opportunity of something to do. It may therefore be deduced that this motivated him to participate in the research.

#### 6.7.2 TIMING OF PARTICIPATION

Comments from respondents indicated that patients were unable to participate in the interview at the worst stages of their illness, before recovery had begun. During the recorded part of the interview, 3 interviewees explicitly stated that they would have been unable to take part at an earlier stage of their illness.

I mean before I could not sit here and speak to you. I would have had every excuse to do something else.

Respondent 503, 494-500

Other respondents expressed this view informally, after the interview. Interviewees were also interested in the response rate. During discussions about the response rate some respondents said that they knew others who would be too ill to take part and suggested this as a reason for non-participation by some patients.

#### 6.7.3 REASONS FOR NON-PARTICIPATION

Self reported reasons for non-participation have been described in section 5.2.2. It may be deduced that the stigma attached to taking antidepressant medication (see section 6.2.2.1) may also have deterred some patients from wishing to discuss their experiences. As reported in section 6.6.2, there were indications that patients may have been too ill to participate.

#### 6.7.4 PERCEIVED ROLE OF RESEARCHER AND INTERACTION PROCESS

Sections 6.6.1 to 6.6.3 not only give information about the types of patients who were more likely to have been present in the sample but also provide insight into the respondents' perceptions of the researcher and the interaction process. Some respondents regarded the interaction process as research. This view was also demonstrated by the fact that questions such as, 'Am I helping you?' were asked during the interview. In addition, interviewees were interested in the procedures for data processing and some respondents conveyed that they would be interested in the findings.

Other respondents viewed the researcher as a counsellor. In one interview the researcher had to clarify her role. Even where respondents did not perceive counselling as a formal role of the interview, it was still considered as a by product of the process.

In a way, it's like talking to you now, you're somebody I've never met before, you've got no input into my life. You're just listening to me talking and asking me odd questions [as oppose to the welfare officer who knows me very well]. ... So maybe having an opportunity to speak with the counsellor and talk about all these things, I feel might be helpful. [Respondent responding to questions about counselling].

Respondent 531, lines 1351-1355

In addition, the researcher was sometimes considered in the role of a pharmacist. Interviewees often asked questions about their medication. In addition, during a discussion about the use of alternative medication, one respondent said:

I'm probably wrong because they don't test their effectiveness. [Laughter]. I've got to be careful what I say to you, pharmacist. Respondent 525, lines 411-418

Although this was a tongue in cheek remark it may represent a view of the interview

as a medical encounter.

The implications of respondents' views of the researcher, for the findings will be discussed further in section 8.1.

#### 6.7.5 INFLUENCE OF RESEARCH ON PARTICIPANTS

The researcher may have influenced respondents' decision-making in 2 ways. Firstly, some respondents asked the researcher medical questions in her capacity as a pharmacist. However, the researcher generally postponed answering these questions until the end of the interview. The responses would therefore have only have influenced respondents decisions after the interview. They had the potential to influence respondents' decision-making between interviews. However, at the second interview, no respondents made reference to the researcher having influenced their decisions.

Secondly, the process of talking about experiences and thoughts concerning medication might have in itself influenced respondents.

Maybe sitting here and discussing it with you might make me feel different, I don't [know]. I might feel more confident about it all. Respondent 531, lines 2014-2018

#### 6.7.6 RECALL BIAS

Not only were respondents unable to participate in the research at the worst period of their illness, this time became a bit of a blur to some interviewees after recovery had started. The amount of information which respondents could give to the researcher about the initial stages of treatment was therefore limited.

To be honest it's quite a while away, you know. So I can't really remember that far back. But it's quite a blur those months. Respondent 318b, lines 164-166

Even where respondents did not specifically mention difficulties in remembering the initial stages of their illness, their recall may have been limited.

To conclude, a range of factors were identified which influenced whether or not patients participated in the study. Different perceptions of the researcher and

interaction process were identified amongst the respondents. Participating in the research could have had some effects on patients' decision-making regarding treatment. However, steps were taken to minimise the influence of these on the research findings. Some difficulties were experienced in obtaining views on the very beginning of treatment. The implications of all these findings for the validity of the results will be discussed in chapter 8.

## <u>CHAPTER 7</u> <u>ANALYSIS OF QUANTITATIVE DATA IN TERMS OF MEDICATION</u> <u>TAKING BEHAVIOUR</u>

Chapter 7 states the responses obtained from the quantitative instruments used in the study and reports the results of a principal components analysis (Nunnally, 1978) used to reduce the number of beliefs about depression on the Jorm et al questionnaire (1997a; 1997b). The first and second interview data are first considered separately. Changes which occurred between the first and second interviews are then described. The chapter continues by examining the quantitative data in the context of treatment decision-making. Finally the factors affecting the usefulness of each instrument in the study, such as the validity and reliability, are examined.

Fifty one patients participated in the first interview. One respondent was able to contribute to some parts of the qualitative interview but had insufficient English to enable completion of the quantitative instruments. Therefore the sample size for the quantitative data collected during the first interview was 50. Forty four patients participated in the second interview. Again the respondent with insufficient English did not complete the quantitative instruments. In addition, one respondent was unable to complete the quantitative instruments in the second interview due to lack of time. The sample size for the quantitative data for the second interviews was therefore 42.

#### 7.1 Responses to the quantitative instruments

#### 7.1.1 RESPONDENTS' BELIEFS ABOUT DEPRESSION

The study sought to investigate associations between beliefs of depression and the use of medicines for depression with choices about therapy. The Jorm et al Questionnaire (1997a; 1997b) was used to measure beliefs about the causes and risk factors for depression and the helpfulness of various interventions (see section 4.2.6.2). The instrument was presented in 3 sections: causes, risk factors and interventions. The responses obtained from each section are shown in tables 7.1 to 7.6 respectively.

Cause	Very likely (%)	Likely (%)	Not likely (%)	Unable to answer (%)
Recent bereavement	38 (76)	9 (18)	3 (6)	0 (0)
Day to day problems	33 (66)	14 (28)	2 (4)	1 (2)
Childhood event	30 (60)	9 (18)	8 (16)	3 (6)
Traumatic events	26 (52)	14 (28)	8 (16)	2 (4)
Inherited	14 (28)	19 (38)	14 (28)	3 (6)
Weak character	12 (24)	19 (38)	16 (32)	3 (6)
Nervous person	11 (22)	25 (50)	13 (26)	1 (2)
Infection	6 (12)	24 (48)	20 (40)	0 (0)
Allergy	3 (6)	15 (30)	28 (56)	4 (8)

Table 7.1 : Respondents' beliefs about the causes of depression : firstinterview (n=50)

<b>Table 7.2:</b>	Respondents' beliefs about the causes of depression: second
	interview (n=42)

Cause	Very likely (%)	Likely (%)	Not likely (%)	Unable to answer (%)
Recent bereavement	30 (72)	9 (21)	3 (7)	0 (0)
Day to day problems	28 (67)	11 (26)	3 (7)	0 (0)
Traumatic events	24 (57)	13 (31)	5 (12)	0 (0)
Childhood event	18 (43)	16 (38)	5 (12)	3 (7)
Inherited	7 (16)	23 (55)	10 (24)	2 (5)
Nervous person.	7 (17)	23 (55)	11 (26)	1 (2)
Weak character	5 (12)	19 (45)	16 (38)	2 (5)
Infection	4 (10)	19 (45)	18 (43)	1 (2)
Allergy	2 (5)	13 (31)	26 (62)	1 (2)

Tables 7.1 and 7.2 demonstrate that factors rated as likely to cause depression by the majority of respondents at both interviews were in the immediate social environment (recent bereavement, day to day problems, traumatic events), a finding consistent with studies which have researched the views of the general public (Jorm et al. 1997b; Paykel et al. 1998; Priest et al. 1996). In addition, childhood events were rated as likely to cause depression by the majority of respondents in the first interview.

Table 7.3 : Respondents' beliefs about whether some people in the community<br/>are more likely to suffer from depression than others: first<br/>interview (n=50)

Population group	More likely (%)	Less likely (%)	No difference (%)	Unable to answer (%)
Unemployed	43 (86)	0 (0)	7 (14)	0 (0)
Divorced	32 (64)	2 (4)	13 (26)	3 (6)
Poor	29 (58)	0 (0)	21 (42)	0 (0)
Elderly	25 (50)	13 (26)	10 (20)	2 (4)
Young people	21 (42)	18 (36)	10 (20)	1 (2)
Women	18 (36)	4 (8)	26 (52)	2 (4)
Single	14 (28)	8 (16)	23 (46)	5 (10)

Table 7.4:Respondents' beliefs about whether some people in the communityare more likely to suffer from depression than others:second interview (n=42)

Population group	More likely (%)	Less likely (%)	No difference(%)	Unable to answer (%)
Unemployed	34 (81)	3 (7)	3 (7)	2 (5)
Poor	32 (76)	1 (2)	9 (22)	0 (0)
Divorced	31 (74)	3 (7)	6 (14)	2 (5)
Elderly	25 (60)	6 (14)	11 (26)	0 (0)
Women	22 (52)	1(2)	15 (36)	4 (10)
Young people	14 (33)	12 (29)	15 (36)	1 (2)
Single	12 (28)	8 (19)	20 (48)	2 (5)

The unemployed, poor and divorced were perceived as being at greater risk than others, of suffering from depression, by over 50% of respondents at both interviews. Again, this finding is consistent with views of the general public (Priest et al. 1996). Respondents were more likely to rate being elderly as a risk factor than being a young person. This finding supports the qualitative data, which demonstrated that there was a belief that people of a younger age had less need to be on antidepressant medication than older people. However, there was a range of views as to whether young age is a risk factor for depression and that not all interviewees believed that young people were less likely to suffer from depression than older people.

# Table 7.5:Respondents' beliefs about the helpfulness and harmfulness of<br/>various interventions for the treatment of depression: first<br/>interview (n=50)

Intervention	Helpful	Harmful	No difference	Unable to answer
	(%)	(%)	(%)	(%)
People				
Typical GP	46 (92)	0 (0)	1 (2)	3 (6)
Phone counsellor	41 (82)	1 (2)	7 (14)	1 (2)
Close friends	41 (82)	1 (2)	6 (12)	2 (4)
Clinical psychologist	39 (78)	2 (4)	6 (12)	3 (6)
Counsellor	38 (76)	0 (0)	9 (18)	3 (6)
Close family	37 (74)	5 (10)	6 (12)	2 (4)
Psychiatrist	34 (68)	3 (6)	8 (16)	5 (10)
Typical pharmacist	30 (60)	1 (2)	19 (38)	0 (0)
Clergy	23 (46)	6 (12)	17 (34)	4 (8)
Social worker	21 (42)	5 (10)	21 (42)	3 (6)
Naturopath	19 (38)	3 (6)	22 (44)	6 (12)
Deal with it alone	9 (18)	31(62)	7 (14)	3 (6)
Medicines				
Antidepressants	34 (68)	8 (16)	3 (6)	5 (10)
Vitamins/herbal medicines etc.	29 (58)	1 (2)	18 (36)	2 (4)
Tranquillisers	18 (36)	23 (46)	6 (12)	3 (6)
Pain killers	14 (28)	13 (26)	23 (46)	0 (0)
Sleeping pills	13 (26)	21 (42)	9 (18)	7 (14)
Antibiotics	10 (20)	9 (18)	29 (58)	2 (4)
Activities				
Get out more	47 (94)	0 (0)	2 (4)	1 (2)
Physically active	43 (86)	1 (2)	4 (8)	2 (4)
Counselling	42 (84)	1 (2)	4 (8)	3 (6)
Relaxation techniques	41 (82)	0 (0)	7 (14)	2 (4)
Self help books	35 (70)	6 (12)	9 (18)	0 (0)
Special diet	31 (62)	0 (0)	12 (24)	7 (14)
Occasional drink	30 (60)	8 (16)	7 (14)	5 (10)
Cutting out alcohol	25 (50)	4 (8)	13 (26)	8 (16)
Admission to hospital	21 (50)	9 (21)	4 (10)	8 (19)
Hypnosis	12 (24)	8 (16)	11 (22)	19 (38)
ECT	10 (20)	17 (34)	3 (6)	20 (40)

# Table 7.6:Respondents' beliefs about the helpfulness and harmfulness of<br/>various interventions for the treatment of depression: second<br/>interview (n=42)

Intervention	Helpful	Harmful	No difference	Unable to answer
Therical CD	41 (09)		1 (2)	0.00
	41 (98)	0 (0)	1 (2)	0 (0)
Clinical psychologist	33 (79)	0 (0)	3 (7)	6 (14)
Counsellor	32 (76)	0 (0)	6 (14)	4 (10)
Phone counsellor	31 (74)	0 (0)	8 (19)	3 (7)
Psychiatrist	31 (74)	2 (5)	2 (5)	7 (16)
Close family	31 (74)	4 (10)	6 (14)	1 (2)
Close friends	30 (71)	2 (5)	8 (19)	2 (5)
Typical pharmacist	22 (53)	1 (2)	18 (43)	1(2)
Clergy	20 (48)	3 (7)	14 (33)	5 (12)
Social worker	20 (47)	5 (12)	15 (36)	2 (5)
Naturopath	19 (45)	2 (5)	18 (43)	3 (7)
Deal with it alone	12 (29)	21 (50)	5 (12)	4 (9)
Medicines		····		
Antidepressants	33 (78)	4 (10)	3 (7)	2 (5)
Vitamins/herbal medicines etc.	23 (55)	1 (2)	15 (36)	3 (7)
Sleeping pills	15 (36)	17 (40)	6 (14)	4 (10)
Tranquillisers	14 (33)	17 (41)	6 (14)	5 (12)
Analgesics	10 (24)	10 (24)	20 (47)	2 (5)
Antibiotics	10 (24)	7 (16)	23 (55)	2 (5)
Activities			• · · · · · · · · · · · · · · · · · · ·	
Physically active	37 (89)	1 (2)	3 (7)	1 (2)
Get out more	36 (85)	0 (0)	4 (10)	2 (5)
Self help books	35 (83)	2 (5)	5 (12)	0 (0)
Counselling	34 (81)	1 (2)	6 (15)	1 (2)
Relaxation techniques	31 (74)	0 (0)	10 (24)	1 (2)
Special diet	30 (72)	0 (0)	11 (26)	1 (2)
Occasional drink	27 (64)	7 (17)	8 (19)	0 (0)
Admission to hospital	21 (50)	9 (21)	4 (10)	8 (19)
Cutting out alcohol	21 (50)	2 (5)	13 (31)	6 (14)
Hypnosis	14 (33)	5 (12)	12 (29)	11 (26)
ECT	8 (19)	16 (38)	2 (5)	16 (38)

Tables 7.5 and 7.6 support the qualitative findings by showing that a large variety of interventions were considered helpful. Only electroconvulsive therapy, tranquillisers and sleeping pills were rated as harmful more often than helpful. With regards to sleeping pills and tranquillisers, the harmful rating may have been influenced by medical opinion and general public knowledge. Antidepressant medication was considered helpful by the majority of respondents and was rated helpful more often than any other medicine, including vitamins and herbal medicines.

Comparisons between the responses to the questions on the helpfulness/harmfulness of the various interventions obtained in the study being presented in this thesis and those found by Jorm et al (1997a) are made in section 7.1.1.2.

