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Finding a Treatment that Fits: A Grounded Theory Study of
Women's Compliance with Treatments for Depression Using a
Community Sample from a Dietary Intervention Study

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of Master of Arts in Psychology at Massey University,
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Abstract

Compliance with healthcare regimens is becoming an increasingly important area of health research. Depression is thought to be increasing in prevalence world-wide, and so too is the share of the healthcare budget dedicated to treating depression. Research has shown that people tend to discontinue treatments for depression far earlier than recommended. However, very little research has explored why this might be so. Several theories of health behaviour have tried to account for compliance in terms of influential beliefs and attitudes, but generally these theories have not been explored in a mental health context. Additionally, research is only just beginning to consider compliance from a healthcare consumer's perspective.

The Compliance Study reported in this thesis adopted a grounded theory methodology to explore compliance with women's treatments for depression. A community sample of 37 depressed women, participating in a 12 week double-blind placebo controlled trial investigating the effects of fish oil as an adjunct to treatments for depression, provided both qualitative and quantitative data on their compliance experiences with treatments for depression generally, and with the supplement trial specifically.

The basic social process of compliance that emerged from the data involved a complex and dynamic interaction of mutually influential illness variables, significant relationships, meanings given to depression and its treatments, and cost-benefits analyses. In Finding a Treatment that Fits, women balance competing interests and try to ensure good enough compliance to meet their own goals for wellness. The results from the Compliance Study confirmed important prior findings with respect to compliance with depression treatments, but extended these by looking at underlying reasons for decisions to continue or discontinue treatments. The thesis also considers special issues relevant to the particular circumstances of compliance in the dietary intervention trial, including the impact of placebo effects and attitudes towards non-orthodox treatments. Implications for further research and clinical practice are discussed.

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PART 1

INTRODUCTION AND OVERVIEW

Chapter 1

Introduction

"Keep watch also on the faults of the patients, which makes them lie about the taking of things prescribed" Hippocrates (460-377BC)

THE PROBLEM OF COMPLIANCE IN HEALTHCARE

The frustration many health professionals feel with clients and patients who do not follow treatment recommendations echoes Hippocrates warning in the epigraph above. Even the father of medicine himself saw his patients as untrustworthy and unreliable at times (Dukes Hess, 1996), and perhaps a little unfathomable.

Compliance with therapies of all kinds and for every type of malady has concerned healthcare practitioners for thousands of years. A literature review by Trostle (1988, cited in Dukes Hess, 1996) found over 4,000 English language articles dealing with different aspects of compliance.

It has been estimated that up to half of all healthcare consumers do not comply with treatment recommendations (Donovan & Blake, 1992; Roberson, 1992). While many clinicians and researchers have attempted to find ways to improve compliance, only a few have asked individual healthcare consumers why they follow treatment regimens as prescribed, or fail to do so (Roberson, 1992; Donovan & Blake, 1992; Conrad, 1985).

Depression is a serious disease with a serious impact. Treatments abound, from the empirically supported to the outlandish (Solomon, 2002). However, regardless of how well a treatment may work objectively, it will have little impact if people with depression cannot be persuaded to use it, or if they terminate treatment prematurely (Reimherr, Strong, Marchant, Hedges, & Wender, 2001). Therefore, it is important

to understand the reasons why depressed people start, stop and stay in treatment. Both the possible causes (Demyttenaere et al., 2001b; Demyttenaere et al., 2001a; Baker, Russell, & Campbell, 2001) and effects (Mundt, Clarke, Burroughs, Brenneman, & Griest, 2001; Myers & Branthwaite, 1992) of non-compliance by depressed people have been studied. However, no studies primarily directed at depressed women's practice of, or perspectives on, treatment compliance could be located in existing social science literature.

The research reported here ("the Compliance Study") explored factors relevant to women's compliance with therapies for depression, using a nutritional supplement trial ("Dietary Intervention Study" or "DIS") as a vehicle for that research. Both the Compliance Study and the DIS will be outlined in the next chapter. Before then, a brief review of the definitions, prevalence and incidence of depression is provided to situate the Compliance Study in context. The chapter concludes with an overview of the thesis format.

BACKGROUNDING DEPRESSION

Definition

"Depression" is a generic term commonly used to describe a variety of conditions defined in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition (DSM-IV) (American Psychiatric Association, 1994). They include major depressive disorder, dysthymic disorder, a single depressive episode, and, at times, bipolar disorder.

According to DSM-IV criteria, major depressive disorder is characterised by the presence of at least one major depressive episode, which is not better accounted for by any psychotic disorder. A person cannot be diagnosed with major depressive disorder if she or he has ever experienced a manic episode. A major depressive episode must include at least five out of nine stipulated symptoms of depression, lasting at least two weeks, and including either depressed mood or loss of interest or

pleasure. A range of cognitive, somatic and affective symptoms are included in the defining criteria. These are fully described elsewhere (American Psychiatric Association, 1994; Kaplan & Sadock, 1998). The array of depressive symptoms must not be due to the effects of a substance or medical condition, and must produce clinically significant distress or impairment in at least one area of the individual's functioning (American Psychiatric Association, 1994).

Prevalence and Incidence

Kaelber, Moul and Farmer (1995) noted that even among methodologically sound epidemiological research, prevalence and incidence rates of major depression vary considerably. This variability is due to the application of different diagnostic criteria, assessment methods, and ages of participants in research studies. However, some reputable estimates are provided below.

Lifetime prevalence of depressive episodes and major depressive disorder were estimated at 6.3% and 4.9% respectively in the Epidemiologic Catchment Area Study ("ECA study") (Regier & Robins, 1991, cited in Kaelber, Moul, & Farmer, 1995). The ECA study found that women were more than twice as likely as men to meet the criteria for either disorder at some point in their lives. In a follow-up to the ECA study, incidence rates of major depression were estimated at one case per 100 person years for men, and two cases per 100 person years for women. These differential diagnoses rates based on gender have been found in many studies (Brems, 1995; Roades, 2000). There is no single reason why women are more likely than men to be diagnosed with depression. It is generally accepted that there is a multidimensional model of risk factors for depression in women, including socialisation, biological, economic, political, and discriminatory factors (Simonds, 2001).

While estimates of prevalence rates for depression in New Zealand are difficult to make, it is generally assumed that they are similar to those found internationally (Wells, Bushnell, Hornblow, Joyce, & Oakley-Browne, 1989). One large study (n = 1,498) estimated the lifetime prevalence of major depression in New Zealand to be 12.6% among 18-64 year olds (Wells et al., 1989). A study measuring the rate of

detected and undetected depression in patients at an Auckland general medical practice found that 13.8% of patients responding to a screening survey met the cut-off criteria for depression, with 34% of women and 20% of men being classified as depressed (Arroll, Goodyear-Smith, & Lloyd, 2002). The authors noted that similar results have been found in other surveys of medical practitioners' patients in Australia and the United States. However, recent Australian research found that while doctors are good at identifying the somatic symptoms of depression, they are less competent or confident at identifying depression via its cognitive or affective symptoms (Krupinski & Tiller, 2001). The actual rates of depression could therefore be higher.

OVERVIEW OF THESIS FORMAT

This thesis is divided into three parts as follows. **Part 1** introduces the concept of the Compliance Study. Chapter 1 introduces the notion of compliance with treatments for health-related conditions generally and depression specifically. To put the Compliance Study in context, it then defines depression and provides some information on its prevalence and incidence. Chapter 2 describes the Compliance Study's aims and summarises the objectives, methods and rationale of the DIS.

Part 2 delivers a comprehensive literature review. The review covers several disparate topics for two reasons. First, the Compliance Study explored compliance with treatments for depression generally, so information was gathered on a number of potentially relevant factors. What is known about treatment compliance generally, and compliance with respect to depression in particular, was reviewed, as were theories of health behaviour that may account for variations in compliance. Second, the DIS brought into play a number of factors that may have influenced compliance with its particular treatment requirements. The literature review was therefore extended to include why people use alternative and natural therapies, and how placebo effects may influence compliance.

Given that the literature review contains a number of separate topics related by the nature of the Compliance Study, it has been divided into several chapters. Chapter 3 backgrounds compliance in general healthcare research, including special factors that have been found to affect compliance with treatment in research trials. Chapter 4 details some of the findings from research into compliance with treatments for depression. Chapter 5 outlines different models of health behaviour that are thought to elucidate people's decisions to undertake and comply with treatment protocols. Chapter 6 looks at health beliefs, attitudes and values associated with the use of alternative therapies. Finally in this part, Chapter 7 reviews what is known about placebo effects, which is perhaps the most difficult response to understand in terms of therapeutic effect.

Part 3 begins by outlining the Compliance Study's methodology in Chapter 8 and method in Chapter 9. It then presents the Compliance Study findings. Quantitative results are presented first, in Chapter 10. An overview of the grounded theory of women's compliance with treatments for depression appears in Chapter 11, where selective codes are related to the core category of the emergent theory. A more detailed account of the four major components of that theory follows in Chapters 12 to 15. Chapter 16 explains how this grounded theory of women's compliance in depression operated in the context of the DIS. Chapter 17 concludes Part 3, with a discussion and integration of the Compliance Study findings with the existing literature before finally making some recommendations for both future research and clinical practice.

Chapter 2

The Compliance Study: Aims and Relationship to the Dietary Intervention Study

The Compliance Study reported here was associated with a larger study investigating a nutritional supplement dietary intervention for depression. The Dietary Intervention Study (DIS) was initiated by Crop & Food Research, a government-funded Crown Research Institute in New Zealand. The School of Psychology at Massey University in Palmerston North was invited to collaborate in the psychological aspects of the DIS, including psychometric assessment. The Compliance Study was an integrated but separate project initiated by the current author, utilising part of the DIS participant group. Ethical approval for the Compliance Study was obtained from the Massey University Human Ethics Committee. Additionally, both the DIS and the Compliance Study received ethical approval from both the Manawatu-Whanganui and Wellington Ethics Committees.

This chapter begins by setting out the aims of the Compliance Study, before outlining the aims, design and rationale for the DIS.

THE COMPLIANCE STUDY

The Compliance Study used a grounded theory methodology to explore women's behaviours and views on compliance with treatments for depression generally, and with the nutritional supplement regimen of the DIS in particular. Both qualitative and quantitative data were collected in the course of the research. Data was analysed to build a grounded theory of women's compliance with depression treatments. Compliance with treatments for depression generally was defined to include acceptance of treatment recommendations, following treatment instructions, and continuing in treatment for an adequate time. As well as interpreting the women's

narratives about compliance with depression treatments generally, compliance with the DIS supplement treatment was measured quantitatively in three ways: self-reported compliance ratings, completion of the 12-week DIS trial, and increases in supplement markers shown by blood sample analysis. The Compliance Study used some DIS data to report on associations between the efficacy of the supplements used in the DIS and compliance. The full method used in the Compliance Study is provided in Part 3 of this thesis.

AIMS OF THE COMPLIANCE STUDY

The Compliance Study had four broad aims:

- to explore which factors were important in women's decisions regarding compliance with general treatments for depression;
- to explore whether women's compliance with the DIS supplement was associated with the same or different factors as are associated with compliance with other therapies for depression;
- to investigate whether women's levels of compliance were related to treatment efficacy in the DIS; and
- to investigate whether existing health belief theories were useful in predicting compliance with omega-3 (n-3) fatty acid supplementation therapy in depressed women.

The methodology, method and findings in relation to the Compliance Study aims are reported in Part 3 of this thesis.

THE DIETARY INTERVENTION STUDY: AIMS AND DESIGN

Aims

- to assess the relationship between omega-3 (n-3) fatty acid status, dietary intake and the severity of depression; and
- to assess the biochemical and psychological effects of n-3 fatty acid supplementation on depression.

Design

The DIS was a randomised double-blind placebo-controlled 12-week trial. Fish oil, containing n-3 fatty acids, was given to participants in the experimental group. Olive oil, which does not increase n-3 fatty acid levels, was given to the control group. A range of quantitative measures was used to assess diet, mood and related constructs. The substantive findings of the DIS are yet to be reported by Crop & Food Research.

Participant recruitment for the DIS began in May 2000, and ended in September 2001. Groups of participants undertook the DIS trial in one of several 12-week blocks from October 2000 until December 2001. Altogether 41 women and 31 men enrolled in the DIS. The Compliance Study used data collected from the women participants only. The male participants were involved in a separate master's thesis project conducted by another student member of the DIS research team.

RATIONALE FOR THE DIETARY INTERVENTION STUDY

Why Fish Oil?

Fish oil is a rich source of n-3 fatty acids (Burr, 1992). Both n-3 and omega-6 (n-6) fatty acids are polyunsaturated fatty acids (PUFAs) (Edwards, Peet, Shay, & Horrobin, 1998). Omega-3 fatty acids are found predominantly in fish, other seafood

and game, but also in canola oil (Crone, Gabriel, & Wise, 2001). Omega-6 fatty acids are consumed predominantly from seed-based oils (Adams, Lawson, Sanigorski, & Sinclair, 1996). In the last century, dietary changes in the Western world have led to an increase in the consumption of saturated fats, a decrease in n-3 fatty acids intake and an increase in the consumption of n-6 fatty acids (Hibbeln, 1998). These changes have led to an overall depletion of n-3 fatty acids in Western diets (Peet, Murphy, Shay, & Horrobin, 1998).

At the same time, there has been an increase in the lifetime risk of depression, which is not explained by other factors (Klerman & Weissman, 1989). Research has suggested correlations between increasing incidence of depressive illness and either a reduced intake of n-3 fatty acids, or imbalance between n-3 and n-6 fatty acids (Peet et al., 1998). Worldwide, the prevalence of depression has been significantly correlated with low fish consumption (Hibbeln, 1998).

The importance of PUFAs in depressive illnesses lies in their effects on cell membranes. Both n-3 and n-6 PUFAs help modulate cell function by altering the membrane microstructure through action on the membrane's phospholipid layer (Edwards et al., 1998). PUFAs also modulate levels of cell reactivity (Dyerberg, 1992). These changes can have significant effects on the activity of neurotransmitters through their effect on receptor functioning and/or receptor-effector functioning (Crone et al., 2001). Studies have shown that the n-3/n-6 imbalance referred to earlier leads to a significant increase in the proportion of arachidonic acid (AA) and decrease in eicosapentaenoic acid (EPA) in cell membranes (Adams et al., 1996; Edwards et al., 1998). Levels of AA metabolites have been shown to be significantly elevated in people with both unipolar and bipolar depression, and are correlated with the severity of disorder (Peet et al., 1998).

Studies Linking Depression and Omega-3 Fatty Acid Consumption

Links have been made between n-3 fatty acid consumption and bipolar disorder (Stoll et al., 1999). In their research, Stoll et al. conducted a four month, double-blind, placebo-controlled trial of the comparative effects of 9.6 grams daily of n-3

fatty acids from fish oil, and an olive oil control respectively, as an adjunct to normal treatment for 30 participants with bipolar disorder. They found that the experimental (fish oil) group had significantly longer periods of remission than the olive oil control group. The fish oil group also had significantly better symptom reduction than the olive oil group. The study was designed as an investigation into the effects of n-3 as a mood stabiliser. However, Stoll et al. reported that an antidepressant effect may have been operating, as most of those who were considered treatment failures from the control group were assessed as having increased depressive symptoms. Crone et al. (2001) also noted that the lack of change in the mania measure in the Stoll et al. study is indicative of an antidepressant rather than a mood stabiliser effect. Stoll et al. recognised methodological flaws in their own research. These flaws included compromising the double-blind due to the fishy aftertaste of the experimental supplement. This resulted in 86% of the experimental group guessing their group assignment, compared to 63% of the control group.

The results of the first study investigating the effects of n-3 fatty acids on unipolar depression were encouraging (Nemets, Stahl, & Belmaker, 2002). Twenty people with major depressive disorder were given either a specific EPA, ethyl ester of eicosapentaenoic acid (E-EPA) from fish oil, or an olive oil placebo for four weeks, along with their usual treatment (antidepressants in all but one case). The authors reported significant differences in Hamilton Depression Rating Scale (HDRS) scores from baseline for both groups at weeks two, three and four. However, the E-EPA group showed mean reductions in HDRS scores of 12.4 points, compared with 1.6 points for the olive oil group. Treatment and time interactions were significant. Overall, one participant on the placebo and six in the E-EPA group showed reductions in HDRS scores of 50%. Notably, Nemets et al. reported greater success than Stoll et al. (1999) in the blinding of their study, achieved through lower doses of a fish oil supplement with minimal taste and smell. The researchers recommended replication of their study with a larger sample and with a broader range of depression subtypes. They noted that the study did not allow them to distinguish whether E-EPA acted to stabilise mood when taken with an existing antidepressant, or had its own antidepressant effect.

PART 2

LITERATURE REVIEW

Chapter 3

Issues in Compliance Research

This chapter introduces some issues in compliance common across all health fields. It begins by considering the use of terminology to describe how well a treatment regimen is followed. Next the chapter outlines why compliance is an important research topic. Reasons include differential effects on treatment outcomes of prescribed treatments depending on levels of compliance, the economic costs of compliance versus non-compliance, and the difficulties associated with non-compliance in clinical research. Client perspectives on compliance, which may be quite different from clinician perspectives, are then covered. Finally, the chapter briefly reviews conceptual and practical problems associated with operationalising and measuring compliance.

MAKING THE PERSONAL POLITICAL: DEFINING COMPLIANCE AND ADHERENCE

When researching how and why people make decisions about treatments for illnesses, the logical starting point is to define the subject area one is trying to research. In the area of health decisions concerning initiating, co-operating with and continuing treatment regimens, this essentially personal choice is politically laden. Two terms are commonly used in the literature on following treatment regimens. These are 'compliance' and 'adherence'. These terms are fraught with difficulty; fundamentally because of their associations with the exercise of power in the practitioner-client relationship.

An early classic definition of compliance states that it is "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice" (Haynes, 1979)(p.1). This definition is a sensible one given the practicalities of the clinician-patient relationship in the treatment and prevention of many diseases and dysfunctions.

Generally, clinicians are assumed to “know” how to prevent or cure illness, with the full co-operation of the patient or client considered as essential for optimal results. However, the definition also assumes that the *only* reasonable or sensible course of action is for the client to follow treatment recommendations, in order to avoid or ameliorate the effects of ill health (Perkins & Repper, 1999). The very word compliance “denies legitimacy of any actions that differ from professional prescription” (Playle & Keeley, 1998). Difficulties with the Haynes (1979) definition have even been acknowledged by the original author (Haynes, 2001), though Haynes is reticent about choosing an alternative term, or redefining the existing one. He notes that “acceptance of medical advice” may be the best term of all, but settles on the interchangeable use of both compliance and adherence. It has been asserted that the term compliance conjures up a passive role for the healthcare consumer, and that “non-compliance” may imply blameworthiness or deviance (Myers & Midence, 1998).

With a shift towards informed choices in healthcare, and the recognition that the healthcare consumer is capable of pursuing an active role in collaborative treatment decisions, there has also been something of a shift towards the term ‘adherence’ (Noble, 1998). Noble has asserted that unlike ‘compliance’ the term ‘adherence’ implies a choice of behaviour, and that degrees of adherence are acceptable or allowable. Noble stated that adherence is therefore a more complex idea than compliance, which has been viewed as a black and white concept, implying that either the consumer is compliant not. In reality, treatment regimens may be accepted fully or altered in part or wholly. A regimen may be unintentionally altered if treatment advice or information is forgotten or misconstrued. Intentional alterations, on the other hand, occur if the regimen is felt to be an inadequate antidote to either the cause of the disorder or the severity of the symptoms, or the regimen is too complex or expensive to follow in its original form (Schlenk, Burke, & Rand, 2001).

A counter argument posits that in reality a patient has little power in the question of whether or not to follow treatment guidelines. Therefore the term ‘compliance’ better reflects reality and should be the preferred term (Hughes & Hill, 1997). Moreover, it has been argued that rather than ‘adherence’ being a term of

empowerment, it carries the connotation that following treatment instructions is the sole responsibility of the healthcare consumer (Raynor, 1992). It seems, therefore, that researchers are far from consensus on what term should be used to best describe a healthcare consumer's adoption and maintenance of a treatment regimen.

Despite the ideological sentiments associated with the term compliance, some of its definitions are both useful and relatively neutral with regard to locus of power and blame. One such definition (Hughes, Bagust, Haycox, & Walley, 2001) uses a 'stages of change' approach. It defines compliance as the degree to which a patient's drug dosage administration corresponds to the prescription. Hughes et al. suggested three phases to compliance as an individual moves through the treatment process:

- i. acceptance of the drug treatment and regimen during the initial patient/doctor consultation (leading to prescription redemption);
- ii. compliance with the dosage regimen; and
- iii. persistence with the therapy once initiated. (p.1187).

This definition encompasses various stages at which a healthcare consumer makes choices about a treatment regimen, and provides for the recognition of power exercised by both the healthcare professional and consumer when making those decisions. Additionally, the definition recognises that in deciding to accept or reject a treatment recommendation or plan (phase one), healthcare consumers are making their first compliance decision. The definition is, however, specific to treatments using medication.

A definition that encapsulates a wider range of treatment prescriptions (including dietary and lifestyle changes) uses three different terms to describe the process of health behaviours that are elsewhere defined as 'compliance' (Kristeller & Rodin, 1984). The definition's authors developed a 'stages of change' model of compliance, the particulars of which will not be discussed in this thesis. However, it is useful to introduce their definition of compliance and adherence:

Stage 1: Compliance – the extent to which the patient initially assents to and follows the clinical prescription.

Stage 2: Adherence – the extent to which the patient continues a negotiated treatment under limited supervision, in the face of conflicting demands.

Stage 3: Maintenance – the extent to which the client continues health behaviour without supervision, incorporating it into a general life style. (Kristeller & Rodin, p.86).

Kristeller and Rodin (1984) acknowledged the difficulties within the compliance/adherence debate, noting that:

Because of the current complexity of most medical and psychological treatments, it may be difficult to find a single word that accurately captures how changes in a treatment regimen over time impose different requirements on both the physician and the patient. In reality, the confusion over the use of alternative terms may be neither an issue of semantics nor ethics; rather the confusion may be due to a failure to conceptualise adequately a complex and dynamic process that cannot be subsumed under a single term (p.86).

In this thesis the terms ‘compliance’ and ‘non-compliance’ are usually preferred, but will be defined broadly to reflect the stage of acceptance/rejection of a treatment recommendation, and actions taken or not taken to follow the recommended regimen once instituted. ‘Adherence’ here refers to Kristeller and Rodin’s (1984) maintenance phase, wherein the treatment package is fully incorporated into the healthcare consumer’s lifestyle, not just used as a health crisis management tool.

WHY IS COMPLIANCE IMPORTANT?

There are a number of reasons for studying and understanding why people follow treatment protocols or fail to do so. First, incomplete compliance is recognised as a significant factor in treatment failure (Myers & Midence, 1998). Second, there are concerns that poor compliance contributes to escalating healthcare costs (Henry & Rivas, 2000). Third, non-compliance can make the findings of clinical trials

unreliable, or results may fail to generalise to real world treatment programmes. Researchers are therefore interested in factors that may differentiate compliance in naturalistic settings from compliance in clinical trials (Sereika & Davis, 2001; Schron & Czajkowski, 2001).

Effects on Treatment Outcomes

It may be difficult to say with certainty that following the treatment plan is solely responsible for any improvement in the condition (Myers & Branthwaite, 1992). For example, some health problems may naturally remit over time. Major depressive disorder is a case in point, with untreated episodes thought to abate between 6 to 13 months after onset (Kaplan & Sadock, 1998). Additionally, there is research that suggests that compliance and a positive outcome are not necessarily correlated (Roberson, 1992). For example, where the illness of interest is severe and compliance with treatment does not guarantee an improvement, compliance may not be highly correlated with a successful outcome. For example, adhering rigidly to chemotherapy for some forms of cancer can fail to prevent patient mortality.

Noting the cautionary comments above, research has generally shown at least a partial association between treatment compliance and clinical outcome. Haynes (2001) reviewed a number of studies designed to improve adherence with hypertension and asthma regimens. While he noted that some studies showed no clinical benefit either from the intervention per se or from greater compliance, the majority of studies did confirm that complying with the treatment package enhanced treatment outcomes. Treatment outcomes have been enhanced when compliance is high in dietary and behavioural regimens for obesity (Perri, 2001), and diabetes (Warren & Hixenbaugh, 1998). However, compliance with only one portion of a regimen, for example, taking medication as directed, does not mean that the whole regimen will be followed, or that enhanced benefits will be achieved without total compliance. Diabetes is a good illustration of this point. The treatment regimen is typically life-long and complex, requiring individuals to follow medication, diet, exercise and monitoring protocols. Warren and Hixenbaugh (1998) noted studies

showing that poor exercise or dietary compliance can result in poor diabetic control, despite there being close adherence to insulin or oral medication requirements.

Complex or onerous treatments are often associated with very severe illness. In such cases non-compliance can result in the most of serious consequences, including death. Despite this, studies have shown that the rate of non-compliance remains unacceptably high. For example, one study found that of 196 renal transplant patients, 15% could be classified as non-compliant with their medication and dietary regimen. Nearly one-third of the non-compliant group had either experienced rejection of their transplanted organ or died. This compared with only 1% of compliant patients experiencing similar treatment failure (Rovelli et al., 1989).

Issues in Healthcare Economics

When best practice treatment regimens are discontinued early, followed sporadically or incompletely, or rejected, personal and public health costs are incurred. Myers & Midence (1998) noted a 1980 report by the United States Department of Health and Human Services that estimated that, in 1979, the cost of non-compliance with just 10 drugs (including several antibiotics, psychotropics and anticoagulants) was between US\$396-792 million. If, as estimated, 30% of medications are not taken (Horne & Weinman, 1999), unused medications alone account for a substantial portion of the health budget.

Costs of non-compliance in depression are difficult to estimate. Depression is multi-factorial in aetiology, and can vary in symptomatology. Accepted forms of treatment may include any combination of various different antidepressant drugs, forms of psychotherapy and counselling, and in-patient hospitalisation. These factors make analysing the cost-effectiveness of treatments extremely complex compared with that of many other illnesses (Henry & Rivas, 1997).

The New Zealand Ministry of Health and the New Zealand Pharmaceutical Management Agency (PHARMAC) do not retain data on healthcare costs related to depression in a readily accessible form. Nor is data available on costs of non-

compliance with medication in depression kept in a form that would show treatment costs at community mental health settings, or compliance-related expenditure. This was confirmed by a 2001 Official Information Act request to both health agencies. However, there have been various estimates of the total cost of treatment for mood disorders in other countries. For example, research in the United States estimated that mortality, morbidity and care of people with depression cost nearly US\$44 billion in 1990 (Greenberg, Stiglin, Finkelstein, & Berndt, 1993).

In research into claims data from an insurance database for 2,012 antidepressant recipients (Tai-Seale, Croghan, & Obenchain, 2000), healthcare costs for compliant, partially compliant and non-compliant antidepressant users were compared. Where depression-related healthcare costs alone were considered, the fully compliant antidepressant users had the highest mean cost of healthcare (due largely to the ongoing supply costs of the antidepressants themselves), followed by the partially and non-compliant groups respectively. However, when the *total* cost of all healthcare provided (including but not limited to depression-related costs) was considered, the cost of sub-optimal compliance became apparent. It was found that total costs were lower for the fully compliant group, and highest for the partially compliant group. Moderate costs for the non-compliant group seemed due to its members not only failing to continue treatment for their depression (thus reducing depression related costs), but perhaps also failing to seek or continue treatment for other conditions, or failing to treat side effects of their antidepressant medication. The analysis of cost undertaken by Tai-Seale et al., however, did not include the downstream economic and social costs of non-compliance (such as lost productivity and marital break-down). Thus, they do not provide a complete estimate of financial burden of non-compliance with depression treatments. These may have been greatest for the non-compliant group. Nor, of course, can one quantify psychological costs associated with depression. The partially compliant group received inadequate treatment, and may have experienced more somatic complaints as a result of their mental health problems. They may also have found it difficult to adhere to the medication regimen prescribed if they experienced side effects. Again, non-medical costs were not researched, but may have been greater for the partially compliant group than the fully compliant depressed group.

Compliance in Clinical Trials

The Dietary Intervention Study did not involve a clinical trial per se, but did involve a high degree of commitment from participants similar to that expected in some clinical trials. The literature in this area may inform understanding of the compliance behaviour of participants who provided data for the Compliance Study.

The purpose of clinical trials is to assess whether prescribed treatments are effective at reducing or curing specific health problems. This cannot be tested if participants involved in a trial do not rigorously follow the treatment protocol.