#### 7.1.1.1 Data reduction of Jorm et al Questionnaire (1997a; 1997b) data

In an attempt to reduce the number of variables on the Jorm et al Questionnaire (1997a; 1997b) for use in further analysis, a principal components analysis was performed. However, there were few significant correlations between the items. No rotation could be carried out for the first interview data and no distinctive factors could be identified from the second interview data.

7.1.1.2 Comparison between Jorm et al's data regarding helpfulness and harmfulness of interventions for the treatment of depression and the data being presented in this thesis

In order to put the scores into the context of previous results with the instrument, comparisons were made between respondents' beliefs about the helpfulness of various possible interventions in this sample, with those found by Jorm in a study of the Australian public (Jorm et al. 1997a). Each helpfulness rating was given a score of +1 and each harmfulness rating was given a score of -1. The mean ratings of each intervention for both the first and second interview samples were then calculated. The mean ratings reported by Jorm et al (1997a) are shown alongside the mean ratings found in the study being presented in this thesis in table 7.7. The higher the mean rating, the higher the number of people who rated the intervention as helpful.

# Table 7.7:Mean ratings of helpfulness/harmfulness concerning interventions<br/>for the treatment of depression: comparison between this study<br/>and Jorm's study of the general public

Intervention	This study-interview 1	This study-interview 2	Jorm sample of general public			
People						
Typical GP	0.98	0.98	0.87			
Close friends	0.83	0.7	0.78			
Phone counselling	0.82	0.79	0.54			
Counsellor	0.81	0.84	0.8			
Clinical psychologist	0.79	0.92	0.49			
Psychiatrist	0.69	0.83	0.47			
Close family	0.67	0.66	0.77			
Typical pharmacist	0.58	0.51	0.21			
Social worker	0.48	0.34	0.38			
Clergy	0.37	0.46	0.48			
Naturopath	0.36	0.44	0.27			
Deal with it alone	-0.47	-0.24	-0.17			
Medicines						
Antidepressants	0.58	0.73	-0.16			
Vitamins/herbal medicines etc.	0.58	0.56	0.63			
Antibiotics	0.02	0.07	-0.28			
Pain killers	0.00	0.00	-0.35			
Tranquillisers	-0.11	-0.08	-0.65			
Sleeping pills	-0.19	-0.05	-0.44			
Deal with it alone	-0.47	-0.24	-0.17			
Activities						
Get out more	0.96	0.9	0.85			
Physically active	0.88	0.88	0.87 .			
Counselling	0.87	0.8	0.26			
Relaxation techniques	0.85	0.76	0.86			
Special diet	0.69	0.73	0.40			
Self help books	0.58	0.79	0.64			
Cutting out alcohol	0.5	0.53	0.61			
Occasional drink	0.5	0.48	0.22			
Admission to hospital	0.28	0.35	-0.65			
Hypnosis	0.13	0.29	-0.03			
ECT	-0.27	-0.31	-0.80			

Table 7.7 demonstrates that, in general, items were rated as more helpful on the sample obtained in this study than they were in the study carried out with the Australian general public (Jorm et al. 1997a). In addition, the researcher noted that, in the study being presented in this thesis, where interviewees were unsure of the helpfulness of a particular intervention they often chose the response 'helpful,' saying, 'I suppose it could be helpful.'. One possible explanation for the difference between this study and Jorm's study is that those people with a diagnosis of depression may be more open to interventions as they understand the experience of the illness. Another factor pointing to this explanation is that those in this sample were less likely to believe that dealing with problems alone would be helpful than Jorm's sample. Respondents were also relatively less likely to rate other lifestyle interventions as helpful. These included, becoming more physically active, reading self help books, learning relaxation techniques, cutting out alcohol, taking vitamins and support from close family. It is possible that respondents felt that lifestyle interventions would be insufficient alone for dealing with depression. When answering the questionnaire, interviewees commented that activities such as becoming more physically active or getting out and about more may be helpful but that it not always possible to do these when feeling depressed. This finding is also supported by comments made in the qualitative interviews (see section 6.5.4).

However, there is evidence that the picture was more complex than simply choosing between categories of interventions. Jorm et al (1997c) performed a principal components analysis to determine whether the variables on the Jorm et al Questionnaire could be reduced into a smaller number of factors. Three scales of medical, psychological and lifestyle interventions were formed from this analysis. However, in the study being presented in this thesis no distinct factors were identified from a principal components analysis (see section 7.1.1.1). This supports the view that decision-making was complex and was dependent on a large number of variables rather than being simply defined.

For 2 interventions, the mean rating differed from being negative in Jorm's sample (1997a) to being positive in the study being presented in this thesis. Therefore, on average, Jorm's (1997a) sample regarded these interventions as being harmful but the sample obtained in the study being presented in this thesis viewed them as helpful. These interventions were antidepressant medication and admission to hospital. The former finding supports the qualitative data which also showed that interviewees regarded medication favourably. It indicated that people suffering from depression
were more likely to have positive views about medication than the general public, a finding supported by other studies (see section 2.3.10). This may have been exaggerated, in the study being presented in this thesis, by the fact that there were indications that there was a response bias towards those who were more positive about their medication (see section 8.1). Significant differences which occurred between the first and second interviews are described in section 7.2.

## 7.1.2 RESPONDENTS' QUALITY OF LIFE

The Smithkline Beecham Quality of Life Questionnaire (SKB) (Dunbar et al. 1992) is an instrument designed to measure quality of life. The reliability and validity of the instrument have been tested in patients suffering from anxiety and depression (Stoker et al. 1992). The instrument consists of 23 items. Each item on the questionnaire has a visual analogue scale consisting of 10 boxes (as described in section 4.2.6.2). Possible scores for each item range from one to 10, the highest quality of life being represented by the lowest score. Scores for the instrument were calculated by totalling the scores of each of the 23 individual items. The range of possible instrument scores was therefore 23 to 230.

In the first interview, 40 (80%) of respondents completed the instrument fully. Instrument scores for these respondents ranged from 34 to 219, the mean score being 114.9, the median 122.5. Median scores for each item ranged from 2 to 7.5.

In the second interview, 39 (89 %) of respondents completed the instrument fully. Instrument scores for these respondents ranged from 37 to 185, the mean score being 102, the median 106. The median values for each item ranged from 2 to 6.75.

The responses from the SKB demonstrate that respondents had a wide range of quality of life. The significance of changes in quality of life between the first and second interviews is described in section 7.2.

## 7.1.3 RESPONDENTS' SYMPTOM ATTRIBUTIONS

The Symptom Interpretation Questionnaire (SIQ) (Robbins and Kirmayer, 1992) measures respondents' perceptions of the causes of their symptoms, that is their symptom attributions. The instrument consists of 3 scales of attributions: physical, psychological and normalising. Respondents were asked to assess the likelihood of

various symptoms being due to each of these 3 causes. Three scores are obtained for each respondent, to correspond to the 3 scales. The range of possible scores for each scale is 13 to 54. The minimum, maximum, mean scores for the data obtained for the 2 interviews, are shown in tables 7.8 and 7.9.

Attribution	Minimum Value	Maximum Value	Median Value	No. of missing values
Psychological	15	50	30.3	8
Somatic	14	41	25	9
Normalising	18	44	32	10

Table 7.8:Respondents' symptom attributions:first interview (n = 50)

Table 7.9:	<b>Respondents'</b>	symptom attributions:	second interview	(n = 42)	2)
	-			•	

Attribution	Minimum	Maximum	Median Value	No. of missing values
Psychological	13	46	28	7
Somatic	13	48	25	7
Normalising	18	49	31	6

## 7.2 Differences between first and second interview data

In order to determine whether any significant changes had occurred between the first and second interviews, Wilcoxon matched-pairs signed-ranks tests were carried out on the 2 data sets for each variable in the Jorm et al Questionnaire (1997a; 1997b), for the total score of the SKB (Dunbar et al. 1992) and for the total score on each of the 3 scales of the SIQ (Robbins and Kirmayer, 1992). Significant differences were noted on several of these variables at the p < 0.05 level. Variables which were significantly different, together with the p values are shown in table 7.10.

Table 7.10:Significant changes in variables in beliefs about depression, quality<br/>of life and symptom attributions between interviews 1 and 2

Variable	Significance (p)	Direction of change
total score of SKB	0.001	decreased (therefore quality of life increased)
helpfulness of clinical psychologist	0.012	increased (more likely to be rated as helpful)
helpfulness of dealing with problems yourself	0.012	increased (more likely to be rated as helpful)
psychological attribution scale of SIQ	0.016	decreased score (less likely to attribute symptoms to psychological causes)
helpfulness of psychiatrist	0.017	increase (more likely to be rated as helpful)
helpfulness of hospital admission	0.017	increased (more likely to be rated as helpful)
helpfulness of hypnosis	0.032	increased (more likely to be rated as helpful)
helpfulness of ECT	0.048	increased (more likely to be rated as helpful)
female gender as risk factor for depression	0.02	increased (more likely to be rated as risk factor)

Table 7.10 demonstrates that some changes occurred between the 2 interviews. Several factors point to the conclusion that the majority of respondents' conditions improved during the period between the interviews. Firstly, quality of life increased during this time. Secondly, respondents were less likely to attribute the symptoms presented on the SIQ to psychological causes. Previous research has shown that the level of patients' psychological symptoms is associated with the degree of psychological attributions (Robbins and Kirmayer, 1992). Therefore the decrease in score on the psychological symptoms had decreased. Thirdly, from the analysis of the qualitative interview data, it was identified that some interviewees reported that their recovery had progressed between the 2 interviews.

Table 7.10 also demonstrates that there were significant differences between some variables on the Jorm et al Questionnaire (1997a; 1997b). However, the validity or acceptability of the majority of those variables that changed is questionable (see section 7.4.1). This may have made them unreliable. These variables related to the helpfulness of a clinical psychologist, psychiatrist, hospital admission and ECT. Two other variables showed significant change, between the 2 interviews, female gender being a risk factor for depression and solving problems on one's own being helpful.

A possible explanation for respondents being more likely to believe that female gender was a risk factor for depression by the second interview is that they may have obtained more information about depression during the course of treatment. The reason for respondents being more likely to believe that solving problems on their own may be helpful at the second interview is unclear. However, in the majority of cases, respondents' condition improved in the period between the 2 interviews (see earlier in this section). Therefore, one possible hypothesis is that respondents reached a stage in their treatment where they were able to work through their problems themselves, to some extent.

# 7.3 Variables distinguishing those who continued with their medication from those who discontinued

Section 7.3 describes the results of the analysis which sought to identify factors which distinguished between respondents who continued with their medication and those who discontinued. In this part of the analysis respondents were categorised into 2 groups according to whether or not they had continued to take their medication for the minimum recommended treatment time of 4 months. Respondents who reported that they had taken their medication intermittently were classified as 'continuers' if they stated that they had only stopped their medication for a very short period of time (less than one week) (n=3) and 'discontinuers' if they stated that they had stopped taking their medication for more than one week (n=2).

Bivariate analysis was carried out to identify which variables distinguished between the continuers and discontinuers. Chi-square and Mann Whitney U tests were used for categorical and interval variables respectively. As the Wilcoxon matched-pairs signed-ranks tests had shown that there were differences between the first and second data sets, these were examined separately in this stage of the analysis.

Very few variables were found to distinguish between the continuers and discontinuers in the bivariate analysis. Only 3 variables were significantly associated with medication taking behaviour. Continuers were more likely to be of older age (p=0.02), believe that antidepressant medication was helpful (p=0.02 first interview, not significantly associated second interview) and that hypnosis was helpful (p=0.03 second interview, not significantly associated first interview). It is possible that due to the large number of variables which were included in the analysis, these 3 variables were found to be significant by chance. This hypothesis is supported by the fact that 2 of these 3 variables were not consistently found to be associated with medication taking behaviour in both the first and second interview data (age was only collected once). In addition, the face validity of the question regarding hypnosis was questionable (see section 6.4.1.2). However, the finding that belief in the helpfulness of antidepressant medication was associated with respondents being more likely to continue with it seems plausible.

It is possible that a quantitative instrument designed to test specific themes identified in the analysis of the qualitative component of the interview (see chapter 6) may have been able to distinguish between continuers and discontinuers. For example, a more specific instrument to measure beliefs about antidepressant medication which incorporated factors such as stigma (see section 6.2.2.1) and dependency (see section 6.2.2.2) may have been useful.

## 7.4 Use of the quantitative instruments in the study

Section 7.4 considers the factors which affected the usefulness of the instruments with the sample population. To aid in this process, comparisons between the results found in this study and those found in other studies, using the same instruments are sometimes made. Other data which are considered include field notes from the data collection and internal reliability coefficients. Each instrument will be considered in turn.

## 7.4.1 USE OF THE JORM ET AL QUESTIONNAIRE (1997A; 1997B)

Jorm et al (1997a; 1997b; 1997c) noted that responses such as 'don't know' or 'depends' were given in response to some questions. He described different methods of dealing with these responses in analysis (considered missing or neutral) and commented that the results of the analysis were not affected by the method used. However, the frequency of such responses were not given (Jorm et al. 1997a; Jorm et al. 1997b; Jorm et al. 1997c). In the study being presented in this thesis, some questions were unanswered by over 10% of respondents. Possible consequences for the validity and reliability of the instrument in the study are described in section 7.4.1.2 and 7.4.1.3.

## 7.4.1.1 Acceptability

The exact time taken to complete the quantitative instruments was not recorded. However, the Jorm et al Questionnaire (1997a; 1997b) was estimated to take between 10 and 20 minutes to complete in the majority of cases. A weakness of pre-coded response choice questions is that they may not be sufficiently comprehensive and not all answers may be easily accommodated (Bowling, 1997). When completing the Jorm et al Questionnaire (1997a; 1997b) some respondents found it difficult to express their views in one of the pre-determined categories because they felt that the option selected would depend on individual circumstances. Some examples are given below. In the following paragraph, the figures which are not bracketed refer to the first interview data and those bracketed refer to the second interview data. Twenty two percent (19% second interview) of respondents were unable to answer the question on the helpfulness of admission to hospital, feeling that the intervention could be helpful or harmful depending on individual circumstances, such as the severity of depression. Sixteen percent (14% second interview) were unable to state whether cutting out alcohol would be helpful or harmful, either because they didn't drink or because they believed it would depend on the amount normally consumed. Fourteen percent (10% second interview) of respondents reported that it was not possible to categorise sleeping pills as helpful or harmful as the rating depended on the way in which they were used.

In addition, only 60% (62% second interview) of respondents were able to offer an opinion about the helpfulness of ECT and only 58% (74% second interview) answered the question regarding hypnosis. Many of those unable to answer these 2 questions stated that they had not experienced it and were therefore not in a position to comment. Others simply said that they knew nothing about it. As noted earlier in this section, some respondents who did not drink alcohol did not feel that this question was relevant to them.

## 7.4.1.2 Validity

Structured questionnaire methodology is based on the assumption that questions are worded and ordered in a way that will be understood by all respondents (Bowling, 1997). However, a number of questions in the Jorm et al Questionnaire (1997a; 1997b) were unclear to some respondents.