Research has suggested that special conditions exist in clinical trials that can either decrease or increase the degree of treatment compliance achieved (Schron & Czajkowski, 2001). For example, when compared with following a treatment programme in a standard treatment setting, clinical trials tend to be more complex and require more of the participant, which may lead to less compliance (Sereika & Davis, 2001). However, a greater level of motivation may also exist because of a commitment to the research, or through the efforts of the research team to keep the participant “honest”. Although some studies have reported compliance rates of up to 80% in clinical trials, these findings are questionable because many measures of compliance are open to manipulation (Schron & Czajkowski, 2001). Levels of expected compliance in clinical trials are important because they impact on the design of the study (Sereika & Davis, 2001). For example, if compliance is expected to be low, participant numbers will need to be increased in order for the analysis to have sufficient power to detect effects of the treatment being appraised. Schron and Czajkowski state that:

non-adherence leads to underestimating possible therapeutic and toxic effects and can undermine even a properly designed study. High attrition rates will affect generalisability since the study’s results may apply only to those patients who comply with treatment regimens or do not experience side effects” (p.239).

Research investigating factors that influence compliance in clinical trials are reviewed next.

In a survey of people invited to participate in 26 clinical trials (Verheggen, Nieman, & Jones, 1998), it was found that both the *relevance* a person felt the trial had for reducing a health risk and their *expectancy* for the trial helped to explain decisions to either join or not join a clinical trial. General as well as specific health beliefs were seen to impact on this decision. For example, low altruistic motives and a general poor regard for medical experiments correlated positively with a high perception of risk of participating in the trial, and a lower rate of participation. Satisfaction with one's own current treatment for the specific disorder being studied in the trial also tended to reduce participation rates, while dissatisfaction with current treatment increased both the chance of participation and sense of hope attached to the trial. There were also subtle differences in the motivation for participation of people who had been ill for longer and shorter periods of time. People who had been ill for longer tended to consider the urgency of their need for treatment more when making a decision about participation in a clinical trial. For people who had been ill for less time, treatment urgency was secondary in importance to their own worries about their health when deciding to participate or not.

The Verheggen et al. (1998) study suggested that people who participated in clinical trials had different values and expectancies from people who chose not to participate. These differences may influence compliance in a number of ways. For instance, people who enter a trial may have greater expectations for positive change, or more desperation about their state of health. They may have more faith in medical professionals' abilities to make an impact upon their disease. Therefore, they may be more determined to fulfil the requirements of the trial, and see barriers to completion as less of an issue than people who do not participate.

The Verheggen et al. (1998) research investigated the utility of the Health Belief Model (HBM) in predicting who consented to participate in the clinical trials. Verheggen et al. stated that "when health motivational beliefs are defined in terms of the Health Belief Model and trial participation is regarded as illness coping behavior, patients are quite predictable" (p.122). The HBM is discussed in Chapter 5 of this

thesis.

As discussed earlier, researchers are concerned to try to improve compliance levels in clinical trials. Schron and Czajkowski (2002) outlined a number of methods used successfully for this purpose by researchers in drug trials for heart disease medication. These strategies were mainly behavioural interventions, aimed either at improving reminders to comply (such as telephone call reminders to participants) or at making compliance a habit. The authors noted that when such strategies failed to maintain or improve compliance in a clinical trial, it may be because the particular intervention failed to target the reasons for non-compliance. For example, they proposed that cues to take medication would be of little benefit if participants were asymptomatic and therefore saw no direct personal benefit in taking prescribed medication. An intervention that enhanced both belief in the benefits of treatment and motivation to comply would be more useful.

Questions have been raised about whether double-blind drug trials truly 'blind' participants and researchers to treatment status (Oxtoby, Jones, & Robinson, 1989). If the blind is not successful, it can be anticipated that both rates of dropouts from, and responders to, the trial will be differentially affected. Response effects were tested in a study where participants received either double-blind administration of different amounts of decaffeinated coffee, or deceptive administration of the same substance identified as regular coffee (Kirsch & Weixel, 1988). It was found that a placebo caffeine response was generated more effectively in the deceptive administration rather than in the double-blind condition. Kirsch and Weixel contended that that participants in double-blind trials do not have the same expectancies about treatment as those receiving treatment in a normal clinical setting. That is, in a clinical setting patients are told that they are being administered medication, and therefore expect to feel certain effects, including side effects. In a double-blind trial, participants know that they may be in the placebo condition and therefore have different expectations. This may affect both how they respond to the treatment and how compliant they are. The roles of expectation and placebo effects are explored further in Chapters 5 and 7 of this thesis respectively.

HEALTHCARE CONSUMER PERSPECTIVES ON COMPLIANCE

Recognising the value-laden nature of compliance versus non-compliance, a body of researchers has become interested in exploring and reflecting healthcare client perspectives on compliance. Much of this research has come from a nursing perspective (Schreiber, 2001; Roberson, 1992; Dukes Hess, 1996).

Healthcare professionals and chronically ill consumers do not necessarily agree on priorities. Professionals view compliance as a priority in treatment, in order to achieve the best possible clinical outcomes for their clients. However, research suggests that chronically ill people prioritise balancing symptom control, crisis prevention, normalising social interaction, financial comfort and maintaining quality of life over compliance (Roberson, 1992). The goals of the parties may not be mutually exclusive, but create vicious circles of misunderstanding and truculence can arise if mutual priorities are not recognised, understood and collaborated on. Roberson pointed out that the standard definitions of compliance may not reflect the client's understanding of the concept, or capture what the client is seeking to achieve from treatment. Her study of compliance in a group of 23 African Americans living with chronic health problems found that compliance for this group meant doing that which kept them *feeling* in good health, despite the medical opinion on their "condition". Roberson concluded that "there should be less emphasis on identifying non-compliance rates and ways to alter them and more emphasis on enhancing clients' efforts to live well with chronic illness and its treatment" (p.24).

There is a view that non-compliance is used by healthcare consumers as a means of exerting control over their lives or their health (Conrad, 1985; Casey, 2000). Research has also suggested that consumers may use non-compliance as a reaction against the way in which they are treated by doctors, and as a way of fighting the system (Zola, 1981; Wright & Morgan, 1990, both cited in Donovan & Blake, 1992). From the perspective of healthcare consumers, compliance may not even be seen as an issue at all. For them, the clinician's advice (against which one is judged compliant or non-compliant) is set against the advice of not only other health

professionals, but also family and friends, and against their own prior experience of health and illness (Donovan & Blake, 1992).

Contrary to the view that non-compliance is an exceptional occurrence, and therefore deviant behaviour, estimated levels of non-compliance suggest that it is in fact the norm, and compliance can instead be viewed as abnormal behaviour (Donovan & Blake, 1992). In their qualitative study of clients at rheumatology units, Donovan and Blake found that patients purposefully manipulated their own treatment regimens (for example, the amount, time and regularity of medication dosage). That is, they were *active* in their non-compliance. From the participants perspective, they made rational decisions about how they would use treatment, based on information from a range of 'medical' sources, the media, and significant others. Most important in this process, however, were lay beliefs, accumulated from the participants' personal histories, prior treatment experiences (of self or others) and cultures, cemented within their socio-economic contexts. Donovan and Blake noted that lay beliefs about health and illness, while generally consistent among themselves, may be at odds with modern medical knowledge.

Donovan and Blake (1992) stated that personal cost-benefit analyses, combined with the multifaceted contexts in which individuals live, are paramount in decisions about whether to follow treatment guidelines. While not explicitly referring to social cognition models of health behaviour (discussed in Chapter 5 of this thesis), their findings suggested that many of the elements identified in these models are relevant to compliance with treatment. These elements include a value-expectancy component set within a sociocultural context, a cost-benefits analysis, and a self-efficacy component (explicated in Rosenstock's (1974) Health Beliefs Model and its later developments). Self-efficacy is somewhat differently conceived of in Donovan and Blake's analysis than in most theories of health behaviour. The question their informants asked was less "Am I capable of sticking with my treatment programme?" and more "Am I capable of taking action that will meet my health goals, given other elements in my life?". These researchers found that medical advice (to comply) was not generally misunderstood or forgotten, but rather was put within the context of the individual's lay beliefs and life circumstances, which may

present barriers to compliance. Medical advice was followed if it made sense to the patient, and was possible given the patient's lifestyle and situation.

Many researchers seeking to understand the healthcare consumer's view of compliance have emphasised the need to improve relationships between healthcare providers and consumers (Donovan & Blake, 1992; Dukes Hess, 1996; Roberson, 1992; Schreiber, 2001). It is thought that such an improvement would not only assist with the provision of treatment information to encourage the healthcare consumer towards compliance, but also enhance respect for the consumer's healthcare goals. However, Dukes Hess (1996) acknowledged the ethical dilemmas facing healthcare professionals when seeking to empower the patient, especially if the patient is unable or unwilling to accept autonomy in compliance decisions.

MEASURING COMPLIANCE

A major problem encountered in compliance research is the question of how to operationalise and measure compliance (Myers & Midence, 1998).

Conceptual Problems

Conceptual problems begin at the point of deciding on compliance terminology and definitions. The terminology used reflects the researchers' philosophical views of compliance, which in turn affects what is measured and in what way (Dunbar-Jacob & Sereika, 2001). Typically, either intention to comply, or actual performance of compliance behaviours are measured (Dunbar-Jacob & Sereika, 2001).

Another question concerns what criteria are used to define 'compliant' versus 'non-compliant'. While there is no gold standard for determining acceptable or actual levels of compliance, many researchers consider a participant to be medication compliant if they have taken 80% of their doses in a designated timeframe (Hughes et al., 2001). This standard appears to have come originally from Haynes et al. (1979), who used it in a study of anti-hypertensive medications. The 80% standard

may have been linked to particular properties of the drug used in Haynes et al.'s research needed to produce a therapeutic effect having a common standard for measuring compliance may be beneficial to researchers. However, the figure of 80% seems to have been adopted somewhat arbitrarily, given that it is often unclear how much compliance is associated with treatment efficacy (Dunbar-Jacob & Sereika, 2001).

Researchers must be cautious about how any compliance standard is applied and assessed. Patterns of compliance are often hidden by the summary data collected from clients or participants. Dunbar-Jacobs and Sereika (2001) explained some patterns of compliance. For example, they stated that a person may be 80% compliant if:

- 20% of doses are missed in a row (a pill holiday); or
- 20% of doses are missed over the course of the whole treatment (missing doses);
or
- 40% of doses are missed but “extras” are taken an additional 20% of the time.

There is also a recognised phenomenon, called “white coat compliance”, whereby a person’s compliance improves in the day or two before scheduled sessions with their healthcare practitioner or researcher (Urquhart, 2001). Therefore, a summary in whatever form may obscure as much information as it provides. Choices must be made as to the important aspects of compliance that the clinician or researcher seeks to capture, and then the most appropriate measurement method available should be applied.

Methods of Measurement

Most commentators seem to agree that all methods used to measure compliance are flawed (Urquhart, 2001; Dunbar-Jacob & Sereika, 2001; Myers & Midence, 1998; Horne & Weinman, 1999). Five common measurement strategies are used:

1. Self-report methods, which are the most common. Individuals are asked to recall as accurately as possible their behaviour in relation to their treatment programme over a specific period of time. Few if any standardised measures are available. Problems with self-report measures include poor memory, especially if the report period is more than several days. Self-reports generally do not record the pattern of compliance, and a bias towards over-reporting compliance has been found (Dunbar-Jacob & Sereika, 2001). Studies have also shown that people edit or embellish the way they represent themselves to enhance their social desirability (Horne & Weinman, 1999; Herbert, Ma, & Matthews, 2001). The advantages of self-report measures include their unobtrusiveness compared with electronic monitoring, their relative ease of administrative and generally low cost, and the fact that such measures tend to be readily accepted by participants in research studies (Dunbar-Jacob & Sereika, 2001).
2. Direct biological measures, which can take a variety of forms, from observable physical changes that indicate medication has been taken, to blood tests for detection of treatments, tracer chemicals or marker metabolites (Dunbar-Jacob & Sereika, 2001; Urquhart, 2001). The blood tests for fatty acid levels conducted in the DIS are an example of a biological compliance measure. While biological measures are often able to show a sound concordance between compliance and outcome (Urquhart, 2001), they do not take into account metabolic variability between individuals, or reveal the true *pattern* of compliance (Myers & Midence, 1998). Urquhart (2001) explained that the presence of the expected substance in a biological test may show medication was taken, but usually not precisely when, or how diligently instructions were followed. Myers and Midence (1998) noted that such problems exist with many blood and urine tests, and that biological measures have low acceptability among patients when compared to self-report measures, as well as being expensive.
3. Behavioural counts, including pill counts and other direct observations of behaviour, are another compliance measurement option (Dunbar-Jacob & Sereika, 2001). While direct observations may be feasible for some treatments (such as prescribed exercise) they are rarely practical as measures of medication

compliance over time. Pill counts are frequently used as a method of estimating compliance, but are seldom reliable. People can manipulate pill counts by either saving up doses (if they have been taking extra medication) or discarding pills (if they have failed to take them as required). Horne and Weissman (1999) noted that prior warning is usually required before a pill count can be undertaken, giving ample opportunity to “rig” a result. Hughes et al. (2001) explained that pill counts average compliance over time, and therefore mask periods of both pill disposal and treatment holidays that can lead to overestimates of compliance.

4. Electronic monitoring, which has been hailed as the gold standard in medication compliance research (Burke, 2001). Devices are available which record each “medication event”, that is, each time the lid is removed from the container, or a dosage itself is removed (Burke, 2001). While not foolproof, such devices have the distinct advantage of being the only reasonably reliable way to record a pattern of compliance. Dunbar-Jacobs and Sereika (2001) found that only electronic monitoring data was associated with clinical outcome in their study of compliance with lipid lowering medication to reduce cholesterol. This finding was despite the researchers also using self-report and pill count measures. Problems with electronic monitoring include lack of acceptability to participants (Dunbar-Jacob & Sereika, 2001), and high cost (Burke, 2001).
5. Finally, clinical outcomes have been used to estimate compliance. This appears to be a more common compliance measure in clinical settings than in research (Noble, 1998). Ley (1988, cited in Myers & Midence, 1998) contended that changes in levels of compliance may not be picked up in group studies where clinical outcome measures are used. This is because clinical outcomes can lack sensitivity to changes in levels of compliance. While degree of therapeutic change and compliance are not uniformly correlated, Myers and Midence (1998) suggested that clinical outcome can be a good indicator of the level of compliance required to benefit from a treatment package.

The comments above point to a final problem in compliance measurement: the lack of concordance between measures (Myers & Midence, 1998; Dunbar-Jacob &

Sereika, 2001). Dunbar-Jacobs and Sereika (2001) argue this makes comparison of many compliance studies impossible to make.