Respondents did not understand the terminology used in a number of questions and asked the researcher for clarification of some issues. When answering the questions about the causes of depression, respondents often asked for an explanation of the terms 'Being a nervous person' or 'Weakness of character'. When responding to the questions about the interventions, respondents frequently asked the researcher to distinguish between a psychiatrist and a clinical psychologist for them. Where respondents asked for clarification, the researcher defined the terms. For example, respondents were informed that a psychiatrist was a specialist doctor for dealing with problems like depression and a clinical psychologist was a professional trained in talking treatments. Although the same definitions were given to every respondent that asked for clarification, respondents not asking for additional information were not given any. Non-comprehension of questions may have led to respondents being

unable to answer or answering in an invalid way. In the second interview 17% were unable to offer an opinion about the helpfulness of a psychiatrist (10% first interview) and 14% about the helpfulness of a clinical psychologist (6% first interview).

Additional comments made by respondents when answering some questions demonstrated that they misunderstood these items. One question asked about the likelihood of depression having genetic causes. Some respondents interpreted this question as asking whether having a congenital disease would make someone depressed. When responding to the questions about the helpfulness of pain killers and antibiotics, some interviewees answered concerning their general helpfulness, rather than their role in the treatment of depression. When it was clear that respondents misunderstood questions, but they did not ask for clarification, no additional information about the question was given.

Respondents had difficulty in answering multiple questions. For example one question asked whether problems from childhood such as being badly treated or abused, losing one or both parents when young or coming from a broken home would cause depression. Respondents sometimes thought that some of these problems would cause depression but that others would not and were therefore unable to answer.

Therefore, not all items on the questionnaire were clear and unambiguous and such items could not be considered as having face validity. In addition, where respondents interpreted 2 of the questions as asking about the general helpfulness of pain killers and antibiotics, rather than their usefulness in the treatment of depression, the content validity of these items may have been affected. The instrument was designed to measure beliefs concerning depression, rather than illnesses in general.

## 7.4.1.3 Reliability

The test-retest reliability of the Jorm et al Questionnaire (1997a; 1997b) has not previously been tested. Although, in the study being presented in this thesis, the interviews were not close enough together for a formal test of external reliability to be carried out, some indications of the external reliability of the instrument can be deduced from the data. The Wilcoxon matched-pairs signed-ranks tests showed that the majority of variables did not significantly change between the 2 interviews. However, those variables that did change correspond to some of the questions which were unanswered by a large number of respondents (helpfulness of psychiatrist, clinical psychologist, hypnosis, hospital admission, ECT). This suggests that these questions were unreliable in the sample of the respondents used in this study. However, it appears that the reliability of the instrument would have been improved if those questions had been removed. Two other variables showed significant change, between the 2 interviews, but this finding may result from changes in belief, rather than poor reliability (see section 7.2).

As the instrument is not designed to be a measure of underlying constructs it was inappropriate to carry out tests of internal reliability.

## 7.4.1.4 Contribution to the research

Having obtained the results from the qualitative study, a more specific instrument to measure beliefs about antidepressant medication which incorporated factors such as stigma and dependency may have been more useful for distinguishing between continuers and discontinuers.

The Jorm et al (1997a; 1997b) Questionnaire helped to provide support for some of the more general findings from the qualitative data such as the complexity of decision-making (see sections 6.2 and 8.3) and the relatively positive feelings towards antidepressant medication in the sample obtained. However, the data collected from the Jorm et al Questionnaire (1997a; 1997b) had limitations which may have affected the reliability and validity of some of the items.

# 7.4.2 Use of Smithkline Beecham Quality of Life Questionnaire (Dunbar et al. 1992)

## 7.4.2.1 Acceptability

The SKB instrument was estimated to be self-completed within 5 minutes in the majority of cases. However, respondents marked more than one box in a minority of cases. Where these were next to each other, the average of the 2 scores was taken. If they were further apart than this then the item was regarded as missing.

## 7.4.2.2 Validity

Some respondents, who were not working, asked the researcher how to answer the questions relating to the work domain (items 21 and 22). They were then asked to answer it in relation to their general day to day activities. These items, as written on the questionnaire, therefore did not have face validity for all respondents.

Some respondents were unsure whether some questions were specifically asking about depression or also referred to other conditions. For example some interviewees experienced reduced physical mobility which was a result of joint problems. As the questionnaire asked respondents to rate their perceptions of their health generally, rather than specifically in relation to their depression, respondents were asked to answer these questions with regard to their general health.

## 7.4.2.3 Reliability

As has been found previously (Stoker et al. 1992), the internal reliability of this scale was very high. The Cronbach alpha coefficient was 0.93 for the first interview data (n=51) and 0.94 for the second interview (n=42) (the authors' values ranged from 0.85-0.95; n = 129). The Cronbach alpha coefficient for the second interview was also 0.94 with the telephone data excluded. The fact that the internal reliability was extremely high raises the question as to whether some of the questions were redundant. However there was a large spread in the median values obtained for individual items, suggesting that there were distinguishing features between the questions. A principal components analysis was performed to check whether any items could be grouped together but this did not produce distinctive factors.

## 7.4.2.4 Contribution to the research

The SKB provided descriptive data concerning the quality of life of the sample. Use of the instrument also showed that quality of life was not a distinguishing variable between those who continued with their medication and those who discontinued. Thirdly, it supported the qualitative data by showing that quality of life improved between the 2 interviews. The qualitative interviews showed that some interviewees perceived that they had improved during this time.

# 7.4.3 Use of the Symptom Interpretation Questionnaire (Robbins and Kirmayer, 1992)

## 7.4.3.1 Acceptability

This instrument was estimated to take between 5 and 15 minutes to complete in the majority of cases. Some respondents looked to see how many more pages there were, during completion. One respondent commented that it was like an exam paper! Some respondents only filled in one part of each question, making their data unusable. Therefore, 20% of data from the first interview and 17% of data from the second interview could not be used in the analysis.

An alternative forced choice format, which requires respondents to complete less information, has been developed (see section 4.2.6.2). Use of the forced choice format may well, therefore, have resulted in higher acceptability and less missing data. However, as reported previously (see section 4.2.6.2) this may have resulted in a low internal reliability which would have made the instrument less sensitive to changes in time.

The longer version used in the study being presented in this thesis has only previously been tested in a student population and there is therefore little information about the more general acceptability of the instrument. There is no indication, from the study being presented in this thesis, that the difficulties found in completing it were specific to people suffering from depression. It could, nevertheless, be argued that as depression can be associated with short attention spans, the respondents may have found this instrument more difficult to complete than other people. However, there was no evidence that reduced concentration prevented any of the respondents completing the other parts of the interview.

## 7.4.3.2 Reliability

As has been found previously (Robbins and Kirmayer, 1992), the internal reliability of the SIQ was good. Cronbach alpha coefficients, which were produced for each of the 3 scales, are presented in table 7.11. Data from the first and second interviews is presented alongside that found by the instrument's authors.

# Table 7.11 : Internal reliability of the SIQ (Robbins and Kirmayer, 1992):Cronbach alpha coefficients

Scale	This study-first interview $n = 51$	This study-second interview n= 42 (telephone data excluded)	Robbins and Kirmayer sample (n= 233)
Normalising	0.78	0.81 (0.84)	0.81
Psychological	0.86	0.83 (0.88)	0.86
Somatic	0.85	0.83 (0.86)	0.7

The reliability of the version of the SIQ which was used in this study has only previously been tested in a group of medical students (Robbins and Kirmayer, 1992). The data in table 7.11 shows that it is also reliable in a sample of people suffering from depression.

## 7.4.3.3 Contribution to the research

Use of the SIQ (Robbins and Kirmayer, 1992) showed that symptom attribution did not distinguish between those who continued with their medication for the recommended treatment time and those who discontinued. It also demonstrated that respondents' psychological attributions decreased during the course of treatment, that is they were less likely to believe that the symptoms presented on the SIQ (Robbins and Kirmayer, 1992) would be caused by psychological factors. **Section 4-Discussion** 

## Chapter 8 Discussion

Chapter 8 consists of 3 sections. Firstly, the results are considered within the context of the methodological approach which was taken. The advantages and disadvantages of this approach are discussed. Secondly, patients' overall perspectives of antidepressant medication and the influence of such views on decision-making are considered. Finally, the implications of the results for healthcare professionals are considered.

## **8.1 Methodological considerations**

Section 8.1 considers the advantages and disadvantages of the methodological approach taken. The implications of these on the research findings are discussed where appropriate.

## **8.1.1 RECRUITMENT FROM GP SURGERIES**

General practice surgeries were used for recruitment as information regarding diagnosis and length of treatment was necessary to identify eligible patients.

The recruitment of patients from GP surgeries was found to be a time consuming process. A general reluctance of GP practices to participate in research was found. In addition, doctors raised specific concerns relating issues of confidentiality in patients with mental health problems. These issues regarding recruitment of practices for the study, led to a low practice response rate, which had implications for the generalisability of the results, as described in section 8.1.2.

The number of patients recruited from each practice differed. Two factors were involved in producing this variability, the number of eligible patients and the patient response rates. The number of eligible patients was related to both the size of the practice and the number of occasions that the practice was visited. The number of times each practice was visited was associated with the willingness of the practice staff. Differences in patient response rate were probably partly connected with the nature of the practices. Higher response rates were found in a practice where a doctor was involved in her own research and in a practice where one doctor prescribed a large amount of alternative medication as oppose to conventional antidepressant medication. The qualitative data have shown that interviewees perceived there to be less stigma attached to alternative medication, meaning that those taking it may have been more willing to discuss their experiences.

The increase in response rate on sending a reminder shows that this was a valuable procedure in the methodology of the study. However, it is difficult to determine whether or not a telephone reminder produced a higher response rate than a written letter. Reminder procedures were undertaken by practice staff. Although a telephone reminder gave the patient more personal contact, more control over the recruitment by the researcher could be obtained by the practice sending a written letter. When a written reminder letter was sent, the researcher prepared a pack for every patient who had not responded to the first invitation to participate. The practice staff simply had to address and post them. Feedback indicated that all reminders were sent. With the telephone reminder, however, surgery staff did not always make persistent attempts to reach patients who were unavailable when the first telephone call was made. In addition, the doctor who made the calls herself selected those she called on the basis of her perception of their willingness to participate.

Timing of the reminder may also have been an important factor. Where reminder letters were sent at the beginning of December, near the Christmas period, no positive response was seen.

The low response rate of practices and variations in their willingness resulted in a large amount of time needed for recruitment and limitations to the generalisability of the findings (see section 8.1.2). However, a more representative sample was obtained than from the self help groups used in the preliminary fieldwork. Another option would have been to recruit through pharmacies, but no information about diagnosis or treatment length would have been available, which were both necessary for identifying eligible patients. The practical and ethical implications of using patient medication records held in pharmacies would need to be explored if researchers wished to use pharmacies as a source of recruitment in future studies. In the study being presented in this thesis, using computerised records to identify eligible patients and asking surgery staff to send pre-prepared packs to these patients was found to be a more robust method of recruiting patients when compared to relying on doctors to recruit patients during consultations. It cannot be assumed that asking pharmacists to recruit patients when handing out prescriptions would not be a robust method. However, some of the same issues may occur as were found when asking GPs to recruit patients. Patients may be selected on the basis of the busyness

of the pharmacy at the time and the pharmacists' perceived willingness of the patient to participate. These issues need to be addressed with relation to recruitment from pharmacies. Use of patient medication records to identify patients, followed by the sending of pre-prepared packs may therefore be preferable to asking pharmacists to recruit patients when handing out prescriptions.

### 8.1.2 GENERALISABILITY

Claims that the sample of patients obtained in the study was generalisable to other populations of patients cannot be made. The reasons for this include the low response rate of the practices, the fact that inclusion and exclusion criteria were not always adhered to by recruiting practices and patient response bias.

#### 8.1.2.1 Practice response rate

The low response rate of practices meant that the sample of practices from which the patients were recruited was not random. Some types of practices appeared to be more likely to take part than others. For example, no single handed practices participated due to lack of time and resources. The effect of having no single handed practices participating is unknown. In addition, some doctors which agreed had a particular interest in research or mental health. Those doctors who participated in the research may have had different relationships with their patients to those who declined, which may have affected patients' perspectives of treatment. However, where one doctor in a surgery had a particular interest in research or mental health, the whole practice participated in the research. Therefore, some patients were recruited from these practices who were patients of doctors without this particular interest.

Although the participating practices were in some respects a self selected sample, a range of different practices were included. The number of doctors in the practices ranged from 2 to 7. There was also diversity in the treatments prescribed, with patients from some practices being more likely to have been prescribed tricyclics than SSRIs, when compared to others. In addition one doctor prescribed homeopathic remedies.

#### 8.1.2.2 Non-adherence to inclusion and exclusion criteria

Not all respondents strictly met the inclusion and exclusion criteria. The doctors were given the eligibility criteria but were then responsible for recruiting patients. Some patients who met all the criteria were reported by doctors to have been excluded due to concerns over jeopardising their treatment. In addition, patients were included who did not meet the eligibility criteria regarding treatment length. One of the eligibility criteria required patients to be in the first 3 months of being prescribed antidepressant medication at the time of recruitment. It emerged during the interviews that patients had sometimes been taking antidepressant medication for longer than 3 months. The computer system used in the majority of practices did not allow the distinction between new and existing cases and each patient's records had to be searched individually. Sometimes these records showed a new prescription for antidepressant medication when this reflected a change in drug or dosage rather than a first prescription. One practice used a different system which was able to select new cases from the last 3 months. No patients who had been taking antidepressant medication for longer than 3 months were mistakenly selected from this practice. Another difficulty arose where patients had recently changed their GP practice and their medical record therefore showed an original prescription for antidepressant medication at the new practice, even though they had been taking the medication for some time previously to this.

Although patients were included who did not meet the original criteria, information about decision-making regarding antidepressant medication was gained from these patients. The fact that a minority of patients had been taking their medication longterm meant that some insight was gained into changes in individuals' perspectives regarding medication when they continued to take it for extended periods. Although examining perspectives regarding medication over the whole treatment process was not part of the original study objectives, inclusion of the data enabled the researcher to view the results obtained for patients beginning courses of antidepressant medication, in the context of some perspectives concerning therapy further ahead in the treatment process. Another factor influencing the decision to include data obtained from patients who had taken medication for periods of longer than 3 months was that no major differences in the overall themes identified were found in these patients when compared to themes identified from patients who had been taking medication for a shorter length of time.

#### 8.1.2.3 Response bias

Non-respondents of the first interviews were asked for information about their age, gender, prescribed antidepressant medication and reasons for non-participation. In addition, some doctors gave the researcher information about the age, gender and prescribed medication of those not agreeing to participate. However this information was not available for all non-respondents. Therefore, although the following discussion provides indications of where response bias may have occurred, it needs to be treated with caution.

Patients who were older and who had positive views about antidepressant medication appeared to be more likely to participate. Patients who responded were older than those who declined. The relationship between age and response rate was significant in the follow-up interviews. However, there were large age ranges of respondents for both the first and second interviews.

Comments made by respondents indicated that patients were more likely to participate in the research if they were further ahead in treatment and a degree of recovery had already taken place. It may be hypothesised from this that patients with illness of a greater severity would have been less likely to participate. There were also indications that patients having more positive views towards their antidepressant medication were more likely to participate. Reasons given for declining included that patients were not finding medication effective or had stopped taking it. Compliance was higher in this study, than that found in other studies (Maddox et al. 1994; Lin et al. 1995), despite the fact that, as far as it could be ascertained, the same methods and criteria were used. Patients who had a more positive relationship with their general practitioners may also have been more likely to take part in the research. However, there was representation of a range of views concerning antidepressant medication. In addition, the sample included patients who had not started their medication or only taken it for very short periods of time. Therefore, although response bias towards patients with more positive views about their medication may have limited the generalisability of the findings, the data collected enabled a range of perspectives regarding treatment to be identified.