SUMMARY

The very first question when addressing treatment compliance is what to call it. The terms 'compliance' and 'adherence' come with political shades of meaning attached. To some extent, the terminology used depends on the stance taken on issues of personal autonomy and power, and one's view of who is 'expert' in what is best for client. A useful taxonomy could be to use 'compliance' to designate that *stage* of treatment where the client agrees to undertake a recommended treatment, and 'adherence' to describe a more active decision to continue with treatment. However, most research uses the term compliance for all stages of the treatment regimen. In the findings reported in the Compliance Study, compliance and adherence will be differentiated according to the Kristeller and Rodin (1984) definition.

Compliance is important to researchers for several reasons. First, it is associated (though not invariably so) with better treatment outcomes. Second, non-compliance or partial compliance can affect healthcare costs. This was especially well demonstrated in the Tai-Seale et al. (2000) study. Third, researchers are keen to find ways of improving compliance in clinical trials, so that the exact effects of treatments *as prescribed* can be accurately assessed. Fourth, problems may arise in clinical trials that will affect compliance in ways distinct from those found in naturalistic treatment settings. These include: the often more onerous aspects to clinical trial participation when compared to naturalistic treatments; feelings of altruism or desperation on the part of participants; the effectiveness of double-blinds; and characteristics inherent in those who volunteer for clinical trials.

Qualitative researchers in particular ponder whether the concept of compliance is even relevant to people being treated for illness, as it may not reflect their health and lifestyle goals. These researchers point out that compliance with a total treatment package, without any additions or alterations, is far from usual, and that healthcare

professionals need to look at ways to both communicate appropriate information, and respect the values of their clients when designing treatment programmes.

Measurement of compliance can take many forms, none of which are guaranteed to report an objectively accurate level of compliance. Issues to consider in this regard include what is being measured (intention or performance), acceptability to the individuals concerned, type of treatment being monitored, cost and ease of administration. Multiple measures may be better than a single measure at smoothing flaws in any particular method.

The Compliance Study has attempted to address participants' perspectives on compliance, and include multiple methods of measuring compliance. It has also considered the impact of both participation in a quasi-clinical trial and treatment efficacy as factors in participants' compliance with the Dietary Intervention Study.

Chapter 4

Compliance and Depression

This chapter considers the literature on compliance with antidepressant regimens. The effects of demographic and psychological variables, antidepressant class and treatment efficacy on compliance are reviewed. A brief discussion of findings from studies into the links between compliance with antidepressant treatments and clinical outcomes follows. Finally, two untested theories concerning factors that may impact on women's compliance with treatments for depression are outlined.

COMPLIANCE WITH ANTIDEPRESSANT MEDICATIONS

In recent years research into factors which impact compliance with medication regimens for depression has increased in momentum as both the extent of personal suffering and treatment costs related to depression have become evident. Variables that have been associated with levels of treatment compliance exhibited by people with depression are outlined next.

Effect of Demographic Variables

Simon, Von Korkoff, Wagner and Barlow (1993, cited in (Demyttenaere, 2001) found that women were less likely than men to stop antidepressant treatment in the first month of treatment. Middle-aged adults were less likely than both older and younger counterparts to stop their antidepressants at that time.

Gender combined with level of impairment has been found to be associated with early dropout from treatment (Demyttenaere et al., 2001a). Women who reported improved levels of family functioning were at greater risk of earlier withdrawal than those who either did report improved family functioning, or who only reported improvements in other domains. Men were at risk of early withdrawal from

treatment if they reported an improvement in family, social or occupational functioning.

Effects of Individual Characteristics and Psychological Dysfunction

Sensation seeking personality traits have been associated with non-compliance with antidepressant medication (Ekselius, Bengtsson, & von Knorring, 2000). These researchers noted that earlier research had shown that dropouts from a behaviour modification programme for obesity were also high in sensation seeking traits. Ekselius et al. theorised that non-compliance in the sensation seeking personality group may “reflect a general inability to comply with given instructions or strict routines [rather than] a very specific attitude towards pharmacotherapy” (p. 276).

Ekselius et al.’s research measured compliance both by blood serum drug level analysis (blood test) and pill count during 24 weeks of an antidepressant programme. In all but one case, the correlation between sensation seeking personality traits and compliance was only true of those participants classified as non-compliant using the blood test results, not for participants classified as non-compliant based on pill count. The authors suggested that people who wish to conceal the level of their non-compliance with a medication regimen are more likely to “fake” pill count compliance than others.

Ekselius et al.’s (2000) findings are questionable. No differences were found between the non-compliant and compliant blood test groups in terms of responses to the antidepressant regimen used, with response failure rates of 8.0% and 8.7% respectively. The pill count non-compliant group, who were not found to be sensation seeking, had a 27% response failure rate. While compliance does not always predict treatment efficacy (Myers & Branthwaite, 1992), the validity of the blood test used as a measure of compliance in this study should be questioned. If the blood test was misleading, then the correlation found between with sensation seeking traits and compliance was also misleading. The issue, however, was not raised by the study’s authors.

In the research into compliance with depression treatments by Tai-Seale et al. (2000) (reported in Chapter 3 of this thesis), the presence of a comorbid, non-depressive mental health disorder was associated with higher treatment compliance. Most of the comorbid disorders reported were anxiety disorders. Anxiety disorders often respond well to the use of antidepressants due to shared neuropathways with depression. The authors concluded that it made sense that compliance would be enhanced in these cases, as the anxiety and depression would both abate for individuals with both disorders. They also noted that comorbid reproductive disorders decreased treatment compliance in depressed women, and suggested that this may be related to side effects antidepressants have on women's sexual functioning.

Certain characteristics of depression itself impact on people's ability or will to comply with an antidepressant programme (Stimmel, 2001). Stimmel suggested that guilt, self-blame and cognitive distortions often seen in people with depression may interfere with the depressed person's ability to recognise their illness and seek treatment, as well as their motivation to continue treatment once initiated. He also proposed that a lack of knowledge about the causes of depression and benefits of treatment may lead this group to terminate medication early.

Effect of Antidepressant Class on Compliance

Research into rates of non-compliance with antidepressant programmes has found increasing rates of withdrawal from treatment as a function of time on the drugs (Myers & Branthwaite, 1992). Simon et al. (1993; cited in Demyttenaere, 2001) found that all classes of antidepressant drugs followed a similar *pattern* of high numbers of early treatment termination, followed by a gradual decline in medication continuance over time. However, older antidepressants tended to show a higher *rate* of early treatment dropouts.

In a recent study using retrospective analysis of claims data for depressed clients of a large Health Management Organisation in the United States (Baker et al., 2001), compliance with antidepressant treatments was found to be significantly associated with the class of antidepressant prescribed. The Agency of Health Care Policy and

Research's (AHCPR's) best practice guidelines for the treatment of depression were operationalised as the compliance standard in the Baker et al. study. The AHCPR's guidelines recommended at least 6 to 12 weeks of medication to remit depressive symptoms, followed by 4 to 9 months of continued treatment to prevent relapse. Baker et al. defined compliance as "being prescribed ≥ 150 days' supply of an antidepressant (compliance with AHCPR treatment duration recommendations)" (p. 205). It was assumed that the compliance standard had not been met if prescription data showed that less than 7 months' antidepressants had been collected. In other words, it was assumed that lack of prescription data meant either that claimants had failed to see their healthcare provider to obtain further prescriptions, or had decided not to use (and therefore not submit an insurance claim for) the script given. Partial compliance was defined as being prescribed between 31 and 150 days supply of antidepressants, and non-compliance as 30 days or less.

Results showed that compliance was greater for those claimants initially prescribed a selective serotonin reuptake inhibitor (SSRI), such as fluoxetine, rather than a tricyclic antidepressant (TCA) or atypical/heterocyclic antidepressants (for example, bupropion, nefazodone or trazodone). Mean treatment duration was 193, 123 and 148 days respectively for these three antidepressant type groups. Baker et al. (2001) viewed this result as reflecting the more tolerable side effect profile of the SSRIs. However, they also pointed out that the lack of data on disease severity and dosage information may have limited their findings. These factors may affect compliance because different levels of depression severity may be correlated with the prescription of different classes and doses of antidepressants. A recognised tendency of doctors towards prescribing inadequate dosages of TCAs may also have affected claimants' decisions not to continue with treatment in the TCA group. Additionally, there was a gender bias found in the choice of drugs prescribed by healthcare providers. Women were significantly more likely than men to be prescribed an SSRI or TCA, rather than an atypical/heterocyclic antidepressant.

The previously mentioned research by Tai-Seale et al. (2000) also found that continuation with antidepressants was more probable when the treatment was an

SSRI, giving strength to the view that the tolerability of medication affects compliance.

Additionally, Tai-Seale et al. (2000) cross-tabulated type of psychotherapeutic received, medication choice and compliance status. They found that, when results were adjusted for selection bias, the inclusion of any form of psychotherapy enhanced medication compliance when compared with medication alone. Supporting the view that social support is an important variable in medication compliance, it was found that family, marital or group therapy increased compliance more than individual therapy of either short or long duration.

Effect of Treatment Efficacy on Compliance

Within three weeks of initiating treatment, between 20-60% of patients in a primary care environment terminate antidepressant therapy due to either symptom relief or worsening symptoms (Whalley & McKenna, 2000). Much of the literature on improving treatment outcomes in depression has concluded that individuals are at risk of discontinuing treatment when they feel well, even though treatment guidelines recommend the continuation of antidepressants for at least six months (Stimmel, 2001).

Demyttenaere et al. (2001a) found that when the reason for ceasing antidepressant medication was "feeling better" only 72% of respondents told their doctor of their decision. When "lack of efficacy" was the reason for discontinuing, only 60% of patients told their GP. Thus, both efficacy and lack thereof can have a major impact on compliance in depressed individuals. Communication can also impact on the quality of care their treatment provider is able to give, based on compliance information fed back by the client.

Diamond (1983, cited in Perkins & Repper, 1999) criticised clinicians for being too quick to blame the client when psychiatric patients do not show improvement, rather than questioning the efficacy of the drug prescribed. Stimmel (2001) emphasised the importance of forming a strong therapeutic alliance with the client in order to

enhance education about the need to continue treatment if it is effective, and to ensure that efficacy messages are reliably received.

EFFECT OF COMPLIANCE ON TREATMENT OUTCOME

In research designed to test the effectiveness of an education programme in increasing compliance with antidepressant medication (Mundt et al., 2001), results as to the benefits of compliance were mixed. A total of 246 participants diagnosed with major depressive disorder and with a Hamilton Depression Rating Scale score of over 17 received either usual care (no information provided beyond usual doctor's advice), or a patient education programme. The patient education programme consisted of information mail-outs at particular time points over a 7-month period. The information was not specific to any class of antidepressant, but gave advice about recovery patterns and issues of concern to people taking antidepressants. Participants' depression status was assessed through scheduled phone-ins to a computerised assessment line. Compliance was assessed from data gathered on prescription filling.

There were few significant differences found between the two treatment groups, in levels of compliance with the follow-up requirements of the study, responses to treatment, or levels of prescription filling. However, those in the patient education group did show a diminished risk of relapse once their depression scores had reduced to less than 50% of their baseline scores.

By week 30, the fully compliant group constituted only 19% of the remaining 139 participants with assessable prescription records. This fully compliant group had slightly lower scores on the depression measure, but these differences did not reach significance. Over the entire course of the research study differences between participants rated as compliant or non-compliant were either not significant or had very small effect sizes.

Mundt et al. (2001) found that participants whose depression had not improved by week 4, but who had nonetheless continued antidepressants until week 12, were more likely to terminate medication before the week 30 follow-up than participants who had shown both an early improvement and continued antidepressants until week 12. Where participants had both continued to make improvements between weeks 4 and 12, and to take medications to the end of the 30 week study, no further significant improvements were made in depression score to that end point. However, participants who were compliant at either week 12 or week 30 did show significant decreases in their levels of functional impairment at each follow-up. Therefore, the increased benefits of high levels of treatment compliance may not be obvious in the short term. The authors concluded that efforts to improve the patient education programme would be best aimed at enhancing the first 4 weeks' support, as staying on the medication beyond this point was likely to result in improved functioning and reduced dropout rates much later in the treatment protocol.

Allowing depressed people to regulate their own drug dose *frequency* (not drug amount) does not seem to improve compliance overall, or improved treatment outcome. Myers and Branthwaite (1992) found no evidence that improved compliance with an overall 75mg daily dosage of amitriptyline was associated with better treatment outcome in depressed participants. The researchers noted that this could have resulted because participants who improved most dropped out of further treatment. Alternatively, they hypothesised that the antidepressant dosage prescribed in this study was too low to be therapeutic, regardless of compliance levels. This study assessed whether allowing participants to choose the frequency of doses per day improved compliance, when compared with prescribed dose frequency regimens. Compliance improved only for the subset of participants who chose the more rigorous regimen of three 25mg doses per day, rather than one of the other two possible options (either 1 or 2 doses totalling 75mg daily). Though the compliance result was counterintuitive, Myers and Branthwaite (1992) suggested that some personality variable inherent in participants who chose this scheme may have had a special impact in this study. Obsessional traits were suggested as a possible factor, but required further investigation. However, while not reporting on clinical outcomes of treatment, another study did find that participants assigned to a once

weekly 90mg dose of fluoxetine were more compliant than those on a 20mg daily dose (Claxton, de Klerk, Parry, Robinson, & Schmidt, 2000). That research found that those randomised to a weekly dose took more doses as directed during the study period, measured through electronic monitoring. The researcher thought that the weekly dosage reduced non-compliance caused by forgetting treatment. Claxton et al. suggest that a weekly dose of fluoxetine during the continuation phase of treatment could therefore be a valuable option for the long-term treatment of depression.

FACTORS WHICH MAY AFFECT COMPLIANCE IN DEPRESSED WOMEN

As already noted, studies have found that women differ from men in their compliance with treatment, where compliance is operationalised as early treatment termination (Demyttenaere, 2001; Demyttenaere et al., 2001a). This literature review failed to identify any studies specifically focused on women's compliance with treatments for depression. However, two factors have been identified which might theoretically impact on women's compliance patterns.

It has been claimed that depressed women have a more ruminative response style to depression than men (Nolen-Hoeksema, 1990). According to Nolen-Hoeksema's theory, depressed women become more introspective than depressed men, exacerbating episodes of depression. This theory remains unproven. For example, while a study evaluating Nolen-Hoeksema's theory found that response styles did indeed influence the course of depressive episodes, no association was found between response styles and gender (Hanninen & Aro, 1996). However, should women ruminate more than men, they may focus more on the negative aspects of treatment. Women might then fail to recognise positive treatment outcomes, and consequently terminate treatment early or be less compliant.

Schreiber (1998, 2001) explored women's experiences of depression and developed a grounded theory account of their recovery from depression. She discussed the evolutionary (or, sometimes, revolutionary) process of moving towards recovery as

involving great personal growth that may lead women to reassess many aspects of their lives. This includes their approach to treatment. While not explicitly dealing with treatment compliance, Schreiber's grounded theory findings could account for why some women accept or reject particular treatment strategies, or cease to follow treatment recommendations. Personal growth is not, of course, the sole domain of women, and if relevant this factor may generalise to men's compliance as well.

SUMMARY

Many factors have been found to impact on rates of compliance with antidepressants, including the effect of time on medication. Demographic variables that are correlated with greater compliance include being female and middle aged. Women may also respond differently from men to improvements in functioning, tending to stay in treatment rather than terminate early unless family functioning improves. The presence of an anxiety disorder may also enhance compliance in depressed women, due to positive effects of treatment on anxiety via shared neuropathways. Research has suggested that a sensation seeking personality may be associated with antidepressant non-compliance, though methodological problems call this finding into question.

While all antidepressant drugs seem to have a similar pattern of continuation and dropout rates, older classes of drugs with more extreme side effects or less efficacy show a slight exacerbation of the pattern. However, this may be confounded by a lack of adequate dosage often associated with older drugs. Both a presence and an absence of efficacy may lead to early treatment termination, which may not be communicated to the healthcare provider. It has also been found that psychotherapy and social support for treatment enhances compliance with antidepressant treatment.

Mixed results have been obtained in studies assessing whether compliance with antidepressant treatments actually leads to an improved outcome for people with depression. Personality variables may mean that a subset of people with depression will be more compliant if they are able to choose their own dosage regimen.

However improved outcomes may not always result from this strategy. Mundt et al. (2001) found that there was an interaction effect between time on medication, compliance and outcome, in that early dropouts were predicted if treatment was followed for 4 weeks without improvement. Benefits of compliance may not be apparent for many weeks into the treatment regimen. Mundt et al. therefore emphasised the need to fully support early stages of treatment in order to ensure people remain on medication for an appropriate period of time.

Finally, no studies were located which specifically considered women's compliance with treatments for depression. However, gendered response styles and the process of personal growth are possible factors that could account for differential compliance patterns between men and women receiving treatment for depression.

Chapter 5

Theories of Health Behaviour

Much of the research into compliance with treatment regimens has been driven by pragmatic considerations rather than theoretical concerns, often linked to testing whether a particular intervention or educational programme enhances compliance. Such research has typically sought to identify demographic or individual characteristics that determine whether a medication will be taken as directed (Horne, 1998).

However, a number of decision-making theories have been investigated to see how well they explain treatment compliance across a range of illnesses and populations. One group of decision-making theories stems from the same broader theoretical base of social cognition and value expectancy theory. This theoretical basis is introduced very briefly. The chapter then provides a brief overview of five selected frameworks sharing this heritage, which have been used to try to explain various health behaviours. These frameworks are: Fishbein's Theory of Reasoned Action (TRA); Ajzen and Fishbein's Theory of Planned Behaviour (TPB); Prochaska and Velicer's Transtheoretical Model (TM), as representative of stages of change models; Leventhal's Self-Regulatory Model (SRM); and Rosenstock's Health Belief Model (HBM). This list is not exhaustive, but comprises those decision-making theories that seem to have the most potential to explain women's compliance in depression.

The HBM is introduced in greater detail than the other four theories, and two meta-analyses of HBM research are summarised. There are several reasons for this. First, most of its components are contained within the TRA, TBA and SRM, albeit in a different guise and differently weighted. Second, the HBM has been the best researched of these frameworks with regard to health decisions. Third, while all of the theories of health behaviour reviewed were used to enhance theoretical sensitivity in the Compliance Study data analysis, the HBM was used as a point of entry to explore compliance quantitatively. No one theory was adopted as an accepted

standpoint for the research, however. Each theory was compared and contrasted with the emergent grounded theory and components confirmed or distinguished on a reasoned basis.

THEORETICAL UNDERPINNINGS

Social cognition theories of behaviour focus on the subjective assessment of the world made by the actor (Wallston & Wallston, 1984). This broad group of theories emphasises different cognitions within a sociocultural context (Horne, 1997), and construes behaviour as the result of rational decisions based on how people perceive and interpret information.

Value expectancy theories form a subgroup of social cognition theories. They postulate that when choosing freely between alternative behaviours or actions, people will choose the behaviour or action that maximises the potential for good outcomes, and minimises the potential for bad outcomes (Carter, 1990). The quality of “desirability” of any outcomes depends on the *value* attached to it by the individual, and therefore is subjectively assessed. The subjective probability that a behaviour is both achievable and will produce the desired outcome, is called its *expectancy*. Expectancies are shaped by an individual’s personal reinforcement history, and by observations of consequences of the same behaviours for other people. If a person wants to avoid or ameliorate illness (value), any course of action taken by them to protect or improve their health would then be considered in terms of both achievability and efficacy, based on prior experience or knowledge (expectancy).

Of the five theoretical frameworks considered in this chapter, the TRA, TPB and HBM have the closest links to value expectancy theory. The TRA and TPB are theories of general behaviour that have been applied to health behaviours (Ajzen & Fishbein, 1980). In contrast, the HBM (Rosenstock, 1974) is a value expectancy theory developed specifically to explain health behaviour.

THE THEORIES OF REASONED ACTION AND PLANNED BEHAVIOUR

Fishbein's Theory of Reasoned Action (TRA) (Ajzen & Fishbein, 1980) emphasises the individual's behavioural intention (Carter, 1990). Intention is influenced by two factors: attitude towards the behaviour (value-expectancy beliefs), and subjective norm (combining the probability that important others approve of a course of action, and motivation to comply with those opinions). Subjective norm has been described as social pressure for or against a particular course of action (Conner & Sparks, 1996).

While the TRA has been used to predict a wide range of health decisions with some limited success (Miller, Wikoff, & Hiatt, 1992), it has been criticised for failing to account for non-volitional behaviours (Horne & Weinman, 1998). It was expanded in part to resolve this issue. The expanded framework, the TPB, accounts for non-volitional behaviour by introducing the perception of behavioural control (Rutter & Quine, 2002). The TPB asserts that complex behaviours will not occur in the absence of ability or resources needed to take the action in question (Conner & Sparks, 1996). In other words, individuals assess whether an action is easy or difficult, given their view of their own internal and external resources. In broad terms, perceived behavioural control equates to self-efficacy (this is discussed later with reference to the expansion of the Health Belief Model), but incorporates the concept of barriers to action. Figure 1 depicts the TRA and TPB diagrammatically. Figure 1 shows that perceived behavioural control has both an indirect influence on intention (as with subjective norms and attitude towards behaviour), and a direct effect on behaviour (Jones, Harris, & McGee, 1998). Conner and Sparks noted that perceived behavioural control has been broadly defined to include both internal and external obstacles to action, including emotional obstacles and dependence on other people.

The TRA and TPB seek to predict health behaviour outcomes by ascertaining where an individual is positioned on certain belief continua, and allow for bi-directional movement along those continua at any stage (Rutter & Quine, 2002).

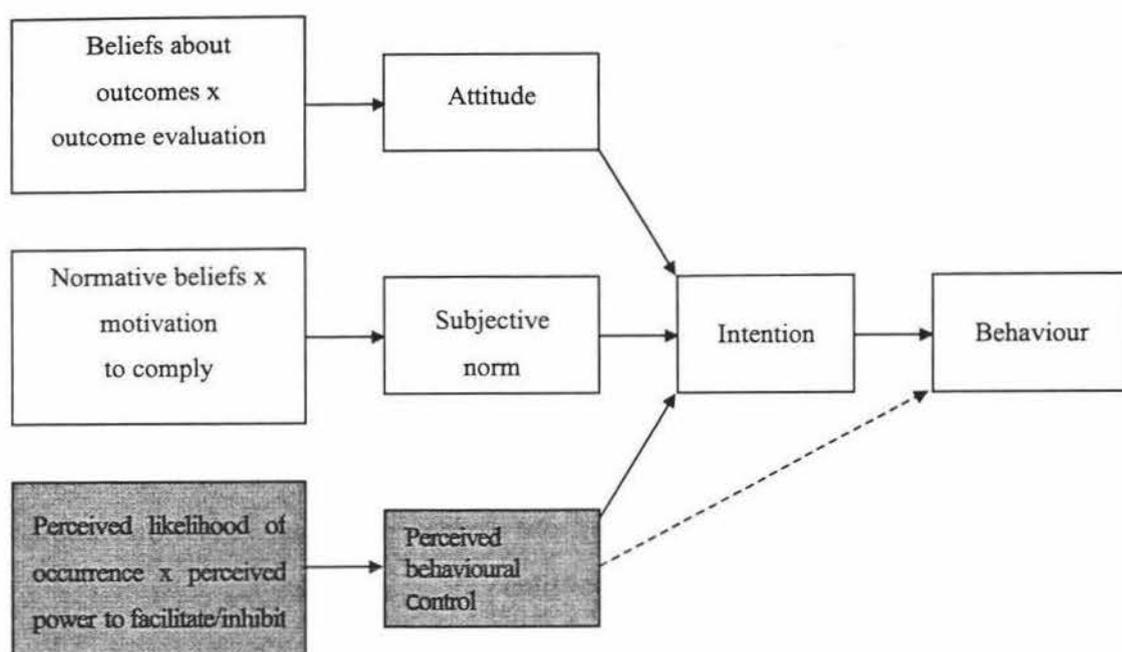


Figure 1 The Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB). Sourced From Rutter and Quine (2002). Components unique to the TPB are shaded.

Both the TRA and TPB require that the content of the individual constructs be evaluated in the context of the relevant health problem (Carter, 1990). Items of TRA and TPB measures should be developed from extensive pilot studies to be thoroughly grounded in the world of those making particular health decisions (Rimer, 1990). Accordingly, the TRA and TPB work best when resources are available to conduct pilot research on a sample of those affected by the illness in question, or targeted for public health intervention. Information on which attitudes and beliefs are salient when forming an intention to act is elicited in pilot studies and then applied in a larger scale research design (Carter, 1990).

Both models add some value predicting health behaviours, though they can be difficult to operationalise successfully, and reports of predictive ability vary widely (Conner & Sparks, 1996). However, while both the TRA and TPB may successfully

identify beliefs that impede desirable health behaviours, they have been criticised for failing to explain how to change salient beliefs once they have been identified (Sutton, 2002). Sutton notes however that this criticism can also be made of most other theories of health behaviour.

An additional criticism of these frameworks is that they do not account for situations where an individual refuses to take action when faced with a dire health threat. Because both the TRA and TPB are theories of rational behaviour they fail to explain how irrational behaviour arises (Horne & Weinman, 1998). For example, they do not explain why an organ transplant patient would fail to take anti-rejection drugs needed to remain well, or why people ignore dietary advice and expose themselves to a significant risk of heart disease and diabetes.

STAGES OF CHANGE MODELS

Stages of change models utilise concepts common to other social cognition models, such as the importance of beliefs, social norms, and self-efficacy. However, unlike the TRA or TPB, stages of change models see individuals as making health decisions in a series of discrete movements based on readiness to take action, rather than at points on a cost-benefits analysis continuum. Instead of attempting to predict behaviour based on knowledge of particular beliefs, these models attempt to classify people according to their decision-making stage. Interventions are then commonly targeted at helping people to overcome stage-related barriers to reaching a desired end state (Weinstein & Sandman, 2002). Barriers at each stage of change are thought to be differentiated from each other.

The most widely cited stages of change model is the Transtheoretical model (TM) (Prochaska & Velicer, 1997). The TM was initially developed with regard to smoking cessation programmes. According to this model, people move through five stages: precontemplation (unaware of a health problem or not considering change), contemplation (thinking about taking action), preparation (intending to take clear action in the future), action (actively trying to change health behaviour) and

maintenance (continued efforts to prevent relapse) of a health-related behaviour (Horne & Weinman, 1998). While acknowledging relapse as a possibility, Prochaska and Velicer saw these five stages as relatively fixed and immutable, notwithstanding that people may cycle through them a number of times before achieving success.

Stages of change models recognise that health-related cognitions change over time, and that particular cognitions are more salient at some times than at others (Horne & Weinman, 1998). Targeting particular cognitions and providing the impetus to change or act upon them at critical points may result in better compliance with treatment. Weinstein and Sandman (2002) have stated that while targeting interventions at common barriers in different stages of change is likely to enhance treatment outcomes, it also adds to the complexity and expense of testing the validity of stages of change theories, and of treatment.

Criticism has been levelled at the TM, and other stages of change variants, for failing to explain how motivation to continue a behaviour is sustained through to the maintenance phase (Horne & Weinman, 1998). The TM has not been applied specifically to issues of compliance with treatment in a mental health context.

SELF-REGULATORY MODEL

One way to account for bewildering or nonsensical health decisions is to consider the impact of emotions on the actions people take. Like Prochaska and Velicer's (1997) TM, Leventhal's Self-Regulatory Model (SRM; Leventhal, 1980, cited in Horne, 1997), emphasises the dynamic nature of the decision-making process. Unlike the TM, the SRM also acknowledges the importance of emotion in making decisions about health-related matters.

The SRM essentially posits that the patient or client is an active problem solver in matters concerning their own health, and may choose action or inaction, logical or illogical behaviours, as a common-sense strategy for dealing with a health threat,

based on an illness representation. An affective fear of illness is acknowledged as one of the drivers of the threat appraisal. A person forms a representation of an illness based around a number of themes and questions: identity ("what is it?"), timeline ("how long will it last?"), cause ("what caused this?"), consequences ("how does/will it affect me?"), and cure/control ("can this be cured or controlled?") (Horne, 1997).

The dynamic nature of the SRM comes from the appraisal of coping strategies (treatment) that have been tried or recommended. Mutually influential feedback loops are created by the simultaneous processing of three elements: forming an illness representation and illness meaning, developing and executing a plan for dealing with the illness, and appraising the outcome of the plan. In the process, cognitive, emotional and behavioural processing occur in parallel (Horne & Weinman, 1998). Coping strategies will be rejected if they do not fit, given a particular individual's illness representation. Horne (1997) reviewed particular elements that appear to be pertinent in forming an illness representation and in appraising treatment efficacy. Among them are general and specific beliefs about medications, such as concerns about being controlled by drugs, which contribute to illness meaning (for example, "I am no longer in control"). Illness representations may change following the appraisal of a coping strategy. Leventhal (1980) emphasised the importance of concrete symptoms in guiding both the illness representation and appraisal of treatment efficacy. As Horne summarised it, "adherence is more likely if there is a high degree of coherence between the abstract (ideas) and concrete (symptoms) aspects of the illness representation, and if the healthcare provider's advice makes sense in the light of the patient's own experience and representations" (p.158). He notes that healthcare providers may need to actively enquire about aspects of the illness representation that may not emerge readily in consultations, such as their general perceptions of medication, and specific treatments in particular (Horne, 1999).