There was a high representation of participants from the managerial/professional social class. However, depression is more common in the lower social classes (Jenkins et al. 1998; Jenkins et al. 1997) and it would therefore be expected that more

patients from these classes would have been present in the original sample of patients approached. Two possible explanations may be suggested for the relatively large number of respondents from the managerial/professional social class. Firstly, the response rate from the managerial/professional class may have been higher than that of classes 2 and 3. People from social class one may be more supportive of research. However, information about social classes of the non-respondents was not collected, which meant that social class between the responders and non responders could not be compared. Secondly, another possibility was that GP practices from affluent areas were used in the original sampling frame. However, the health authorities selected had a range of UPA scores. The UPA score is a measure of the deprivation of an area. UPA score is not a direct measure of social class but the scores for the health authorities used in the study being presented in this thesis, demonstrated that GP practices were recruited from areas of a range of affluence. In addition, the bias towards the higher social classes was found in all but one practice and this practice was in a heath authority with a deprivation level close to average. Even though the highest number of surgeries were recruited from the least deprived health authority, the highest number of patients were recruited from the health authority with the middle score of deprivation. Therefore, a response bias was the more likely explanation. Although the sample had a higher proportion of patients from the managerial/professional social class when compared to national figures, for people with depression (Jenkins et al. 1998; Jenkins et al. 1997), all classes were represented among the respondents. In addition, social class was not associated with medication taking behaviour. Therefore, although sample bias towards those from the managerial/professional social class may have affected the generalisability of the findings, views of patients from a range of social classes were represented.

Another difficulty in the study was obtaining patients' views near the beginning of their treatment, as they were often too unwell to participate. In addition, there was evidence that respondents' recall of the initial period of treatment was sometimes blurred, making it more difficult to collect data about experiences at the beginning of treatment. However, some respondents were interviewed nearer the beginning of treatment. In addition, some interviewees appeared to recall some aspects of the start of their treatment quite vividly, for example those who described the change of identity caused by their first prescription of antidepressant medication. Therefore, although information regarding perspectives at the very beginning of treatment was more difficult to obtain, some data about decision-making at this time was collected.

#### 8.1.3 INTERVIEW PROCESS

Research needs to consider the association between the interaction of the researcher and respondents and the data produced. In the study being presented in this thesis, if the researcher was viewed in her capacity as a pharmacist it may have encouraged respondents to discuss their medication within the medical model, rather than addressing wider issues. However the letter of invitation, patient information leaflet and consent form all made it clear that the research was addressing social issues connected with medication use. The interview schedule itself specifically sought information on these issues and encouraged interviewees to discuss both the positive and negative aspects of treatment. Few respondents raised the role of pharmacists in their interviews, suggesting that the data were not unduly influenced by knowledge of the researcher being a pharmacist. However, it is possible that the researcher being a pharmacist influenced some respondents to classify pharmacists as helpful on the Jorm et al Questionnaire (1997a). Where respondents regarded the interview as having a therapeutic role, by enabling them to discuss their situation, it may have encouraged them to be more open and thus aided the interview process.

Another consideration is that the conduct of the interviews was not identical in all cases. The interview environment may have affected the interviews to some degree. For example, interruptions during home interviews were observed to affect the flow of interactions. Although where patients' partners were present in home interviews, the partners' perspectives were not analysed, it was difficult to determine the extent to which their comments affected those of the respondents. When the interviews were carried out in the researcher's own institution, the researcher was more in control of the interaction, including the layout of the room. However, this could have made the interview more formal for the respondents and inhibited them to some extent. Nevertheless, some interviewees spoke more freely than others generally and this did not appear to be affected by the location. It may be considered possible that where interviews took place in the surgeries, they would be more likely to be viewed as medical encounters by the interviewees. However, this was given as a choice of meeting place amongst other locations and steps were taken to ensure that participants understood the nature of the information being sought. The researcher was concerned about using the respondent's place of work due to the confidential nature of the information being discussed. In 2 cases the interaction took place in a private office and the respondents did not need to disclose its nature to their colleagues. However, in one case the office was more open and there was another

person present working along the corridor. Although he was not visible, the researcher was aware of his presence during the interview. It was difficult to obtain information during the qualitative part of this interview and the environment used may have been a contributory factor. However, the respondent still wished the follow-up interview to take place in the same location. Although conducting all interviews in the same environment would have been ideal, environment did not seem to influence the range of themes identified in interviews. Respondents had different preferences regarding location. Not taking account of patients' wishes may have resulted in a lower response rate and greater inconvenience to respondents.

Some follow-up interviews were carried out by telephone. There were differences between the data collected by telephone and that gathered from the face to face interviews. The qualitative data collected was less rich as word for word verbatim transcripts could not be produced. The interaction was also affected by the fact that the researcher had to concentrate on taking notes and could not focus solely on the interview. The quantitative instruments had to be adapted for telephone usage. However, the number of telephone interviews were small and data derived from both these and face to face interviews were therefore analysed together. Performing some follow-up interviews by telephone was preferable to obtaining no follow-up data from these patients. The reliability and validity of administering the quantitative instruments by telephone is unknown. However, although the number of telephone interviews was too small to perform a separate analysis of internal reliability, the internal reliability of the instruments was very high with the telephone interview data included.

A methodological issue associated with using interviews is the extent to which respondents' accounts mirror reality. However, the purpose of the research was to gain an understanding of patients' perspectives. Nevertheless, respondents were not always aware of the causes of their behaviour and some interpretation was required by the researcher. The way in which this interpretation was derived is made clear in the report.

#### **8.1.4 FOLLOW-UP INTERVIEWS**

Patients were initially to be interviewed at one and 4 months. However, these timings were not possible to achieve (see sections 4.2.4 and 8.1.2.2). Therefore, a range of interviews times was included. At the first interview, the majority of

respondents had already been taking their medication for periods longer than 1 month and some discussed changes to their decision-making during the course of time. However, changes in the decision-making of some patients were identified after the follow-up interviews. In addition, the follow-up interview allowed the detailed exploration of themes identified in analysis of the first interview in some cases. Themes could not be divided into those identified from the first interview data and those identified from the follow-up interview data. However, new data was collected at the follow-up interviews of some patients. Therefore, the follow-up interview was a valuable methodological procedure.

#### **8.1.5 TRIANGULATION USING QUANTITATIVE INSTRUMENTS**

The incorporation of quantitative instruments into the study design provided additional information. Their main role was to validate some of the conclusions drawn from the qualitative data, such as the complexity of decision-making. Whereas the use of triangulation for validation has been criticised for combining results without taking the different contexts within which they were collected into account (Temple, 1997), in the study being presented in this thesis the same sample of patients was used and the data was collected together in the same place. A disadvantage was that whereas an iterative process was used for the development of the qualitative interview schedule, the quantitative instruments were not a direct measure of the emerging theory.

The Jorm et al Questionnaire (1997a; 1997b) has previously been used in studies investigating beliefs about depression in the general population of Australia. Use of the instrument in the study being presented in this thesis provided data about beliefs about depression in patients with a diagnosis of depression in the UK. However, difficulties were found in the application of some of the questions on the Jorm et al Questionnaire (1997a; 1997b) to patients with a diagnosis of depression in the UK. These difficulties affected the face validity of some questions and also resulted in missing data in some cases. In addition, the instrument did not address specific beliefs about depression and the use of antidepressant medication which were identified from the qualitative data, such as those relating to stigma, dependency and fears of adverse drug reactions. Therefore, the development of a specific instrument for measuring patients' beliefs about depression and antidepressant in the UK, incorporating beliefs identified in the qualitative data of this study would be advantageous.

In agreement with previous research, The Smithkline Beecham Quality of life Questionnaire (Dunbar et al. 1992) was found to be acceptable to respondents suffering from depression in the UK and have a high reliability with this patient group. However, issues regarding the face validity of 2 items for respondents who were not working were identified. Therefore, the validity of the instrument may be increased by altering the wording of these questions.

The Symptom Interpretation Questionnaire has previously been shown to be reliable and valid in a student population (Robbins and Kirmayer, 1992). The study being presented in this thesis demonstrated that the instrument (Robbins and Kirmayer, 1992) was reliable in a sample of patients suffering from depression. No problems were identified regarding the face or content validity of the instrument in this sample. However, some respondents perceived that the instrument was lengthy to complete. Although a forced choice format has been developed which takes less time to complete, the internal reliability of this format has been found to be low (Robbins and Kirmayer, 1992). Therefore, it may be preferable to adapt the instrument in other ways, such as reducing the number of questions.

The sample size used in the study being presented in this thesis was smaller than that used in other studies which used the same instruments. However, it was sufficient to meet the research objectives by identifying any large associations between variables.

Although there were some limitations to the methodological approach used in the study, these affected the generalisability rather than the validity of the study. The sample was self selected in some respects but there are indications that there was a degree of representativeness of people with a diagnosis of depression. The respondents had a range of socioeconomic characteristics and had been prescribed different types of antidepressant medication. The sample consisted of both those who had continued to take their medication and those who had discontinued. As the aim of the study was to identify factors affecting decision-making rather than to test their generalisability, limitations regarding this did not prevent the project from meeting the research objectives.

The Jorm et al Questionnaire (1997a; 1997b), Smithkline Beecham Quality of Life Questionnaire (Dunbar et al. 1992) and Symptom Interpretation Questionnaire (Robbins and Kirmayer, 1992) provided information concerning the respondents' beliefs about depression, quality of life and symptom attributions respectively.

However, some limitations were identified with the use of each of the 3 instruments which need to be addressed in future research concerning the use of these instruments with people with a diagnosis of depression.

# **8.2 Factors affecting patients' decisions regarding therapy when beginning** <u>courses of antidepressant medication</u>

Section 8.2 discusses the initial help-seeking process to obtaining treatment. Respondents' perceptions of antidepressant medication and associations with decision-making are then discussed. The results of this study are considered alongside other studies which have investigated help-seeking behaviour and patients' perceptions of medication.

## 8.2.1 Help-seeking process

Previous research in the USA (Karp, 1994; Hagerty et al. 1997) found that respondents experienced many symptoms of depression before recognising the severity of their condition. The study being presented in this thesis has extended this finding to people suffering from depression in the UK. Interviewees in this study had reached 'crisis point,' at the time when they sought help. The identification of the need to seek help at this time was influenced by a number of different factors, some of which were the same as triggers which have previously been identified by Zola (1973) as influencing general help-seeking behaviour. However, in addition to the triggers identified by Zola (1973) respondents' perceptions of their symptoms and illness were also associated with help-seeking behaviour.

A range of expectations of the initial consultation with the general practitioner was identified. Although some respondents had expected a prescription for antidepressant medication, other interviewees reported that they had consulted the general practitioner to obtain a diagnosis or for a referral for counselling When medication was prescribed, the majority of respondents viewed it as a short term measure.

## 8.2.2 RESPONDENTS' PERCEPTIONS OF TAKING ANTIDEPRESSANT THERAPY

The findings concerning respondents' perceptions of antidepressant medication in this study had features in common with those of other sociological studies which have investigated patients' personal understanding of their medication (Donovan and Blake, 1992; Adams et al. 1997; Helman, 1981; Morgan and Watkins, 1988; Conrad, 1985; Britten, 1994; Dowell and Hudson, 1997). However the relative emphasis of different themes differ between studies. In common with other research, this study shows that patients' medication taking behaviour is based on reasoned decisionmaking and that patients weigh up the relative benefits and costs of treatment. The study also agrees with the finding that patients are often reluctant to take medication and will only take it as a last resort (Britten, 1994). However, this reluctance may primarily be based on different concerns in different disease states. For example, patients with arthritis were particularly concerned about the noxious side effects which occur with anti-rheumatic medication, although they also expressed some concern regarding dependency and of the weakness of relying on medication (Donovan and Blake, 1992).

Respondents' experiences of their medication, in the study being presented in this thesis, however, were most similar to those reported by Conrad (1985), who investigated medication taking behaviour in patients suffering from epilepsy and Karp (1993) who studied the illness career pathway of patients taking antidepressant medication in the USA. This study therefore helps to build a picture of the representation of medication in illnesses which are perceived by patients to be stigmatised and are controlled by pharmacotherapy. Medication has a paradoxical role in these conditions. It enables patients to return to normality by controlling symptoms but has a stigma attached which reduces patients' sense of being normal. Goffman (1964) noted that people with physical blemishes sometimes had plastic surgery in order to make themselves appear normal but that having had plastic surgery was, in itself, a sign that they had once been deformed. Similarly, in stigmatised illnesses, medication. In addition, adverse drug reactions sometimes reduced social functioning.

The paradoxical role of medication in affecting the return to normal life was associated with ambivalent views about taking pharmacotherapy. Patients in this study could not easily be divided into those who were positive about their medication and those who were negative. Rather, the majority of patients identified both positive and negative features of medication. Similarly, Gabe and Thorogood (1986) found that two thirds of middle aged working class women expressed ambivalent views towards taking benzodiazepines. In contrast, Adams et al (1997) found that the majority of patients either accepted or rejected prophylactic medication for asthma. Britten (1994) found that it was possible to distinguish positive and negative orientations towards medication in a general practice population, although some patients had mixed views depending on the situation. The difference in the findings maybe due to the fact that Adams et al (1997) and Britten (1994) did not specifically investigate stigmatised illness, although Adams et al (1997) found that there were some perceptions of asthma as a stigmatised condition.

Therefore, perspectives of medication which have been found in a range of disease states in Britain and in depression in the USA were extended to patients beginning courses of antidepressant medication in the UK. Specifically, perspectives were identified which have previously been found in patients in the UK suffering from epilepsy and patients in the USA with a diagnosis of depression. The study therefore informs the role of medication in the treatment of stigmatised illnesses which are controlled by pharmacotherapy.

#### 8.2.3 DECISION-MAKING PROCESS REGARDING ANTIDEPRESSANT TREATMENT

Ambiguous views concerning antidepressant medication were associated with a complex decision-making process regarding treatment. The paradoxical role of medication can help explain the seemingly contradictory findings, in relation to the locus of health control model found in this study. The health locus of control model (Wallston et al. 1978) predicts that internals, that is those who believe that health is under their own control, will be more likely to engage in health promoting activities (see section 2.3). On the one hand, the results of the study being presented in this thesis support the health locus of control model. Where respondents wished to be more in control, they were more compliant with treatment as it helped them to feel that they were taking steps to make themselves well. However, on the other hand, having such an internal locus of control could also make respondents less compliant with treatment as they saw taking medication as an indication of loss of control in itself. Respondents felt a dependency on something external to produce a normality which they felt they should be able to produce themselves. Two contradictory perspectives were therefore experienced by respondents. In Karp's study (1993) of people with depression in the USA it was reported that accepting a biomedical view of depression absolved respondents from the feeling that they were responsible for their illness but also suggested personal enfeeblement.

The complexity of decision-making, in the study presented in this thesis, is demonstrated by the fact that very few factors distinguished between those who continued with their treatment for the recommended treatment time and those who discontinued. However, this result also supported the view that it is difficult to predict the patients who will comply with the prescriber's instructions. Lin et al (1995) found that there was no significant association between age, sex, education or severity of depression and compliance with antidepressant therapy in the USA. Only the number of severe side effects experienced and the receipt of educational messages were found to be significantly associated. Although age, was significantly associated with medication taking behaviour in the study being presented in this thesis, further investigations are needed to confirm this finding. Complexity of beliefs regarding interventions for depression, in general, can be seen by the fact that a principal components analysis on the Jorm et al Questionnaire (1997a; 1997b) did not produce distinct factors. Jorm et al (1997c) previously found that interventions could be reduced into medical interventions, psychological interventions and lifestyle interventions. However, the data being presented in this thesis, did not reduce into distinct categories. Decision-making was based on a large number of variables, rather than being simply defined.

Differences were identified between decisions which were made concerning antidepressant medication in the study being presented in this thesis and those which were made concerning anticonvulsant medication by people suffering from epilepsy in Conrad's study (Conrad, 1985). Although negative aspects of medication were experienced by interviewees in both studies, the response to these experiences differed. In Conrad's study interviewees typically responded to negative aspects of medication by what has been termed as partial non-compliance (Mcgavock, 1996) (eg lowering dosage, stopping for short period of time) whereas the majority of respondents in the study being presented in this thesis who altered medication taking behaviour as a result of negative experiences discontinued their medication completely. From analysis of the interview data, it may be hypothesised that the difference in the decisions which were made was due to anticonvulsant medication being perceived as being more essential to those suffering from epilepsy than antidepressant medication was to those with a diagnosis of depression.

Therefore, using triangulation methodology, the study being presented in this thesis demonstrated that the findings of previous research in the USA regarding quantitative associations between socioeconomic characteristics and medication taking behaviour (Lin et al. 1995), and people's experiences of depression (Karp, 1993) could be extended to patients' decision-making at the beginning of treatment with antidepressant medication in the UK. Although perspectives of the positive and negative aspects of medication were similar to those identified by Conrad's study of

people suffering from epilepsy, the decisions made as a result of these perspectives differed. It is hypothesised that these differences were due to anticonvulsant medication being perceived as being more essential to those with epilepsy than antidepressant medication was to those with a diagnosis of depression.

## 8.2.4 CHANGES TO PATIENTS' PERSPECTIVES OF MEDICATION DURING THE COURSE OF TREATMENT AND ASSOCIATIONS OF SUCH CHANGES ON DECISION-MAKING

There were indications from the interview data that some respondents adapted to taking their medication and its social meanings, which may have been associated with reduced ambivalence towards taking medication. Respondents in this study were generally interviewed near the beginning of treatment. However, there are indications that for the small minority of respondents who had been taking their medication on a long term basis, antidepressant therapy had become an integral part of their reality. Even with the respondents who had been taking their medication for a shorter time, there was some evidence of a gradual adjustment process, for example regarding acceptance of longer periods of treatment. Karp (1993) interviewed patients who had been taking their antidepressant medication on a longer term basis and found that they slowly adopted a medical view of their illness and that negotiating short periods of treatment time was a stage of this adaption process. Interviewees' expressions of preferences for lower dosages in the study presented in this thesis may also have been a part of the process of slow adaptation. Respondents who subsequently adapted to taking their medication long term may have used mechanisms such as disassociation of the medication from the label of depression or normalisation of the label by identifying others taking antidepressant medication. For Karp, (1993) adopting a medicalised view of depression, accepting that it had a biological basis and accepting medication went hand in hand. However, some respondents in the study presented in this thesis took medication but did not consider themselves clinically depressed. In addition, when compared to the general public, interviewees in this study had similar views about the causes and risk factors of depression and were most likely to rate factors in the immediate social environment as causes of depression. However, they had more positive beliefs about antidepressant medication than the general public. There were a range of possible explanations for the fact that taking antidepressant medication was not associated with the acceptance of a medical view of depression. Firstly, it could be argued that this too was a stage in the adjustment process and that in the long term respondents would identify themselves as depressed. Williams and Healy (2001) found that at the beginning of treatment interviewees jumped between causes of their depression, social versus biological. This uncertainty helped them maintain hope and avoid an identity that they did not want. Secondly, Karp's (1993) patients had often been hospitalised and it may have been more difficult for them to cut themselves off from the identity of having a chronic mental illness. Thirdly, it is possible that some respondents recognised that they had a medical illness but felt that this was caused by factors in their social environment. Priest et al (1996) found that the cause of depression was thought to be due to life events by the majority of the general public (n= 2003) but that the majority agreed that depression was a physical illness like any other illness.

The adaption process can be incomplete and reversible, meaning that ambivalent feelings may return. Karp (1993) noted that respondents could eventually become disenchanted with their treatment. Further ahead in the treatment process, respondents, in the study being presented in this thesis, indicated that they would want to come off their treatment but were also concerned about relapsing if they did so.

Therefore, the adaption process described by Karp (1993) in his study of the illness career pathway of depression, in the USA, was found to be applicable to patients taking courses of antidepressant medication in the UK. Associations between this adaption process with perspectives of antidepressant medication and decision-making at the start of treatment have been demonstrated, in terms of patients' preference for lower dosages at this time and the mechanisms which were used for dealing with stigma, such as disassociation of medication from the illness of depression.

# 8.2.5 RESPONDENTS' PERSPECTIVES OF COMPLEMENTARY MEDICINES AND ASSOCIATIONS OF THESE PERCEPTIONS WITH DECISION-MAKING ABOUT TREATMENTS

Karp (1993) did not investigate the role of complementary medicines in the illness career pathway of depression. In the study being presented in this thesis, the paradoxical role of antidepressant medication was not extended to complementary medicines. Taking herbal drugs such as St John's Wort was not perceived to label the respondent as depressed. Complementary medicine was also not considered to be addictive, which meant the respondent was in control, rather than the drug. Therefore perceived benefits of the medication did not need to be balanced against social consequences of taking the medication. Although some patients reported adverse drug reactions, complementary medicines were perceived as having less adverse drug reactions than licensed antidepressant therapy. These findings may, in part, explain why patients may prefer to use alternative medication, rather than licensed antidepressant therapy.

## 8.2.6 ASSOCIATIONS BETWEEN CLASS OF ANTIDEPRESSANT AND MEDICATION TAKING BEHAVIOUR

Some respondents had used different classes of antidepressant medication, in order to find the agent which provided the most benefit, while causing the least adverse drug reactions. The findings of the study do not answer the question of whether one class of antidepressant medication should be recommended over another. The class of prescribed antidepressant medication was not found to be associated with medication taking behaviour and no differences in perspectives of medication were identified between patients taking tricyclics and those taking newer agents. However, this interpretation needs to be treated with caution as a larger proportion of patients had been prescribed newer agents than tricylics. In order, to obtain more equal groups, it is recommended that future research uses a sampling strategy which is stratified in respect of antidepressant medication prescribed.

Overall, in agreement with other studies, the study being presented in this thesis demonstrates that medication taking behaviour is associated with rational decisionmaking. In particular, findings related to medication use in epilepsy in the UK and the illness career pathway of depression in the USA were extended to medication taking behaviour at the beginning of treatment with antidepressant medication in the UK. This study provides evidence of the paradoxical role of pharmacotherapy in the treatment of depression and the associated complex decision-making process. From the results of this study, it may be hypothesised that initial expectations concerning a short-term process of recovery, and experience of stigma, fears of dependency and adverse drug reactions have a negative association with medication taking behaviour in patients suffering from depression. Further research could quantitatively test associations between these factors and medication taking behaviour. Differences in perspectives regarding the use of licensed antidepressant medication compared with complementary medicines were identified in terms of dependency and stigma. Future research could quantitatively test whether differences in these factors affect preference for licensed antidepressant medication or complementary medicines.

# **8.3** The role of healthcare professionals in supporting individuals in their decision-making about treatment for depression

Section 8.3 examines the implications of the results for healthcare services. Firstly, the general value of the study for healthcare professionals is discussed. Then its specific relevance to pharmacy is considered.

# 8.3.1 IMPLICATIONS FOR HEALTHCARE PROFESSIONALS WHEN TREATING PATEINTS WITH A DIAGNOSIS OF DEPRESSION

8.3.1.1 Recommendations for improving communication between doctors and people with a diagnosis of depression

The White Paper, 'Saving Lives, Our Healthier Nation' (Department of Health, 1999a) identified mental health as a priority area for the government. Further to this the National Service Framework for Mental Health (Department of Health, 1999b) set out 7 national standards for the promotion of mental health and treatment of mental illness. Standards 2 and 3 of The National Service Framework for Mental Health (Department of Health, 1999b) relate to the quality of primary mental health care. The report has recommended that assessment and management protocols for the treatment of depression are implemented throughout primary care. The document states that currently, many patients feel that they do not receive adequate information about their antidepressant treatment and also suggests that there is scope for improvement in the communication skills of health care professionals. Section 8.2 will describe the unmet information needs regarding antidepressant medication identified in the study being presented in this thesis and will make recommendations for improved communication.

Previous research (Lin et al, 1995) has shown that patients who had received key messages from healthcare professionals were liable to be more compliant with their treatment. The messages included asking about prior use of antidepressants, saying that it would take 2 to 4 weeks before there was a noticeable effect, advising to continue with their medication even if they felt better, saying to check with their doctor before discontinuing medication, advising to take medication daily and instructing them on what to do in case of questions. This is in line with a medical model of compliance.

Another way to consider medication taking behaviour is as a partnership between patients and healthcare professionals (Department of Health, 2000b). The concordance model (RPSGB and Merck Sharp & Dohme, 1997) recognises the importance of the beliefs and wishes of the patient in making decisions about treatment. 'The Expert Patient' (Department of Health, 2001) has highlighted the importance of using patients' insight into chronic illnesses to inform the development of future services. The study being presented in this thesis has investigated patients' own perceptions of therapy. Gaps between medical guidelines and respondents' own perspectives have been identified from the analysis. Other studies have also identified that misunderstandings occur during general practice consultations (Barry et al. 2000). This study has identified the specific gaps which occurred between doctors and patients with a diagnosis of depression. Patients had different perceptions regarding length of treatment to that recommended by clinical guidelines, attached different meanings to the term dependency compared to medical definitions and expressed concerns regarding stigma which may not have been addressed by doctors. In addition, respondents may have benefited from more information about adverse drug reactions, the process of recovery and dosage. The study therefore informs the type of discussions which patients may find advantageous when communicating with healthcare professionals about depression. Factors which may be beneficial for doctors to raise with patients are considered further below.

#### Process of recovery

Respondents wished to understand the process of recovery more fully. Informing patients that treatment can take 2 to 4 weeks to begin its effect has been found to increase compliance (Lin et al. 1995). However, the results of the study being presented in this thesis suggest that patients also find it beneficial to understand that the whole process will be very gradual and that although the general trend will be towards recovery, there will be lower points on the way. Discussing this at the beginning stages of treatment may mean that practitioner and patient will have similar expectations regarding therapy from the outset.

Many interviewees were unaware of the minimum recommended treatment time for therapy, and this again was a gap between medical guidelines and respondents' own expectations. Respondents often considered their medication as a short term measure and discontinued it at the first available opportunity. Lin et al (1995) demonstrated that telling patients to continue with treatment when they felt better and not to discontinue without the advice of their medical practitioner improved compliance. However, giving patients information about the recommended treatment length and dosage reduction on withdrawal may be beneficial as it would give the patient more opportunity to take control over their own treatment. Frank (1997) identified the middle phase of treatment as a time when patients needed encouragement to continue with their medication, although they were feeling better. However the results obtained in the study being presented in this thesis indicated that later discontinuation was influenced by expectations surrounding treatment length at the beginning of treatment, meaning that patients may benefit from being given information about length of treatment at the beginning of therapy.

#### **Dependency**

Previous research has found that the general public believe that antidepressant medication is addictive (Priest et al. 1996; Paykel et al. 1998). The Royal Pharmaceutical Society has noted that medication which is not regarded as addictive by the medical profession, is considered addictive by the public (RPSGB and Merck Sharp & Dohme, 1997). The study being presented in this thesis suggested that patients may have a broader definition of dependency than healthcare professionals. Practitioners may think in terms of medically defined physical dependence (World Health Organisation, 1993). Respondents of this study, however, considered withdrawal reactions as suggestive of addiction. Patients and doctors may be able to work together to develop individual withdrawal strategies which take concerns of relapsing into consideration. Some respondents reported being reassured after understanding the gradual reduction process. Respondents also used the term dependency to describe a psychological dependency on the tablets i.e. they were concerned about relying on the tablets, rather than solving their problems in other ways. Therefore, although practitioners may inform patients as to the nonaddictiveness of medication, they may only be responding to part of the patients' fears concerning dependency.

#### <u>Stigma</u>

In general, practitioners may build a stronger relationship with patients if they think of the social as well as the physical effects of the medication. The relationship between medication and stigma should be considered. Patients may not initiate discussions about the social associations of treatment, describing their problems in terms of the medical model when speaking to healthcare professionals. However, this study demonstrated that receiving a prescription for antidepressant medication was perceived to label the interviewee as depressed and was therefore a traumatic experience in the respondent's life. Practitioners need to be aware of the impact of their prescription when communicating with their patients about it. One of the mechanisms by which respondents reported reducing their stigma, was identifying others with the same condition and thereby understanding the widespread occurrence of depression. Patients, in general, may therefore find it beneficial if doctors talk about the number of similar people that they treat for depression each day, thereby normalising the condition.

#### Adverse drug reactions

Previous research has identified the experience of adverse drug reactions as a self reported reason for discontinuing antidepressant medication (Lin et al. 1995; Maddox et al. 1994). The fact that knowledge of adverse drug reactions was the most common unmet information need in the study being presented in this thesis suggests that an increased focus on this in discussions with healthcare professionals may be advantageous. This study has demonstrated that adverse drug reactions which affected functioning were viewed as problematic by patients. Practitioners may therefore find it beneficial to discuss adverse drug reactions in terms of their effects on patients' day to day functioning and disease state. Patients may also have less anticipatory fears, when faced with lists of side effects in patient information leaflets, if more information is given about their impact on patient functioning and what can be done to limit the impact.

#### **Dosage**

Respondents in this study reported that knowing that they were taking a dosage at the lower end of the recommended range made them feel more comfortable about their treatment. Such dosages are used at the start of treatment (British Medical Association and Royal Pharmaceutical Society of Great Britain, 2000). Patients may therefore benefit from being informed that they are being prescribed a relatively low dosage.

## Patient information leaflets

Some respondents reported reading patient information leaflets, which suggests that it may be advantageous for prescribers to have knowledge of what these contain and to consider this in their discussions with patients. Where verbal and written information conflicted, this affected interviewees' decision-making. If practitioners prescribe outside the recommendations in the leaflet, their rationale for this should be clearly explained.

## Level of control over treatment

The results indicated that the level of internal control which respondents wished to have varied at different points in treatment. As treatment progressed some respondents wished to become more involved in decision-making and prescribers may find it advantageous to consider the type of relationship which they have with their patients at different stages of treatment.

Where respondents were unable to take part in decision-making to the level they desired during the consultation, they took decisions outside of the consultation. Healthcare professionals may find that discussing the issues described in section 8.2.1.1 within the consultation, may help patients make more informed decisions regarding their treatment.

In addition, family and friends were found to have a range of roles in influencing decision-making. Frank (1997) has discussed the importance of the doctor involving a patient's social support system in therapy. Future research should identify the extent to which the patient's social support system should be involved in consultations and mechanisms of utilising its role in aiding patients in making informed decisions.