While the SRM theoretically has great utility for predicting and exploring medication compliance, few studies have used it in this way. No research could be located that used this theoretical framework to assess medication compliance in a mental health

setting. Horne and Weinman (1998) suggested that the complexity of the model may make it more difficult to put into practice than any of the other social cognition models. However, the SRM's acknowledgement of emotional content in health decision-making, its emphasis on the dynamic nature of the decision-making process, and the concept of developing meaning from illness, could help in assessing why people with depression choose particular treatment pathways.

THE HEALTH BELIEF MODEL

Concepts underlying the modern HBM were first developed in the 1950s by social psychologists working in the United States Public Health Service as a tool for understanding people's decisions and behaviour related to tuberculosis screening (Rosenstock, 1990). By that time, it had already been established that health behaviour was correlated with demographic characteristics such as gender, age, socio-economic status and educational level. However, there was no clear mechanism by which they influenced the decision-making process.

In early research, both perceived susceptibility to tuberculosis and perceived benefits of screening asymptomatic individuals by x-ray were able to discriminate between people who took up the screening option, and those who did not (Sheeran & Abraham, 1996). Beliefs were seen to be the intervening, modifiable mechanism by which demographic variables had an effect on individuals' decisions for or against health action (Sheeran & Abraham, 1996). In the subsequent twenty years, perceived severity and perceived barriers to action were identified as elements that contributed to predicting variance in a population's acceptance of preventive health action (Rosenstock, 1974). These two elements were added as basic components of the Health Belief Model.

Since then, the HBM has become one of the most accepted and tested frameworks for evaluating individuals' decisions on health related behaviour (Rutter & Quine, 2002). When critiquing competing theories of health-protective behaviour, Weinstein (1993) stated that the HBM was one of the four most frequently used

models of health behaviour, based on a literature search of the PsychLit database. More recently, a Medline search covering the 1974-1994 period found that 64% of all the identified health behaviour articles employed the HBM (Clarke, Lovegrove, Williams, & Machperson, 2000).

While initially researched almost exclusively within the preventative medicine framework with physical disease threats, the HBM has been expanded and explored to include sick role behaviour. Put simply, sick role behaviour consists of “those things that people who consider themselves ill do in order to get well” (Perkins & Repper, 1999). Numerous health researchers have looked at sick role behaviour, including compliance decisions, using the HBM in a variety of contexts. These include diabetes management in both adults (Wdowik, Kendall, Harris, & Auld, 2001) and adolescents (Bond, Aiken, & Somerville, 1992), follow-up appointment keeping in emergency department admissions (Jones, Jones, & Katz, 1991), cardiac rehabilitation compliance and dropouts (Oldridge & Streiner, 1990), and medication adherence in people with psychiatric illnesses (Budd, Hughes, & Smith, 1996; Cohen, Parikh, & Kennedy, 2000; Kelly, Mamon, & Scott, 1987).

Basic Elements of the Health Belief Model

The HBM has been modified over time and in different circumstances to include a range of variables. Two of these are discussed later in this chapter. However, at its core are the original four constructs used in public health research. These are: perceived susceptibility, perceived severity, perceived benefits, and perceived barriers. All four components are based on the subjective evaluation of the individual concerned (Rosenstock, 1990). The basic Health Belief Model, incorporating cues to action (discussed in this chapter), is shown in Figure 2.

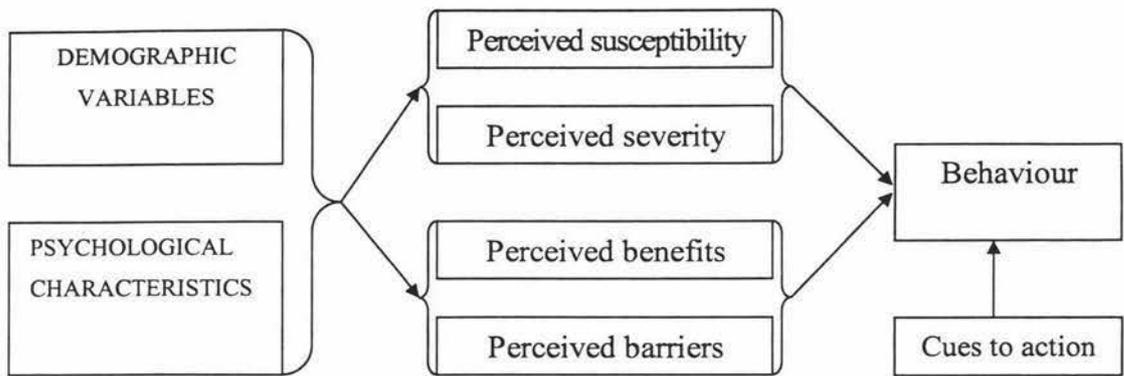


Figure 2 The Health Belief Model, Incorporating Cues to Action. Adapted from Rutter and Quine (2002) and Sheeran and Abraham (1996)

Fundamentally, the basic HBM theorises that a person will take a health action to prevent or ameliorate an illness, including complying with treatment requirements, if he or she believes:

- they are vulnerable to the illness;
- the illness has serious consequences;
- the action under consideration will be effective at reducing the illness threat; and
- there will be minimal difficulties or side effects (Rosenstock, 1974).

Perceptions of each basic component are influenced by demographic variables such as age, gender and level of education, as well as psychological characteristics, of the individual (Rutter & Quine, 2002). For example, gender would influence perceptions of illness threat for prostate or breast cancer, and increasing age might increase the perceived threat of diseases such as heart disease and dementia. In a specific demographic finding with respect to the HBM, older age has been associated with increased barriers to compliance with medication because of poor prospective memory (Ellis, 1998).

In preventive and public health research, perceived susceptibility refers to an individual's evaluation of their vulnerability to a particular health risk. Examples include the risk of injury if child restraints are not fitted in cars (Harrison, Mullen, & Green, 1992) and risks of diet-related illness generally (Sapp, 2002).

Where the disease state already exists, Rosenstock (1990) notes that research has at times operationalised perceived susceptibility to include estimates of the likelihood of getting the disorder again, of susceptibility to illness generally, and of acceptance of diagnosis. In a mental health context, perceived susceptibility has been operationalised as susceptibility to relapse of schizophrenia (Budd et al., 1996) and acceptance of diagnosis of bipolar disorder (Keck, et al. 1996, cited in Cohen et al., 2000).

Perceived severity of illness may include evaluations of both physical and social consequences (Rosenstock, 1990). For example, while a person may assess the physical consequences of alcoholism as being negligible, they may perceive the social consequences (for example, family and occupational disruption or breakdown, risk of legal consequences) as severe. Generally, studies of existing medical conditions have asked participants to rate the severity of their condition but have not included a specific differentiation of physical and social effects.

Together, perceived susceptibility and perceived severity make up the construct of perceived threat. According to Rosenstock (1974), while acceptance of a serious threat will produce a "force leading to behaviour, it does not define the particular action that is likely to be taken" (p. 332). This is assessed using a type of cost-benefits analysis, weighing the perceived benefits and barriers to particular courses of action.

In order for a health consumer to take a proposed action, the perceived benefits of doing so must be maximised. Thus, the action should be seen as effective at reducing or eliminating the illness threat by reducing perceived susceptibility, severity, or both (Rosenstock, 1974).

Perceived barriers is the remaining basic element of the HBM. While a treatment may be considered efficacious, it may also be under-utilised if aspects of adhering to the regimen are perceived as onerous, dangerous, uncomfortable or inconvenient (Oldridge & Streiner, 1990). There has been a call to acknowledge that “barriers” may well incorporate not only medical and financial risks and costs, but also unwanted effects on other aspects of people’s lives (Hughes & Hill, 1997). For example, despite a high degree of clinical efficacy a woman may decide that the negative impact of taking an antidepressant is too high, if her partner views the medication as unnecessary or is worried about side effects. Note that the possibility of such an effect is specifically accounted for in the idea of subjective norm in the TRA and TPB, but not in the HBM (Weinstein, 1993).

RESEARCH FINDINGS INTO BASIC ELEMENTS OF THE HEALTH BELIEF MODEL

A major meta-analysis of 29 post-1974 and 17 pre-1974 studies that used HBM constructs was carried out in the early 1980s (Janz & Becker, 1984). Overall, Janz and Becker found that “these investigations provide very substantial empirical evidence supporting HBM dimensions as important contributors to the explanation and prediction of individuals’ health-related behaviours” (p.41).

Janz and Becker (1984) divided the 46 studies into three categories: those that looked at preventive health behaviours (e.g. influenza vaccination); those that dealt with sick role behaviours (e.g. compliance with medication and dietary regimens in diabetes patients); and clinic utilisation (e.g. appointment keeping and frequency of medical services used). Within each category, they grouped the studies into those that were retrospective, and those that were prospective in nature. For each of the four core HBM constructs, they created a significance ratio, calculated by adding the number of statistically significant positive findings for any dimension, and then dividing the total by the number of studies that reported significance levels for that dimension. Based on this method, they found that perceived barriers, with a significance ratio of 89%, was the HBM construct most significantly associated with health behaviours. Susceptibility (81%), benefits (78%), and severity (65%) were next in rank order.

Those studies that looked at preventive health behaviour ($n = 24$) tended to rank susceptibility to be of higher predictive value than those that looked at sick role behaviour ($n = 19$), although perceived barriers still assumed primary importance in explaining and predicting health related behaviours. Janz and Becker (1984) suggested that this may be because of difficulties in operationalising susceptibility where individuals have already been diagnosed with an illness, since susceptibility has already been confirmed. Conversely, perceived severity assumed greater importance in the sick-role behaviour studies than in the preventive health behaviour studies. Again, Janz and Becker suggested that this concept has far more salience for people already living with an illness than those merely contemplating preventative action.

Of the studies Janz and Becker (1984) included in their analysis, 19 assessed some aspect of sick role behaviour, mostly compliance related. Most of these studies occurred in the 1974-1984 period. Before that time the HBM was mainly used as a framework for understanding preventive health actions, including decisions on vaccination, diet, exercise and mammography screening. However, even among the later studies in the Janz and Becker (1984) review, none involved a mental illness.

Janz and Becker's (1984) review has been criticised by Rosenstock and his colleagues (Rosenstock, Strecher, & Becker, 1988) for including measures of self-efficacy in the perceived barriers component. Rosenstock et al. described barriers as a catch-all component, and remarked that the quality of HBM research would benefit from reducing its scope rather than expanding it. Therefore, if measures of self-efficacy were separately evaluated, the high significance ratios perceived barriers achieved across Janz and Becker's categories would be reduced, and the relative contributions of the basic HBM components would need to be reassessed.

While strongly supportive of the usefulness of the HBM framework, based on the empirical evidence they reviewed, Janz and Becker (1984) had many criticisms of the methods used in the research included in the meta-analysis. These criticisms fall into several broad categories. First, the lack of generalisability of many of the studies due to their retrospective nature, or the use of small or homologous samples.

Second, the inconsistent or even dubious operationalisation of the four basic elements of the HBM. For example, in a study that assessed relationships between attitudes and beliefs around drink-driving behaviours, perceived effectiveness (combining perceptions of both benefits and barriers) of a health action was operationalised by asking how good individuals thought they would be at avoiding detection by the police while drink-driving. This question does not assess the value placed on taking up a recommended health action. Third, the lack of standardised tools for measuring health beliefs. As well as contributing to a lack of validity and reliability of data being reported, these reviewers saw inventing novel measures as reinventing the wheel, and creating problems when trying to compare findings.

These criticisms have been repeated (Champion, 1984; Horne & Weinman, 1998). The problems outlined make it difficult to judge how much variance in health-related behaviours the HBM elements explain. Some attempts have been made to use well validated instruments to measure HBM variables. For example, Champion (1984) outlined both a development procedure and possible content for an instrument assessing the utility of the HBM in the context of a preventive health behaviour (breast self-examination). This instrument could be adapted for use in other contexts. However, the use of diverse measures and operational definitions of concepts, and the inclusion of some HBM components but not others, remains widespread.

A more recent meta-analysis of HBM studies (Harrison et al., 1992) found somewhat less utility in the HBM. In contrast to Janz and Becker (1984), Harrison et al. had very strict inclusion criteria for their analysis and netted only 16 qualifying studies for the period between 1966-88. To qualify, research had to concern adults only, be published (although not as a dissertational abstract), relate to a particular health behaviour, and include all four basic elements of the HBM. The small number of qualifying studies largely demonstrated the failure of researchers to operationalise all components of the model.

Harrison et al. (1992) employed a somewhat different method in their analysis to that used by Janz and Becker (1984). Harrison et al. formulated weighted average effect

sizes for each HBM component, based on the individual study effect sizes. Overall, they found that each component accounted for between 0.5 and 4% of variance. These levels are much lower than those reported in the 1984 meta-analysis. However, Harrison et al. noted that the combined effect may be much greater than the individual component effects. Like Janz and Becker, Harrison et al. stated that differences in conceptualisations of components may have contributed to the poor predictive ability of the HBM.

EXPANSION OF THE HEALTH BELIEF MODEL

Several additional components have been included in the HBM over time. These include self-efficacy and cues to action.

Self-Efficacy

In 1988 self-efficacy was suggested as a separate variable that could be added to the HBM to improve the model's ability to explain variations in health behaviour (Rosenstock et al., 1988). The concept of self-efficacy was developed by Bandura (1977) as part of his social cognitive theory (SCT, originally called social learning theory). As noted earlier, self-efficacy had often been considered as part of the perceived barriers component of the HBM until this point.

SCT is a complex theory incorporating a number of variables that are beyond the scope of this review. It explains behaviour as a "triadic, dynamic and reciprocal model in which behavior, personal factors (including cognitions) and environmental influences all interact" (Perry, Baranowski, & Parcel, 1990). SCT posits that expectancies determine behaviour. There are three types of expectancies: expectancies about environmental cues; outcomes of one's actions (outcome expectancies); and competence to take the action required to produce the desired outcome (self-efficacy expectancies). Each type of expectancy is shaped by reinforcement histories as outlined in the discussion of value expectancies.

SCT proposes that one's expectancy of personal mastery of a task affects both the decision to proceed with a particular behaviour, and of particular relevance here, to show persistence in that behaviour (Bandura, 1977). Bandura stated that efficacy expectancy is gained through four sources. In order of strongest to weakest source, these are: performance accomplishments (mastery by doing); vicarious experience (mastery modelled by others); exhortation (verbal encouragement by others); and emotional arousal (feedback from one's physiological state). Each source and the information processed through it is, of course, open to interpretation. Self-efficacy expectancies can be affected not only by the strength of the information received, but also by the effects of cognitive appraisal. Cognitive appraisals can include distinguishing successful mastery or modelling on the grounds that it was achieved under optimal conditions, which are unlikely to be repeated again. For instance, performing a previously avoided task in therapy may not enhance self-efficacy if the client perceives that the task was accomplished under conditions of safety, which will not be present in the real world. Alternatively, causal attributions may interfere with an enhancement of self-efficacy. Believing an achievement to be a fluke, rather due to ability or effort, may not enhance a sense of mastery despite strong information to the contrary. This differential processing of self-efficacy information may lead to the same information affecting motivation and persistence differently across individuals. For example, by watching a friend successfully cope with a difficult treatment regimen one person may take heart that the rigours of treatment can be overcome. Another person, however, may attribute the success to their friend's personal characteristics, and believe those traits are not shared by themselves.

Rosenstock et al. (1988) pointed out that the failure of the original HBM to include a self-efficacy component probably stemmed from its roots in public health. Little self-efficacy is required to follow through on a single action, such as undertaking screening for tuberculosis, or getting a vaccination against influenza. However, those situations are different from the sustained health behaviours that are now often the realm of research. These include preventive lifestyle changes to induce weight loss, compliance with medication, and compliance with lifestyle and appointment-keeping regimens required in many acute and chronic illnesses.

Rosenstock et al. (1988) saw benefits to adding self-efficacy to the HBM, as both an expectation about outcome (benefits and barriers) and an expectation about an individual's capacity to carry out the required behaviour are prerequisites to action being initiated. Having self-efficacy as a separate dimension in the HBM would lead to greater specificity of the perceived barriers dimension, and help refine the predictive ability of the model. They argued that, despite the early omission of self-efficacy, the concepts of SCT and HBM are closely related. For example, Rosenstock et al. saw environmental cue expectancies as similar in scope to the two perceived threat variables in the HBM, while outcome expectancies are equivalent to perceived benefits minus perceived barriers.

There are strong arguments for including self-efficacy as an explicit variable in HBM research designs. Despite this, the variable is still not uniformly included in current research designs. A search of the PsychInfo database for the years 1995-2002 identified only 26 articles detailing new research that explored any combination of HBM variables and self-efficacy. Of these, 11 involved research into safe sex practices (Smith & Stasson, 2000). The remainder covered diverse health issues, including compliance with an occupational therapy programme (Chen, Neufield, Feeley, & Skinner, 1999), cancer screening behaviour (Savage & Clarke, 1996; Katz, Meyers, & Walls, 1995), and even predictors of recycling (Lindsay & Strathman, 1997). None, however, dealt with any mental health issue. The same search in the Web of Science database yielded 34 additional studies using at least one basic HBM component plus self-efficacy. These included one study investigating a mental health topic, bulimia (Smalec & Klingle, 2000). This study examined the effectiveness of messages designed to persuade people with bulimia to seek help for their condition. Here, the efficacy variable combined both self-efficacy and outcome efficacy (defined previously) which makes it difficult to account for variance in behaviour according to the HBM.

Cues to Action

The second component suggested for an expanded HBM is cues to action. Rosenstock (1974) noted that while the threat of ill-health provided the motivation to

act, the action pathway is determined by the cost-benefits analysis individuals undertake when assessing benefits and barriers. Even then, without a trigger to act, there may be no actual steps taken along the chosen pathway. So, the concept of a “cue to action” was developed. Acting as the impetus to begin the health decision process (for example, to decide to take medication or not), cues to action are internal or external stimuli that perform the role of a trigger (Horne & Weinman, 1998). The spread or increase of symptoms of disease, or anxiety about the possibility of illness or accident may be internal cues to action. Reminder cards, comments from significant others, media advertising campaigns, or discussions with a health provider may all be external cues to action. Cues to action are thought to operate directly on the behaviour itself, as represented in Figure 2.

Janz and Becker’s (1984) review of HBM research mentioned that “cues to action” had been added to the HBM, but that few studies had tried to assess its impact in the previous 10 years. Their review noted only three studies that specifically included a “cues to action” component. Harrison et al. (1992) noted that “cues to action have received so little attention in empirical studies that we excluded this dimension” (p.109).

SUMMARY

While pragmatic concerns have often driven compliance research, there are a number of theoretical models that seek to predict health behaviour. The dominant group of theories stems from social cognition and value expectancy theories. The five frameworks of health behaviour outlined here all share this base, so have developed theories that seek to explain the behaviour of individuals in their environmental context.

The Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB) are general theories of behaviour that have been applied to health decision-making, including compliance decisions. These theories emphasise intention to act. Intention is shaped by value expectancy beliefs towards behaviours, called attitudes, and by

the perceptions of the subjective norm with respect of the target behaviour. The TPB represents an expansion of the TRA and considers perceptions of behavioural control (similar to self-efficacy) to be important to the decision-making process. The TRA has been criticised for failing to explain non-volitional behaviour. Both the TRA and TPB predict health behaviour by assessing a person's position on belief continua. Both have been criticised for failing to account for irrational inaction in the face of extreme threats to health.

Stages of change models, such as the Transtheoretical Model, utilise the concepts of beliefs, social norms and self-efficacy slightly differently from the TRA and TPB, in that they emphasise these variables in distinct ways at different decision-making stages. Stages of change models target cognitive barriers commonly encountered at particular points in the health decision-making process. They recognise that people at different points in the process will have different concerns that may impact on their treatment compliance. Criticisms of the stages of change models include a claim that targeting different cognitions at different stages is too complex, and that the models fail to account for sustained behaviour through to the maintenance phase.

Leventhal's Self-Regulatory Model advances a step further by explicitly considering how emotions affect people's decisions. Rather than assuming decisions are completely rational within the context of a person's knowledge and environment, people may choose to actively engage or not, to be logical or not, when faced with an illness threat. People form illness representations based on identity, cause, time-line consequences and possibility of cure or control. Coping strategies (treatments) are evaluated according to cognitive, affective and behavioural dimensions. These dimensions are assessed simultaneously and are mutually influential, so constantly changing evaluations are to be expected. While the SRM has appeal for research into issues of medication compliance, its complexity makes it more difficult to use as a framework than many other models.

The Health Belief Model (HBM) was specifically developed to assess and predict health behaviour in a public health setting, but has been applied more generally over time. It is the most widely used model of health behaviour according to recent

literature reviews and has been used specifically in compliance research. The HBM consists of four basic components: severity, susceptibility, benefits, and barriers. Each component may be very broadly defined to include impacts beyond the illness state itself, such as impacts on social or occupational functioning. Demographic and psychological characteristics shape perceptions of the basic components given a particular health threat. Proponents believe that if the basic variables are known, then behaviour can be predicted. However, HBM research has been criticised as not being sufficiently valid, reliable or generalisable. This is because of inconsistent operationalisation of constructs, use of small, homologous samples, and a lack of standardised assessment tools to measure HBM elements.

The HBM postulates that people essentially conduct a cost-benefit analysis: given a particular perceived threat (severity and susceptibility), “what course of action is most likely to reduce the threat to me (benefits) while minimising any onerous, dangerous or inconvenient consequences for me (barriers)?”.

The HBM seems to be most useful in predicting uptake and compliance with preventive health behaviours. Difficulties have arisen in the past when attempting to operationalise the concept of susceptibility in sick role research, because the illness threat has in fact materialised already.

The HBM has been expanded to specifically include Bandura’s (1977) concept of self-efficacy, in part to pare down the scope of the barriers component in the original model. Self-efficacy refers to the expectation of personal mastery that will lead to both positive action and persistence in that action. As for the basic HBM components, cognitive appraisal influences the self-efficacy perception. Thus, prior or current mastery may be attributed to luck or special conditions that will not be repeated again, and thereby negate the impact of the potentially positive feedback. Despite a call for the inclusion of self-efficacy in the HBM since the late 1980s, researchers have failed to use it consistently.

Cues to action has also been added to the basic HBM. These are internal or external triggers to carry out a health-related action. Again, reviews suggest that cues to action have only been sporadically researched.

The HBM, incorporating self-efficacy, was adopted as the basis for the quantitative component of the Compliance Study reported here. The decision to look at the HBM was based on both administrative and theoretical considerations. The TRA, TPB and SRM were considered too complex for this initial exploration of issues in compliance in depression. A pilot study to assess the necessary components of the models was not possible. The Dietary Intervention Study (DIS) did not allow for an exploration of stages of change models, as the same intervention was to be applied to all participants at all stages of depression. Cues to action were not measured or manipulated in the DIS itself, as doing so may have reduced the quality of the data collected in the DIS. However, the Compliance Study set out to assess what factors shape compliance in women with depression, including whether beliefs formed in a sociocultural context impact on treatment compliance. Given the limitations outlined above, the HBM was the logical framework for a quantitative assessment of the impact of beliefs and attitudes towards compliance. Despite its limitations, the HBM has been well researched and critiqued, and has even been applied in some mental health contexts.

Theoretical sensitivity to compliance issues was enhanced by considering all five health behaviour frameworks. No theoretical standpoint was adopted, but rather the grounded theory that emerged from the data was compared with each framework. This allowed an assessment of consistency with prior findings (Stiles, 1990) to be made from an informed standpoint. Earlier research could then be accepted, rejected or distinguished on a reasoned basis.

Chapter 6

Alternative Therapies

This chapter examines issues in the use of non-traditional or alternative therapies to treat both general health and mental health problems. Definitions and estimates of prevalence are presented before discussing the demographic, psychiatric and health characteristics of people who turn to such remedies. The importance of ascertaining whether mental health clients use alternative remedies is briefly outlined.

This chapter does not, however, consider research into compliance with non-traditional therapies. An extensive search for literature on the topic did not uncover anything relevant, suggesting that such research is scarce. Nevertheless, some of the issues raised in this chapter are relevant to compliance with the Dietary Intervention Study itself.

NON-TRADITIONAL THERAPIES DEFINED

For the purposes of this thesis, the broad term “non-traditional therapies” can be defined as those therapies not normally prescribed by or associated with orthodox Western medicine. It is noted, however, that the boundaries are becoming increasingly blurred as orthodox medicine concedes there is merit in some non-traditional therapies. This has resulted in increasing medicalisation of such practices. Osteopathy, hypnosis, and acupuncture are examples of therapeutic systems which are generally regarded as non-traditional in Western medicine, but which in some contexts are becoming accepted as within the bounds of orthodox medical practice. Other treatments are non-orthodox depending entirely on their context. For example, massage may be accepted as beneficial to sports injuries, but not to schizophrenia. In the Compliance Study reported here, the use of a dietary supplement as a treatment for depression is a non-traditional therapy. This is so, not because Western medicine

never prescribes dietary supplements, but because it does not normally do so in the context of depression.

There are various modes of delivering non-traditional therapies. Sometimes treatments are administered by trained health practitioners. These include osteopaths, homeopaths and hypnotists. In other instances, treatments are simply adopted by healthcare consumers at home with no expert guidance (Jorm, Christensen, Griffiths, & Rodgers, 2002).

Alternative terms are used to describe non-traditional therapies. These include 'complementary therapies', 'alternative therapies', 'folk healing', 'popular medicine' and 'self-help remedies', which are at times used interchangeably. In the past, the more derogatory terms of 'unconventional' or 'fringe medicine' have also been used to describe the work of therapists, who now often see their work as complementing orthodox practices (Vincent & Furnham, 1999). Druss and Rosenheck (1999) suggested that the use of the term 'complementary' rather than 'alternative' implies that orthodox and non-traditional medical practices can and should be used together. However, the terminology in the research literature in the area can be unclear at times, especially regarding mode of delivery. In this thesis the terms "complementary and alternative medicine" (CAM) and "self-help treatment" are used, and defined according to Jorm et al.'s (2002) definitions: "[CAMs] involves practices and beliefs that are not generally upheld by the dominant health system in Western countries and a self-help treatment is one that can be used by a person without necessarily consulting a healthcare professional." (p. S84). According to these definitions, the use of dietary supplements to treat depression could be considered as both a complementary treatment and a self-help treatment, depending on whether an individual is prescribed the supplement or simply begins taking them on their own initiative.

PREVALENCE OF CAM AND SELF-HELP THERAPIES

General Health

In the last decade, the use of CAM and self-help therapies has increased dramatically. A United States survey found that, in 1991, 33.8% of 1,539 respondents had used one of 16 complementary or self-help therapies in the previous year. That figure increased to 42.1% of 2,055 respondents in 1997 (Eisenberg et al., 1998). However, the definition of “alternative therapies” used by these researchers has been criticised as being too broad because it included measures also recommended by orthodox therapists, such as taking exercise and relaxation techniques (Vincent & Furnham, 1996). In Europe, surveys have found that in any given year about one third of the population use at least one CAM, including self-help herbalism and homeopathy (Vincent & Furnham, 1999). An Australian study (MacLennon, Wilson, & Taylor, 1996) found that 48.5% of more than 3,000 respondents had used a non-medically prescribed therapy in the previous year. It has been estimated that up to 80% of the world’s population, many of whom subscribe to a non-western model of health and illness, use herbal medicines (Norcross, 2000).

Contrary to the trend showing high rates of use of complementary and self-help therapies is a United States study that was conducted as part of the Medical Expenditure Panel Survey (Druss & Rosenheck, 1999). It found that just 6.5% of the population used both unconventional and conventional medical services, only 1.8% used only unconventional therapies, while 59.5% used conventional medical care services only. These results were obtained despite including ‘nutritional advice’ in the categories respondents could choose from. Druss and Rosenheck posited that their focus on practitioner-based therapies, together with the inclusion of non-English speakers and a high concentration of low socio-economic group respondents in the survey may account for the lower rates of CAM use among the 16,000 adults who supplied information. Results may therefore have been quite different if self-help therapies had been included.

Research has suggested that CAMs are more likely to be used by people with chronic rather than acute conditions. These include ongoing back pain, anxiety and depression (Eisenberg et al., 1998). Also included are chronic life-threatening conditions such as cancer, asthma and AIDS (Vincent & Furnham, 1998).