A brief summary of the information and discussions which healthcare professionals may find it advantageous to cover in the initial stages of treatment is given below. The issues are presented in the order which healthcare professionals may wish to discuss them with patients, starting with the positive aspects of treatment and moving towards possible concerns. Healthcare professionals may wish to:

1) inform patients that large numbers of similar people take antidepressant
medication,

2) discuss the prescribed dose in the context of minimum and maximum dosages,

3) discuss the realistic benefits that patients may expect from treatment, including process of recovery and minimum expected length of treatment,

4) discuss adverse drug reactions of the medication and their possible impact on patients' functioning and disease,

5) address fears of dependency, including psychological dependency and fears of withdrawal reactions.

A large amount of information and discussion is required at the beginning of treatment. The most appropriate approach to communicating this information to patients needs careful consideration. A randomised controlled trial (n= 203) investigated the effects of giving patients with a diagnosis of ulcerative colitis guided self management training (Robinson et al. 2001). Relapses were found to be treated significantly faster in the intervention group. Patients in the intervention group had a longer initial consultation after being entered into the trial but required significantly fewer subsequent consultations than those in the control group. However, newly diagnosed patients were excluded from the trial. Recall of information by respondents beginning courses of antidepressant medication in the study being presented in this thesis was low at the initial consultation. Therefore, simply increasing the length of the initial consultation at the general practice surgery when patients are prescribed courses of antidepressant medication may not be sufficient. Repeated opportunities for information provision at this time may be more advantageous. This will be discussed further in section 8.2.2. In addition, the provision of written information, regarding the issues which have been identified, in combination with verbal counselling may be beneficial. A randomised controlled trial found that patient information leaflets did not improve compliance in patients starting new courses of antidepressant treatment (Peveler et al. 1999). However, the only information the authors gave about such leaflets is that they were designed in accordance with European directives and that they contained information about the drug, unwanted effects and what to do in the case of a missed dose. A leaflet based on the information needs of respondents which were identified in the study being presented in this thesis (see earlier in this section) may have a greater association

with compliance.

#### 8.3.1.2 Access to services

The National Service Framework For Mental Health (Department of Health, 1999b) has stated that help and advice should be consistent to every service user, at every point of contact. In the study being presented in this thesis access to different treatments varied between doctors. For example, respondents who were patients of one doctor reported that she was very enthusiastic about the prescribing of homeopathic therapies, which meant that her patients had greater access to this treatment. However, the same doctor was reluctant to prescribe licensed antidepressant therapy, which resulted in her patients having less access to treatments of proven effectiveness. Respondents expressed a range of preferences regarding different treatments and did not always begin with the expectation of receiving antidepressant medication. In a truly concordant relationship, patients would have the opportunity to discuss all options with healthcare professionals. Licensing St John's Wort would enable it to be prescribed, giving more choice to practitioners and patients. Standard 2 of the National Service Framework For Mental Health states that patients should be referred to specialist services where required. However, long waiting lists for counselling services and lack of quality of psychological treatments were reported by the respondents in this study. Therefore this study indicates that consistent access to treatment is an area where there is scope for improvement to meet government standards. The development of protocols for the referral of patients for psychological therapy may be advantageous.

#### **8.3.2 SPECIFIC IMPLICATIONS FOR PHARMACISTS**

Section 8.3.2 will suggest contributions which community pharmacists can make to the treatment of patients beginning courses of antidepressant medication. The section will conclude with a review of the considerations which will need to be addressed to enable pharmacists to carry out such roles.

The results obtained suggest that pharmacists do not become very involved in the pharmaceutical care of patients with a diagnosis of depression. Very few respondents mentioned pharmacists as a source of information or advice about depression. Indeed, when completing the Jorm et al Questionnaire (1997a; 1997b) many respondents asked the interviewer in what way a pharmacist could be helpful or

simply said that as pharmacists were unable to prescribe, pharmacists were unable to assist. This was despite the fact that respondents may have been biassed towards rating pharmacists as helpful, as it was a pharmacist who was conducting the interview (see section 8.1.3). There was also an indication that pharmacists may be less involved with depression than other conditions.

However, the data which has been collected suggests many potential roles for the pharmacist in the management of antidepressant medication. The National Service Framework for Mental Health (The Department of Health, 1999b) has identified the community pharmacist as an access point for those with mental health problems. In addition, The Royal Pharmaceutical Society of Great Britain (2000) has identified that support to patients and carers in maintaining adherence to treatment is an important area of development for pharmacists in the field of mental heath. Gaps in the access to information for patients with a diagnosis of depression can be identified from the results of the study being presented in this thesis. With regards to the timing of information, receiving a first prescription for antidepressant medication was a traumatic experience for some people, with the prescribing of medication perceived as labelling the condition. Provision of information concerning medication at the time of diagnosis in the doctor's surgery was not always absorbed by respondents. However, the amount of information which patients required at this stage of therapy was vast. Therefore, pharmacists have an important opportunity to reinforce information. Some respondents in this study identified that the decision to take medication, was separate to the decision to have it dispensed. This confirms the importance of counselling at the supply stage. Depression can result in some people having short attention spans. Therefore, repeated opportunities for the provision of information could be advantageous. As an accessible health professional, pharmacists can have a valuable role in providing information between appointments at the doctor's surgeries. With regards to the type of counselling, key areas for discussion have been identified, such as the process of recovery. Pharmacists are also a potential source of information about alternative remedies, such as St John's Wort. Complementary therapies were an important part of therapy for some of the participants in the study, with pharmacists being a source of supply. Analysis of interview data suggested that respondents would have benefited from more information regarding side effects and interactions, particularly with the recent publicity concerning St John's Wort. Many of the respondents in this study were using self prescribed complementary therapies in addition to their conventional antidepressant therapy. However it is possible that there are patients not under

doctor's care for depression who also use alternative remedies. Such patients would not have been included in this study as they would not have entered the clinical system. However, pharmacists may be able to encourage them to seek help further help where necessary. The sensitivity of the subject matter means that pharmacists need to exercise caution in the mechanisms used to develop this role.

The pharmacy environment may, however, also be a barrier to enabling interactions to occur. The high level of stigma attached to taking antidepressant medication, resulted in many respondents in this study wishing to disguise the fact that they were taking it. This finding has implications for pharmacy as the open environment of a retail shop may be a barrier to communicating with patients. Although not directly mentioned in the study, it is possible that respondents experienced difficulties in simply obtaining supplies of their medication, for fear of others knowing about their condition. Some respondents may have had their prescriptions dispensed in places other than their usual pharmacy, where they were less well known by other customers. Previous research (Gardner et al. 2001) has shown that pharmacists ranked lack of personal space as the biggest barrier to communication with users of antidepressant medication. In addition, Gardner et al (2001) found that antidepressant users were critical of the lack of privacy in pharmacies. Lack of privacy has also been identified by pharmacists as a constraint to giving advice to patients with schizophrenia (Maslen et al. 1996). Having a private room available in pharmacies is a possible way of overcoming difficulties of confidentiality. However, the room may simply act as a stigmatising attribute in itself, with other customers identifying that patients have a personal problem if the consultation takes place in private. Confidentiality may be an issue which needs to be addressed when considering the general structure of pharmacy services. One possibility maybe to have a separate counselling room in which all prescriptions, for any condition are handed out and all healthcare advice is given. However, this would require a second pharmacist to be present.

Previous research has also identified other factors, in the present structure of pharmacy services, that community pharmacists perceive as barriers to further developing their role (Anderson, 1998; Bell et al. 1997; Krska et al. 2000; Maslen et al. 1996; Gardner et al. 2001) (see section 2.1.1 for further information about these studies). Lack of time and remuneration have been identified by pharmacists as barriers to communicating with people with mental health problems (Maslen et al. 1996; Gardner et al. 2001), as well as constraints to providing general health

promotion and pharmaceutical care services (Anderson, 1998; Krska et al. 2000; Bell et al. 1997). Community pharmacists are still primarily paid according to the number of prescriptions which are dispensed, with additional fees being paid for some additional services such as needle exchange and services to residential homes. Anderson et al (1998) found that some pharmacists were more likely to spend time on these remunerated services than other aspects of health promotion. Other pharmacists have expressed the view that pharmaceutical care activities could be practised by community pharmacists if the remuneration increasingly rewarded such activities (Krska et al. 2000). Pharmacists are being given increasing responsibility for managing illness. With the Department of Health target being that pharmacists begin repeat dispensing in chronic illnesses by the year 2004 (Department of Health, 2000b), the current remuneration structure urgently needs to be addressed. One way forward could be to pay pharmacists a salary, rather than making remuneration depend on the number of prescriptions dispensed. In addition, pharmacists have identified that a lack of access to medical records can impair the extension of the pharmacist's role (Anderson, 1998; Gardner et al. 2001). The latter constraint may be resolved by the use of the more up-to-date technology systems, that will allow electronic prescribing by the year 2004 (Department of Health, 2000b). It may be possible to transfer other aspects of patients' medical records with the prescription. However, issues concerning patient consent would need to be addressed.

In addition, previous research has identified factors concerning individual pharmacists which may act as barriers to developing their role, such as lack of confidence and feelings of discomfort towards dealing with those with mental health problems (Gardner et al. 2001; Maslen et al. 1996). Pharmacists participating in a survey concerning their perceived constraints into advising patients with schizophrenia, were significantly less confident in dealing with schizophrenia than asthma, diabetes, hypertension, depression and drug addiction. Differences in the responders' confidence in dealing with depression, in comparison to asthma, diabetes and hypertension were not tested for significance. However, the median confidence score for dealing with depression, was identical to the median confidence score for dealing with schizophrenia and drug addiction and was higher than the median confidence score for dealing with asthma, diabetes and hypertension (possible scores ranged from 1, indicating very confident to 5, indicating not confident). Therefore, it is possible that pharmacists were less confident in dealing with depression, than asthma, diabetes and hypertension. The minority of pharmacists who had participated in continuing education courses in mental health were found to be

significantly more confident about advising patients with schizophrenia, than those who had not. The pharmacists believed that they were more limited by knowledge of the condition of schizophrenia, than their knowledge of the relevant therapeutics. These findings suggest that incorporating more training concerning mental health conditions, at both undergraduate and postgraduate level, would help increase confidence in dealing with those with mental health problems. Pharmacists in the UK have been found to be concerned about embarrassing patients with schizophrenia by giving advice to them in the pharmacy (Maslen et al. 1996). Similarly, pharmacists in a USA survey ranked the belief that patients were not interested in engagement in discussions about their medication as one of the greatest barriers to communication with antidepressant users (Gardner et al. 2001). In addition, some pharmacists ranked being uncomfortable discussing antidepressants, due to the nature of illnesses associated with their use, as the greatest barrier to communication with antidepressant users. However, the results presented in this thesis demonstrate that respondents perceived that they had unmet information needs associated with their antidepressant medication. It may be deduced that they would have welcomed an additional source of information. Receiving a prescription for antidepressant medication was perceived as having a stigma attached. If pharmacists are reluctant to discuss antidepressant medication due to their own feelings of discomfort, this will only serve to heighten the stigma attached to this class of medication. Again, further training of pharmacists at both undergraduate and postgraduate level in communicating with those with mental health problems may reduce pharmacists' feelings of embarrassment or discomfort and inform pharmacists as to how to reduce the discomfort of patients. A randomised controlled trial has shown that antidepressant drug counselling by nurses increased patients' compliance with antidepressant medication (Peveler et al. 1999). The nurses required only 4 hours training to enable them to fulfill this role. Pharmacists are the experts in medication use. Therefore, only a small amount of training and resources should be required to enable pharmacists to provide drug counselling services to those beginning courses of antidepressant medication. Training should also focus on the use of herbal medicines such as St John's Wort as previous pharmacist surveys in both the USA (Chang et al. 2000) and the UK (Barnes, 2001) has identified a lack of pharmacists' knowledge base regarding complementary medicines. In another USA survey, 96% of pharmacists perceived that they did not have enough information about herbal medicines (Bouldin et al. 1999. Although the generalisability of these studies (Chang et al. 2000; Barnes, 2001; Bouldin et al. 1999) was limited by the sampling strategy used (Chang et al. 2000; Barnes, 2001) or a low response rate (Bouldin et al.

1999), the finding that pharmacists need further training on herbal products has some cumulative validity.

#### 8.3.3 GENERAL RELEVANCE TO THE CONCORDANCE DEBATE

The results of this study strengthen the argument for partnership in consultations about medication. A symptom of depression is the inability to make decisions. However, even amongst patients suffering from depression, there were indications for shared decision-making about therapy. This demonstrates the general need for healthcare professionals to recognise the role of patients in the active management of their illness. However, there were occasions where respondents did not wish to be involved in making decisions about treatment. It is recognised that concordance can sometimes involve the patient wishing to hand over control to the doctor (RPSGB and Merck Sharp & Dohme, 1997). Healthcare professionals therefore need to be aware of patient' preferences regarding level of involvement if they are to form truly concordant relationships.

In this study, the level of involvement which respondents wished to have over therapy varied at different points in treatment. This suggests that preferences regarding involvement in decision-making are dynamic, dependent on changes in the illness state. Future research may focus on identifying the factors that predict treatment preferences, enabling healthcare professionals to identify when changes in preference are likely to occur.

Therefore, this study informs the development of the role of healthcare professionals in the treatment of patients with depression. Gaps in the provision of information have been identified. Discrepancies occurred between respondents' own perceptions of their treatment and medical guidelines. Pharmacists have the opportunity to fill these gaps as they are accessible healthcare professionals with expert knowledge on the use of medicines. However, previous research has identified constraints which will need to be overcome in order to develop pharmaceutical services further.

#### <u>Chapter 9</u> <u>Conclusions</u>

This thesis has demonstrated that decision-making regarding antidepressant therapy was a complex process. On the one hand, medication slowly controlled symptoms and thereby led to a return to normal life and functioning. However, on the other hand, it labelled respondents as being depressed, taking away their own inner sense of being normal. In addition, some adverse drug reactions prevented respondents from carrying out their social roles. It was also noted that fears of becoming dependent on medication were prominent amongst the interviewees. Decisionmaking about antidepressant medication was made in conjunction with decisions about other treatments such as complementary medicines and psychological therapies. A large amount of information was therefore required to support individuals in their decision-making including the process of recovery, the impact of adverse drug reactions on patients' lives and information regarding dosage and dependency. A role for healthcare professionals was also identified in reducing fears of stigma. However, current healthcare services did not provide individuals with all the information they required.

The findings therefore inform the development of services for patients with a diagnosis of depression. Community pharmacists were found to currently have little role in influencing decision-making regarding antidepressant medication. Future research should concentrate on developing and evaluating interventions concerning the provision of verbal and written information by community pharmacists to those beginning courses of antidepressant medication, based on the information gaps identified in this study. Such research will also need to address the barriers to communication between pharmacists and patients with mental health problems which previous research has identified.

In addition, this thesis has informed the role of partnerships in the medicines management of chronic conditions. The findings support the development of shared decision-making between patients and healthcare professionals. However, they also show that patients preferences for involvement in decision-making can change during the course of an illness. Factors influencing such changes have been identified. Examples include improvement in the condition or the occurrence of an adverse drug reaction. Future research will involve developing a model of factors affecting patients' preferences for involvement in decision-making and testing this in other chronic conditions.

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Appendices

## APPENDIX 1 LETTER OF INVITATION FOR SUPPORT GROUPS TO PARTICIPATE IN THE PRELIMINARY FIELDWORK

LETTER HEADED NOTEPAPER 11<sup>th</sup> January 1999

Dear,

## **Re: Antidepressant Research Project**

I am a research pharmacist at the School of Pharmacy exploring the relationship between medication and quality of life for patients suffering from depression. Although many studies have looked at the effects of different treatment stratergies, there is limited information on the patients' perspectives of their antidepressants. I aim to investigate this further, in order to enhance our understanding of the way in which patients relate to their medication and the effects that they feel it has on their quality of life.

As an initial stage in my research I was hoping that it would be possible for me to attend a meeting and possibly arrange some interviews with some participants. This would be extremely helpful by helping me to gain an insight and knowledge about depression and its treatment from people with first hand experience. I will contact you by telephone in the next few days to discuss this further. Alternatively you can reach me on 0171-753-5959 or 0171-753-5851.

Thanking you in anticipation,

Yours sincerely,

Miss Sara Chait Research Pharmacist

# APPENDIX 2 INTERVIEW SCHEDULE FOR PRELIMINARY FIELD WORK WITH SUPPORT GROUPS

## 1) General Introduction

My name is Sara Chait and I'd like to thank for agreeing to let me talk to you.

I'm a research pharmacist, based at the school of pharmacy. I am carrying out a project in which I'm looking at how antidepressants affect the quality of life of those who take them.

I'm at the first stage in my research in which I'd like to find out what the important issues are for you, as a patient. I will then use this information to develop a more detailed research proposal.

## 2) Ask for consent to use the tape recorder. Give reassurance of confidentiality

As I am will not be able to write everything down, it would be very helpful if I could tape record this interview. This will save time and enable me to remember all the important information you tell me about. All information which you give me will be strictly confidential and your personal details will be erased at a later date. Is it all right for me to switch on the tape recorder?

## 3) Switch on the tape recorder (After consent given)

## 4) Introduction to questions

I'd now like to start to go through the questions. Take your time and talk in your own words. If you need time to think about what to say, that's fine. If at any time you feel uncomfortable with any of the questions just let me know and we'll move on.

## 5) Ask Questions

To begin with, I'd like to explore your views on taking medication..

1) First of all, do you currently take medication?

2) What are your feelings about taking medication?

If taking medication:

3) How long have you been taking medication for?

4) Can I ask you which tablets you are taking?

5) How many do you take?

If not taking medication:

6) Have you taken medication in the past?

Now I'd like to ask you some more detailed questions about how your medicine affects your life.

5) In what ways do your antidepressants affect you?

Prompts:

How do they affect your Symptoms? What do you see as the benefits? What about the down side? How do they affect you in your every day life? Relationships, employment, leisure activities other Are the things that you can do different to the things you could do before? Are the things that you can do different to the things you could do before? Are there any particular times when they affected you? How do they make you feel? Can you describe that in more detail? How have things changed while you have been taking them? How did you feel the very first time you received a prescription for antidepressants? Has the way you feel about your medication changed over time?

6)What are your long term expectations of your therapy?

#### Prompts:

How do you expect them to make you feel long term? Do you think that they could make you feel better/worse than you do already? What difference do you feel they could make to your long term goals/aspirations? Relationships, employment, leisure activities, other What is the best thing you could hope for with taking them? How likely do you think it is that that could happen? What is the worst thing that you feel could happen? How likely do you think it is that that could happen? How likely do you think it is that that could happen?

If patients have not been taking medication then change to past tense

7) There may have been many times when you have had to make a decision as to whether it was better for you to continue to take your tablets or not. How did you decide?

Who decided? How did you feel about that? How did you feel that that decision affected you?

8) Have other people noticed any changes in you since you've been taking the tablets?How does that make you feel?

9)Have you had any talk therapy?If yes:How would you say the two treatments compared?How do you think they have affected each other?

9) Can you tell me whose care you are under?

10) Do you have any further comments which you wish to add?

# 6) Close Interview

That's everything I need to know. Thank-you for participating in the interview. The information that you have given is most helpful

### APPENDIX 3 LETTER OF INVITATION FOR GPS TO PARTICIPATE IN THE MAIN STUDY

LETTER HEADED NOTEPAPER

DATE

Dear Dr,

### **Re: Antidepressant Research Project**

I am a research student working towards a PhD at the School of Pharmacy, University of London. I am investigating factors which affect compliance or adherence to antidepressant therapy. I hope to compare different groups of patients, including those who choose to continue with treatment to those who decide to stop taking their tablets after a short period.

Preliminary interviews have been carried out with patients through consumer support organisations, including Depression Alliance, Depressives Anonymous and Mind. This has resulted in the identification of many factors which may affect patients decisions about their therapy. These include beliefs about depression, beliefs about medicines, choice of agent and dosage, perceived risks and benefits and the level of personal control which patients wish to have over their therapy.

The main study will involve identifying patients with a diagnosis of depression who are beginning courses of antidepressants so that they can be invited to participate in the study and later be interviewed.

I would like to recruit patients through GP practices. I am contacting surgeries from two health authorities: Barnet and Camden & Islington. I was wondering if you or one of your colleagues may be interested in participating in this research. It will involve identifying patients for the study and inviting them to take part and be interviewed. I envisage that I will need approximately one hundred patients for the study. I would be happy to send you more details or meet with you to discuss the project. I will contact you by telephone in a few days time. Prior to this, if you have any questions, please do not hesitate to contact me on 0171-753-5959.

Yours sincerely,

Miss Sara Chait Research Pharmacist

#### APPENDIX 4 GP SCREENING TOOL FOR IDENTIFYING PATIENTS FOR MAIN STUDY

Tool to check whether patients meet Inclusion and Exclusion Criteria

Patient Identification no.

.....

# 1) The following factors would <u>exclude</u> a patient from taking part in the study. Please check whether any are present.

Patient under 18 years Patient over 65 years Depression secondary to physical illness Schizophrenia Psychotic symptoms Manic episodes Hallucinations Alcohol or drug abuse problem Been taking antidepressants longer than three months in this episode.

Does the patient have any of the above

Yes 🗆 No 🗖

If the answer to the above is no then the patient may be eligible for inclusion in the study. Please could you answer the next question which is based on the WHO ICD-10 criteria of depression.

2) Does the patient have at least two of the following:

Depressed mood Loss of interest and enjoyment Increased fatiguability

At least two symptoms present

Yes 🛛 No 🗖

If the answer is yes the patient may be eligible for inclusion. Please answer the next question which is also based on the ICD-10 criteria. If the answer is no then exclude the patient from the study.

3) Does the patient have two or more of the following:

Reduced Concentration and attention Reduced self-esteem and self confidence Idea of guilt and worthlessness Bleak and pessimistic views of the future Ideas or acts of self harm or suicide Disturbed sleep Diminished appetite Two or more symptoms present **Yes** No **If the answer is yes then the patient is eligible for inclusion in study.** 

# APPENDIX 5 LETTER INVITING PATIENT TO TAKE PART IN THE MAIN STUDY, WITH REPLY CARD

#### LETTER HEADED NOTE PAPER

Sara Chait Bsc(Hons), MRPharmS PhD Student, School of Pharmacy Tel: 0171 753 5959

Dear Patient,

### **<u>Re: Study about Medicines for Depression</u>**

We are undertaking a study on patients' views about taking medicines for depression. The aim of the study is to increase our knowledge about the effects of medicines on people's lifestyle and general health.

There have been many clinical studies about the use of medicines, but few from the perspective of the patients themselves, regarding <u>their</u> views and experiences. We are contacting patients from a number of practices in London and would like to interview you about your views and opinions. We will arrange the interview at a time and place convenient for you. We envisage that it will take around sixty minutes. All the information collected will be **strictly confidential.** The names and addresses of those who have taken part will not appear in any report.

# We are very interested in hearing your views, even if you are not currently taking or have never taken any medicines.

I enclose an information leaflet about the study. I would be very grateful if you would complete the reply form to indicate whether or not you would like to discuss the possibility of taking part. Please then return the form in the Freepost envelope provided.

Thanking you in anticipation,

Yours sincerely,

Miss Sara Chait Research Pharmacist
# **Medicines For Depression: Patients' Views**

Please read the two statements below and tick one of the boxes. Please tick one box only. If you tick the first box, please could you also write down your name and telephone number. If you tick the second box, please write down your name

I am willing to discuss the possibility of taking part in the study.

Name	•••••
Telephone no.	

I do not wish to consider taking part in the study. Please do not contact me again.  $\Box$ 

# Name

•••••

It would still be very helpful if you could fill in the enclosed decline form. This is to help us identify which types of patients have taken part and which have not. We are only interested in which groups of patients have participated, not in which individuals.

# **Decline Form**

Please fill in this form if you have decided not to take part. If you feel uncomfortable with any of the questions, please leave these blank.

Sex	(Please delete as appropriate)	Male/Female
Drug	s being taken	
		•••••••••••••••••••••••••••••••••••••••
Date	of Birth	
Reas	on for not wishing to take part	
		•••••
		•••••

## THE SCHOOL OF PHARMACY UNIVERSITY OF LONDON

## Contact for further information

If you would like any further information on any aspect of the study, then do not hesitate to contact me.

Sara Chait Centre for Pharmacy Practice School of Pharmacy, University of London Brunswick Square London WC1N 1AX

Tel: 0171 753 5959

## MEDICINES FOR Depression: PATIENTS' VIEWS

THANK YOU FOR TAKING PART

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## What is the purpose of this study?

We would like to increase our knowledge about the effects of medicines on people's lifestyle and general health. The aim of this study is to find out the views and experiences of people taking medicines for depression.

## Who is organising this study?

The research is being carried out by the School of Pharmacy, University of London (an independent establishment involved in education and research, we are not a commercial organisation).

## Why have I been chosen?

People who are taking certain types of medicines and are attending selected surgeries will be invited to take part in the study.

## Is the study confidential?

Yes. All information collected will be kept strictly confidential. The names and addresses of those who have taken part will not appear in any reports.

## What will happen to me if I take part?

At your convenience, a researcher would like to interview you on two occasions. The researcher will ask you a series of questions about your views and experiences of taking medicines. This will take between thirty and sixty minutes. She will also ask for your permission to see your medical notes.

## Do I have to take part?

No, but we hope that you will be happy to take part. We believe that the study will give us important information about how these medicines affect people's every day lives. Your participation is voluntary, and you are free to withdraw at any time without your medical care or legal rights being affected.

Thank you for your time. Please ask if you would like more information.

#### APPENDIX 7 PATIENT CONSENT FORM FOR MAIN STUDY

#### AGREEMENT TO TAKE PART IN RESEARCH PROJECT <u>MEDICINES FOR DEPRESSION</u> <u>PATIENTS' VIEWS</u>

#### **INFORMATION FOR PATIENTS**

We would like to increase our knowledge about the effects of medicines on people's life style and general health. The aim of this study is to find out the views and experiences of patients taking medicines for depression. People who are taking certain types of medicines and are attending selected surgeries will be invited to take part in the study.

At your convenience, a researcher would like to interview you on two occasions. The researcher will ask you a series of questions about your views and experiences of taking medicines. This will take between thirty and sixty minutes. She will ask for permission to tape-record the interview. She will also ask for your permission to see your medical notes.

All the information we collect will be <u>strictly confidential</u> and will not be revealed to anyone. The names and addresses of those who have taken part will not appear in any reports. Your doctor has given me permission for the study and will be informed of the overall results of the study but will **not** be informed of what individual people have said. We hope you are willing to help us with this study. Agreeing to take part will not affect your treatment. Similarly, if you do not wish to take part or wish to withdraw during the course of the study, this will not affect your treatment in any way.

If you are willing to take part in this study, please could you sign the form below.

## Consent Form

I (Name of participant)	
Of(address)	
·····	agree to take part in the research study-
Medicines for depression: Patien the research have been explained permission for the researcher to a the patient information leaflet and from the research project.	ts Views. I confirm that the nature and demands of to me and I understand and accept them. I also give access my medical notes. I confirm that I have seen d understand it. I understand that I may withdraw
Signed	Dated

#### Appendix 8 Interview schedule for main study

There were 2 qualitative interviews; one for patients who were still taking medication and one for patients who had stopped. The quantitative questionnaires are common to both groups. The qualitative interviews are expected to take approximately twenty minutes and the questionnaires a further ten minutes. Therefore the whole interview should be about thirty minutes in length.

#### **Interview** schedule

#### 1) General introduction

My name is Sara Chait and I'd like to thank you for agreeing to let me talk to you.

I'm a research pharmacist, based at the School of Pharmacy. I am carrying out a project in which I'm investigating how patients feel about treatment for depression and how it affects quality of life.

As part of my project it would be very helpful if you could answer some questions about it and then fill in some forms.

#### 2) Obtain consent

Please could you firstly read through this leaflet. If you are happy with it and would like to take part then please could you sign here.

#### 3) Ask for consent to use the tape recorder. Give reassurance of confidentiality

As I will not be able to write everything down, it would be very helpful if I could tape record this interview. This will save time and enable me to remember all the important information you tell me about. All information which you give me will be strictly confidential and your personal details will be erased at a later date. Is it all right for me to switch on the tape recorder?

4) Switch on the tape recorder (After consent given)

#### 5) Introduction to questions

I'd now like to start to go through the questions. Take your time and talk in your own words. If you need time to think about what to say, that's fine. If at any time you feel uncomfortable with any of the questions just let me know and we'll move on.

#### 6) Ask Qualitative Interview Questions

#### Interview Questions for patients continuing to take medication

1) Could you start by telling me a bit about yourself?

Prompts: Where are you from? What do you do? Who do you live with?

2) What do you understand by depression?

3) What difference has depression made to your life?

4) How did you make the decision to go to speak to your doctor?

5) How did you feel about it?

6)What were you're expectations?

7) How do you feel about taking your medication? Prompts: Happy Unhappy Indifferent

8) Some people say that medication helps them to build a better life, some say that it makes no difference and others say that the medication can make their lives worse. What is your experience of your medicine?

9) How do you decide whether the medication is working?

10) If you experience symptoms of your illness when taking your medication, what do you do?

11) Do you feel different when you take your tablets to when you don't take them?

12) Do you have any problems, difficulties or concerns with your medicines? If no go to question 14.

13) What kind of problems?

14) Do you experience any side effects from the medicines? If no go to question 16. If no to questions 12 and 14 go to question 19.

15) What kind of side effects?

Prompt: How often

When do they occur

16) What do you do about the side effects?

17) From your experiences, do those side effects or problems that you have just told me about affect anything that you do or would like to do?

18) In what ways?

- 19) How have your medicines affected you in your every day life?
- Prompts:General day to day activitiesWorkRelationships with friendsRelationships with familyGeneral Social lifeAbility to driveThe way you feel about yourselfThe way that you feel others feel about youThe way in which you view the worldSleepAbility to ConcentrateAny Other things that you would like to do.

20) How does the fact that you take medicines affect the way you feel about yourself as a person?

21) How do you feel about other people knowing you are taking medicines?

22) Do you feel that you are treated any differently because you take your medication? If no go to question 26. If yes explain.

Prompt: Have you ever been concerned that you might be?

23) Have you ever felt discriminated against because of the medicines which you take?

#### Prompt: Have you ever be concerned that you might be?

24) How does this affect you in your life?

25) What do you do about it?

26) Have other people noticed any changes in you since you've been taking your tablets? If no go to question 29.

27) What kind of changes?

28) Do you feel that these affect you?

29) What are you thoughts on taking your medicines a)short term

b)long term

30) How do you think that your medicine could affect you in the future?

31) How do you think that the medicine your doctor has given you compares to similar medicines?

32) How do you feel about your dosage?

33) Where have you had information from about your treatment?

34) What type of information have you received?

Prompt: Length of treatment, what were your own expectations?

35) Is there any other information that you would like to have had? Please explain.

Prompts: Social information Medical information

Self

36) What discussions did you have with your doctor regarding length of treatment?

36) How have different people influenced your decisions about your treatment?

Prompts:

Doctor Family Friends Counsellor Anyone else Have they encouraged/discouraged you?

37) How do you decide whether or not to take your tablets?

Prompts: When to take them How many to take

38) Do you know anyone else who takes a similar type of medication to you? If no, go to question 40

39) How does this affect you?

40) Do you think you'll go back for another prescription?

41) How have you made that decision?

42) Do you feel that you currently need your medication?

43) Have you ever felt like not taking your medicines?

44) What made you feel like that?

45) What did you do about it?

46) How do you feel about talk therapy/counselling?

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47) How do you think it (would) compare(s) to your drug therapy?

48) Have you ever considered taking alternative medication?

Prompts: Herbal Homeopathic

49) How does (would) this compare to other antidepressant medication?

Prompts:	Effectiveness
	Safety/interactions
	Side effects
	Stigma
	Expense

50) Do you have any other alternative strategies to manage your illness or your side effects?

51) How do (would ) these compare to your drug therapy?

52) We have discussed a lot about your experience with your medication. Do you have any further comments to add?

#### Interview questions for patients discontinuing medication

1) Could you start by telling me a bit about yourself?

Prompts: Where are you from? What do you do? Who do you live with?

2) What do you understand by depression?

3) What difference has depression made to your life?

4) How did you make the decision to go to speak to your doctor?

5) How did you feel about it?

6)What were you're expectations?

7) What are your thoughts on taking medicines for depression?Prompts: Happy

## Unhappy Indifferent

8) How did you feel about your first prescription?

9) How did you think that the medicines which you were prescribed compared to similar medicines?

10) How did you feel about the dosage you were prescribed?

11) How did you decide whether to get your first prescription dispensed? If did not get dispensed go to question 30.

12)How did you decide whether to take the tablets? If did not take any go to question 30.

13) Some people say that medication helps them to build a better life, some say that it makes no difference and others say that the medication can make their lives worse. What is your experience of your medicine?

14) How did you decide whether the medication was working?

15) If you experienced symptoms of your illness when taking your medication, what did you do?

16) Did you feel any different when you took your tablets to when you didn't take them?

17) Did you have any problems, difficulties or concerns with your medicines? If no go to question 19

18) What kind of problems?

19) Did you experience any side effects from the medicines? If no go to question 22. If no to both questions 17 and 19 go to question 24.

20) What kind of side effects?
Prompt: How often?
When did they occur?

21) What did you do about the side effects?

22) From your experiences, did those side effects or problems that you have just told me about affect anything that you did or would like to have done?

23) In what ways?

24) How have your tablets affected you in your every day life?

Prompts:General day to day activitiesWorkRelationships with friendsRelationships with familyGeneral social lifeAbility to driveThe way you feel about yourselfThe way you feel that others feel about youThe way in which you view the worldSleepAbility to concentrateAnything else you would like to do.

25) How have things changed since you've stopped taking them?

26) How long did you take them for?

27) How did you decide to stop taking them?

28) Why did you decide to stop taking them?

Prompts: Side effects lack of efficacy interference with life style long term fears/concerns

29) Did anything that we've talked about so far affect your decision?

Ask rest of questions to everybody

30)What thoughts did you have on taking the medication?

a) short term

b) long term

31) How do you feel about it now?

32) Do you feel that you currently need medication?

33) How did the fact that you were taking tablets affect the way in which you saw yourself as a person?

34) How did other people feel about you taking your medication?

35) Did you feel that you were (would have been) treated any differently because you were taking them?Prompt: Have you ever been concerned that you might be treated differently?

36) Have you ever felt (Do you think you would have felt) discriminated against because of the medicines which you take?

Prompt: Have you ever been concerned that you might be treated differently? If no go to Question 39.

#### If patients have not taken any medication go to question 42.

37) How does this affect you in your life?

38) What do you do about it?

39) Did any other people notice any changes in you while you were taking them?

40) What kind of changes?

41) Do you feel that these affect you?

42) Where did you obtain information about your treatment from?

43) What type of information did you receive?

## Prompt: Length of treatment, what were own expectations?

- 44) Is there any other information that you would like to have had? Please explain.
- 45) Do you know anyone else who takes a similar type of medication to you? If no, go to question 40
- 46) How does this affect you?

47) How have you and other people been involved in decisions about your therapy?

Prompts:

Self Doctor Family Friends Counsellor Anyone else? Have they encouraged/discouraged you?

48) How do you feel about talk therapy or any other therapies?

49) How do they compare to drug therapy?

50) Have you ever considered taking alternative medication?

Prompts: Herbal Homeopathic

51) How does (would) this compare to other antidepressant medication?

Prompts: Effectiveness Safety/interactions Side effects Stigma Expense

52) Do you have any other alternative strategies for managing your illness?

53) How do you think that these compare to your drug therapy?

54) We have discussed a lot about your experience with your medication. Do you have any further comments to add?

[The next part is for all patients whether or not they are continuing or have discontinued therapy.]

Thank you very much for your help. I would now like to fill in some questionnaires with you

7) Administer Quantitative Questionnaire

#### Quantitative Interview concerning Beliefs about Depression

Patient Identification number .....

I'm going to read out a series of questions to you. Please choose the card which is most close to how you feel.

#### Section A (Pink Card)

The next few questions are about problems like depression developing in anybody? How likely do you think each of the following is to be a reason for such problems? Please could you look at the card and tell me whether they are very likely, likely or not likely.

	Very likely	Likely	Not likely
1) A virus, or other infection?	D	D	ū
2) An allergy ?		ū	G
3) Day to day problems such as stress, family arguments, difficulties at work or financial difficulties?		D	
4) The recent death of a close friend or relative?		ū	ū
5) Some recent traumatic event such as a severe traffic accident or being mugged.	٦	ū	
6) Problems from childhood such as being badly treated or abused, losing one or both parents when young or coming from a broken home?			
7) Inherited or genetic?		٦	D
8) Being a nervous person ?	G	۵	ū
9) Having weakness of character?			D

#### Section B (Blue card)

The next few questions seek your opinion about whether there are some people in the community who are more likely to have these problems and others who are perhaps less likely. Please look at the card and say whether you think they would be more likely than other people, less likely or no difference.

	More Likely L	ess Likely	NoDif
1) Do you think that women would be more or less likely to suffer than men from these sorts of problems?			ū
2) Would young people under 25 years of age be more or less likely?	ū		
3) Would older people, those aged over 65 be more or less likely?	G		٦
4) Would poor people be more or less likely to suffer these sorts of problems?			ū
5) Would unemployed people be more or less likely?	D		D
6) Would divorced or separated people be more or less likely?	D	Q	D
7) Would single people, who have never been married or in a long term relationship be more or less likely?			

#### Section C (Yellow card)

The last questions asks you your opinion on various people and treatments which could help with depression. For each, please look at the card and tell me whether you think they would be helpful, harmful or would make no difference.

1) Which of the following people could be helpful with depression?	Helpfu	l Harmful N	No Dif.
A typical GP or family doctor	ū	ū	
A typical chemist (pharmacist)	Helpful	Harmful D	No dif. 🗖
A counsellor	ū	ū	D
A social worker	٦	ū	
Telephone counselling Service (E.g. Samaritans)	ū	ū	
A psychiatrist	D		D

A psychologist	ū	ū	D
Help from close family	D	ū	
Help from close friends	۵	ū	
A naturopath or herbalist		ū	
The clergy, a minister or priest	۵	ū	۵
Better to deal with problems on own	G	D	ū
2) Which of the following medications may be helpful?			
Vitamins and minerals, tonics or herbal medicines			۵
Pain relievers such as aspirin, codeine or panadol	۵	D	۵
Antidepressants	۵		
Antibiotics	۵		
Sleeping Pills	۵		۵
Antipsychotics	G		D
Tranquillisers such as valium	Helpful	Harmful D	No dif
3) which of the following activities may be helpful?	_		_
Becoming more physically active such as playing more sport, or doing a lot more walking or gardening	ū		
Reading about people with similar problems and how they dealt with them	٦		۵
Getting out and about more	D	۵	ū
Courses on relaxation, stress management meditation or yoga	٦		ū
Cutting out alcohol altogether	۵	٦	٦

Counselling/psychotherapy			
Hypnosis		ū	G
Admission to a psychiatric ward of a hospital	ū	ū	
Electro convulsive therapy	D	ū	۵
Having an occasional alcoholic drink to relax	ū	ū	D
A special diet or avoiding certain foods		G	ū

## Smithkline Beecham Quality of Life Measure

#### Patient Identification number

Below are some pairs of statements with boxes in between. Please tick the box which most closely identifies where you see yourself in relation to these.

.....

I do not have overwhelming problems		I do have overwhelming problems
I feel secure		I feel insecure
I feel without hope		I feel hopeful
I feel comfortable with myself	0000000000	I feel uncomfortable with myself
I do not feel a failure	0000000000	I feel a failure
I sleep well	0000000000	I sleep badly
I have reduced		I do not have reduced
physical mobility		physical mobility
I am always full of energy		I am lacking in energy
I experience no physical pain		I experience physical pain
I have a good appetite		I have a poor appetite
I am irritable		I am not irritable
I wish I were dead	0000000000	I am glad to be alive
I am never worried		I am always worried
I feel in control of my life	0000000000	I do not feel in control of my life
I have no difficulty making decisions	0000000000	I have great difficulty making decision
I feel helpless		I do not feel helpless
I am unable to make and/or maintain relationships with friends/workmates		I am able to make and/or maintain relationships with friends/workmates
I am self-confident	0000000000	I am not self-confident
I feel inferior	000000000000000000000000000000000000000	I do not feel inferior
I am dissatisfied with my daily work	000000000	I am satisfied with my daily work
I feel unable to cope at work	0000000000	I feel able to cope at work
I derive no pleasure from my hobbies	000000000	I derive pleasure from my hobbies
I am worried about money	0000000000	I am not worried about money

## Symptom Interpretation Questionnaire

Patient Identification no.

Listed below are conditions you may or may not have experienced. For each condition, please circle the letter next to the reason or group of reasons that corresponds to how that might explain your condition. Please check every item for each question. Also, answer whether you have had the condition in the last 3 months by circling Yes or No. Please answer all the questions.

Α	В	С	D
Not at all	Somewhat	Quite a bit	A great deal

#### 1) If I had a **prolonged headache**, I would probably think that it is because:

I am emotionally upset	Α	В	С	D
There is something wrong with my muscles, nerves or brain	Α	В	С	D
A loud noise, bright light or something else has irritated me	Α	В	С	D
Have you had a prolonged headache in the last three months?		Yes	No	
2) If I was sweating a lot, I would think that it is because:				
I must have a fever or infection	Α	В	С	D
I'm anxious or nervous	Α	В	С	D
The room is too warm, I'm overdressed or working too hard	А	В	С	D
Have you noticed yourself sweating a lot in the last three months?	Yes	No		
3) If I got dizzy all of a sudden, I would probably think it is becaus	e:			
There is something wrong with my heart or blood pressure	Α	В	С	D
I am not eating enough or I got up too quickly	Α	В	С	D
I must be under a lot of stress	Α	В	С	D
Have you felt dizzy in the last three months?	Yes	No		
4) If I noticed my mouth was dry, I would probably think that it is	because:			
I must be scared or anxious about something	Α	В	С	D
I need to drink more liquids	А	В	С	D
There is something wrong with my salivary glands	Α	В	С	D
Have you had a dry mouth in the last three months?	Yes	No		

I've exerted myself or drunk a lot of coffee	А	В	С	D
I must be really excited or afraid		В	С	D
There must be something wrong with my heart	Α	В	С	D
Have you noticed your heart pounding in the last three months	Yes	No		
6) If I felt <b>fatigued</b> , I would probably think that it is because:				
I'm emotionally exhausted or discouraged	А	В	С	D
I've been over-exerting myself or not exercising enough	А	В	С	D
I'm anaemic or my blood is weak	Α	В	С	D
Have you ever felt fatigued in the last three months?		Yes	No	
7) If I noticed my hand trembling, I would probably think that it is	because:			
I might have some sort of neurological problem	А	В	С	D
I'm very nervous	А	В	С	D
I've tired the muscle in my hand	Α	В	С	D
Have you noticed your hand trembling in the last 3 months?	Yes	No		
8) If I had <b>trouble sleeping</b> , I would probably think that it is becaus	se:			
Some kind of pain or physical discomfort was keeping me awake	А	В	С	D
I'm not tired or I had too much coffee	Α	В	С	D
I'm worrying too much or I must be nervous about something	Α	В	С	D
Have you had trouble sleeping in the last three months?	Yes	No		
9) If my stomach was upset, I would probably think that it is becau	ise:			
I've worried myself sick	А	В	С	D
I have the flu or stomach irritation	А	В	С	D
I've had something to eat that did not agree with me	Α	В	С	D
Have you had an upset stomach in the last three months?	Yes	No		

5) If I felt a sudden **pounding in my chest**, I would probably think that it is because:

#### 10) If I lost my appetite, I would think it is because:

I've been eating too much or my body doesn't need as much food	А	В	С	D
as before I've been worrying so much that food just doesn't taste good	А	В	С	D
any more I have some stomach or intestinal problem	A	В	С	D
Have you lost your appetite in the last three months?	Yes	No		

## 11) If I had a hard time catching my breath I would think it is because:

My lungs are congested from infection, irritation or heart trouble	Α	В	С	D
The room is stuffy and there is too much pollution in the air	А	В	С	D
I'm over-excited or anxious	Α	В	С	D
Have you had a hard time catching your breath in the		Yes	No	
last three months?				

## 12) If I noticed numbness or tingling in my hands or feet, I would think it is because:

I'm under emotional stress	А	В	С	D
There is something wrong with my nervous or blood circulation	А	В	С	D
I am cold or my hand or foot went to sleep	Α	В	С	D
Have you had numbness or tingling in your hands or feet in the	Yes	No		
last three months?				

## 13) If I was constipated or irregular, I would probably think that it is because:

There is not enough fruit or fibre in my diet	Α	В	С	D
Nervous tension is keeping me from being regular	Α	В	С	D
There is something wrong with my bowels or intestines	Α	В	С	D
Have you been constipated or irregular in the last three months?	Yes	No		

End of Symptom Interpretation Questionnaire

## 8 Obtain Sociodemographic Details

To end off with, I need to ask you some questions about yourself.

## Form for obtaining Socio-Demograpic Information

Identification number	•••••
Age on last birthday	•••••
Sex	Male/Female

## Employment status: Are you

	Employee	
	Self-Employed	
	On a government Scheme	
	Unemployed	Ο
	Student	
	Permanently sick	
	Retired	
Occupation-if applicable (Or previous occupation)		
Country of birth		
Ethnic Group:	White (Non Irish)	
	White (Irish)	
	Black-Caribbean	
	Black-African	
	Black-Other	
	Indian	
	Pakistani	
	Bangladeshi	
	Chinese	Ο
	Asian	Ο

Thank-you for your help.