Mental Health

Very little literature is available on the extent to which people with mental illnesses use complementary or self-help therapies. Most of the literature provides only anecdotal evidence of an increase in the use of CAMs and self-help therapies among people with mental illnesses. However, two recent United States studies (Druss & Rosenheck, 2000; Kessler et al., 2001) and one large-scale survey by a popular magazine (*Mainstreaming of Alternative Medicine*, 2000) do provide some quantitative data on the use of such treatment options for mental health problems.

Results from the Medical Expenditure Panel Survey (Druss & Rosenheck, 2000) showed that 9.8% of respondents who reported a mental health condition visited a complementary health practitioner (Druss & Rosenheck, 2000). However, only about half of those visits were to treat a psychiatric or psychological condition. The researchers stated that “the excess use of complementary services among individuals reporting mental conditions is only partly explained by the explicit use of these therapies to treat mental conditions” (p.711). The presence of a mental disorder also predicted an increase in the use of acupuncture or herbal remedies (rather than any other CAM) for any other health condition. Regarding the use of non-traditional therapies to treat an actual mental health condition, Druss and Rosenheck found that respondents with adjustment disorders or stress-related conditions were more likely than those with mood, anxiety or psychotic disorders to use a complementary therapy. They noted that this investigation appeared to be the first available piece of research in the United States to estimate the use of practitioner-based CAMs for those with a mental condition.

A telephone survey investigating the prevalence of 24 CAMs was conducted in the late 1990s (Kessler et al., 2001). Of respondents who reported having anxiety

attacks (9.4% of the sample, n =193) or severe depression (7.2%, n = 148) within the last 12 months, 56.7% and 53.6% respectively had used CAMs for their condition. Approximately two thirds of CAM users with depression and anxiety had also consulted an orthodox health professional. Also of note was the finding that only 20% of the anxiety group and 19.3% of the depression group actually consulted any alternative healthcare provider. That is, most used self-help remedies.

Although Kessler et al. (2001) concluded that more people with self-defined anxiety attacks and severe depression used CAMs than orthodox therapies, there are two methodological difficulties with their study. First, participants' conditions were not independently verified. Respondents may not have met standard diagnostic criteria for disorder. Second, it is debatable as to whether all of the treatments identified by respondents would normally be defined as CAMs. The list of treatments identified included four groups of CAMs: cognitive feedback (such as relaxation techniques, self-help groups and imagery); oral medications (including herbal medicine, homeopathy, naturopathy, and megavitamins); physical treatments (such as massage, yoga and acupuncture); and other therapies (including spiritual healing, dietary modification, therapy to manage pain, folk remedies and aromatherapy). Many mental health practitioners would consider relaxation and the use of imagery to be mainstream therapies for anxiety and depression. Overall, 34.4% of the anxiety group and 30.2% of the depression group used cognitive feedback techniques, while only 6.8% and 8.7% from the two groups respectively reported using remedies from the oral medicines category to treat their condition.

A survey of subscribers conducted by the United States *Consumer Reports* magazine (The Mainstreaming of Alternative Medicine, 2000) found that 30% of respondents who reported having depression had tried St John's wort, a herbal supplement believed to be useful in treating depression. Other treatments tried by respondents with depression included meditation (11% of those with depression), diet (8%) and physical exercise (44%). Prescription drugs, however, remained the overwhelmingly popular treatment, having been tried by 85% of respondents with depression.

PUBLIC OPINION ABOUT COMPLEMENTARY THERAPIES

While there is some data on the general population's attitude towards the concept and practice of CAMs, no research was located linking people's compliance with CAM or self-help therapies and their attitude towards these therapies. In addition, research into attitudes towards CAM or self-help therapies specifically for mental health conditions is scarce. A few general health studies have looked at attitudes towards 'hands-on' treatments such as acupuncture and homeopathy. Even fewer articles are available on people's attitudes to nutritional therapies except those aimed at weight reduction. However, the literature reported below does give an indication of how people view CAMs generally, and CAMs used to treat depression in particular.

In research specifically focused on attitudes towards homeopathy, Furnham (2000) asked over 430 participants if they had heard of, understood or used any of 39 different complementary therapies. Herbal medicine was the listed therapy most similar to that used in the study reported in this thesis. It was rated as modestly efficacious by respondents (mean rating of 5.85 on a 10-point scale). Overall 96% of respondents said they had heard of herbal medicine, though only 36% had tried it. Factor analysis, based on efficacy ratings, found four groups of treatments which together accounted for 57% of the variance in efficacy: a mixed group of 20 treatments regarded as ineffective; a modestly effective relaxation group; a spiritual or traditional medicine group, rated as moderately effective; and a group of six very well-known CAMs (the Alexander technique, acupuncture, acupressure, chiropractic, osteopathy, homeopathy), which had mean efficacy ratings of between 4.91 and 6.37. Herbal medicine loaded most strongly on the spiritual/traditional group. Furnham did not collect data on which conditions respondents believed the CAMs would effectively treat. The study does not therefore provide any information on views about efficacy for any mental health condition.

Kessler et al. (2001) reported that just over 52% of the depressed group using any CAMs found the treatments to be very helpful, compared with the same rating by 58% of the depressed group using any conventional therapy. The ratings are comparable, and no significant variation in perceived helpfulness of these therapy

types was found when the data was examined to see if respondents used both kinds of treatments. In other words, if respondents used both conventional and CAM therapies, their rating of each therapy type did not change. Of those with depression who used treatments from the CAMs oral medicines group 38.4% rated them as very effective. Kessler et al. (2001) noted that as their research did not ask what specific herbal medicines or supplements respondents were taking, they were unable to compare particular treatment efficacies.

No research could be located on attitudes towards CAMs by people with mental health conditions in New Zealand or Australia. However, based on a survey of community attitudes towards treatment for depression, Jorm et al. (2002) estimated that only 50% of Australians with depression receive an orthodox, evidence-based intervention by a health professional. They suggested that this may be partially due to a preference by Australians for self-help and CAMs for depression. They found that only 29% of those surveyed believed that antidepressants would help depression, whereas 57% felt that a nutritional intervention would be likely to assist.

CHARACTERISTICS OF CAM AND SELF-HELP THERAPY USERS

Furnham and Beard (1995) compared people using three different treatments: a CAM only group; an orthodox medicine only group; and a group who used both CAM and orthodox medicine. People in the CAM-only group were more likely than those in the other groups to be younger, female, of higher job status, less religious and politically to the left of centre. Level of education was not significantly different between the groups. There were no differences found in coping styles.

Psychiatric Disorder

The question of whether people who use CAM have more psychiatric disorders than orthodox medicine users is unresolved.

Furnham and Smith (1988, cited in Furnham & Beard, 1995) found that people using homeopaths had higher scores on a scale of minor neuroses than clients of orthodox healthcare providers. Another study (Furnham & Beard, 1995) hypothesised that greater psychiatric morbidity would be associated with CAM use. The three treatment groups (outlined previously) were assessed for levels of psychosomatic complaints. The authors found no significant differences between the three groups. They noted that this result might be due to inherent flaws in the survey instrument, or to obscuring the traits of users of particular CAMs by grouping together the clients of several types of practitioner (for example, including shiatsu massage, acupuncture and mixed CAM clinics).

Druss and Rosenheck (2000) concluded that people with a major or chronic psychiatric disorder were no more likely than the general population to seek the help of a CAM therapist. By contrast, people with more temporary emotional distress were more likely to use CAM. However, the authors noted that the respondents' mental health conditions were not independently verified, so the precise level of disorder may be difficult to gauge. Additionally, they had only asked about visits to a CAM provider, not about self-help therapies. They stated that patterns of self-help CAM by people with mental health diagnoses may be different from those seen in their survey, and further research into that area would be valuable.

Health Beliefs

In a study designed to assess what factors lead to different attitudes to CAMs, three main explanations for using CAMs were identified (Siahpush, 1999). First, the healthcare consumer may be dissatisfied with the outcome of conventional medical interventions. Second, the consumer may be unhappy with the doctor-patient relationship. Third, CAMs use may be associated with a set of values associated with a post-modern philosophy. People who hold to a post-modern philosophical belief system "... regard nature as benevolent, hold anti-science views, believe in a holistic view of health, reject authority, believe in individual responsibility for achieving good health, and hold consumerist attitudes" (Siahpush, 1999, p. 266).

Siahpush (1999) stated that, while health beliefs were the primary reasons for using CAMs, earlier studies had failed to adequately differentiate between dissatisfaction with the *outcome* of orthodox treatments, and the *encounter* with the orthodox treatment provider. The author cites his own earlier research (Siahpush, 1998) where dissatisfaction with outcome was found to have no impact on attitudes to CAMs. However, both post-modern values and dissatisfaction with the orthodox medical encounter were predictors of such attitudes.

In an expanded version of the 1998 study, Siahpush (1999), conducted a telephone survey of over seven hundred Australians which confirmed the presence of two elements to the medical consultation, being encounter and outcome. However, the survey found that neither dissatisfaction with outcome nor dissatisfaction with the encounter explained people's attitudes to CAMs. The 'dissatisfaction with the medical encounter' measure explained only an additional 1.3% of the variance in attitudes towards CAM. However, including the post-modern values scales explained 23% of the variance between positive and negative attitude respondent groups. The only significant demographic variable was education, showing a small positive correlation between more years of education and positive attitude towards CAMs. This supports the findings of Furnham and Forey (1994) discussed previously.

Furnham and Forey (1994) reported that when CAM clients were compared with orthodox medicine clients, the CAM clients were more likely to be sceptical about orthodox medicine, believe that their condition could be improved, show more loyalty to their treatment provider, and to have already tried more alternative therapies. The CAMs clients believed more strongly than the GP group that treatment should take a holistic approach. The authors suggested that this may be due to having been influenced by alternative therapists' explanations of the underlying philosophies of their treatments, which focus on health maintenance and illness prevention rather than on simply rectifying disorder. Notably, this study failed to confirm earlier findings (Furnham & Bhagrath, 1993) that patients' dissatisfaction with their doctor led them to consult an alternative medicine practitioner. This suggests that other factors motivate people to seek out CAM

providers. Overall, these results supported Siahpush's (1999) post-modern philosophy hypothesis.

In finding that the CAMs client group was more sceptical about the value of orthodox medicine, Furnham and Foley (1994) suggested as one possible explanation, that people may choose an alternative health provider then embrace the post-modern philosophy, thus becoming more critical of orthodox practice. Therefore, elements of consumer dissatisfaction and existing belief systems, combined with a modification of the health belief system by an influential figure, may be responsible for scepticism towards orthodox medicine.

Finally, researchers recently tested whether the Theory of Reasoned Action (TRA) and Theory of Planned Behavior (TPB) (discussed in Chapter 5) could predict the use of homeopathy (Furnham & Lovett, 2001). They found that the TPB components of attitude, subjective norm, and perceived behavioural control predicted the intention to use homeopathy in the portion of a convenience sample that participated in a follow-up interview (139 out of 343 survey respondents). Actual use was predicted by intention. In this study, self-efficacy was distinguished from perceived behavioural control. However, it did not predict either intention to use, or actual use of homeopathy, suggesting that perceptions of ability are not important when evaluating this type of treatment.

ORTHODOX PRACTITIONERS' ATTITUDES TOWARDS CAMS

A number of articles have recently appeared urging orthodox practitioners to put aside their personal and scientific views that use of CAMs and self-help therapies constitutes non-compliance with orthodox therapies. Clinicians are asked to include questions about CAMs in their assessments (Yager, Siegfried, & DiMatteo, 1999; Paquette, 2000; Norcross, 2000). Yager et al. listed three reasons why it is important for clinicians to attend to use of CAMs. First, they cited the high use of such therapies to treat many ailments. Second, they drew attention to research already cited which suggests that depression, anxiety, headaches and fatigue are common

reasons for seeing a CAMs practitioner. Lastly, they noted “an explosive marketing push for the development of new ‘nutraceuticals’ or ‘pharmafoods’” (p.1432) which may be effective, ineffective or dangerous, and which are not governed by the same regulatory requirements as medications. These three reasons mean that the mental health professional needs a good working relationship with the client in order to assess treatment needs, and track possible onset of deleterious effects. Jorm et al. (2002) see orthodox practitioners discussing CAMs as an opportunity to prevent dangerous drug interactions, and to educate patients about better choices.

SUMMARY

Complementary and alternative medicine (CAM), whether practitioner-based or self-help, seems to be increasing in popularity (Eisenberg et al., 1998; MacLennan et al. 1996). Orthodox medicine has medicalised some CAMs in certain situations, such as the use of acupuncture for pain relief and hypnosis for smoking cessation. However, it remains wary of others, including the use of dietary supplements to treat depression (Yager et al., 1999; Ernst, Rand, & Stevinson, 1998).

Research suggests that practitioner-based CAMs might be used more by people experiencing chronic serious illnesses and transitory stress-related conditions, rather than for acute medical conditions or severe mental illness. However, the CAM’s definition used in some research is very broad, and there is a lack of research into precisely what self-help treatments are being used without guidance from any health practitioner (Druss & Rosenheck, 2000; Kessler et al., 2001).

Public opinion of CAMs varies. Some therapies are well-known and well thought of, even if they are not used by most people (Furnham, 2000). However, the public discriminate between those they see as efficacious and those they do not. The general public seems to have a positive view of the use of dietary supplements to treat depression, regarding them in a better light than antidepressants (Jorm et al., 2002).

There is no clear consensus on what set of demographic traits make someone more likely to use CAMs. However, women use more CAMs than men, and CAM users have been found to have more years of education than non-users (Furnham & Forey, 1994). The findings on the role of psychiatric illness are unclear (Furnham & Beard, 1995), and may be different for people using practitioner-based and self-help CAMs (Druss & Rosenheck, 2000).

Currently, research suggests that dissatisfaction with orthodox medical encounters does not explain why people choose CAMs treatments (Siahpush, 1999; Ernst et al., 1998). A belief in post-modern philosophical values, including holism, consumerism, and individual responsibility for health increases the likelihood that one will become a CAMs user (Siahpush, 1999). However, it may be that a post-modern philosophy becomes embedded due to the influence of CAM providers during the consultation and treatment process (Furnham & Forey, 1994). Furthermore, attitudes towards the treatment, the views of significant others, one's own perceived behavioural control (but not self-efficacy) and positive intention to use a CAM service, as well as past behaviour, were shown to predict actual CAMS use (Furnham & Lovett, 2001). This finding demonstrated the usefulness of the TPB when assessing CAMs consumer behaviour, and mirrors elements of treatment decisions found when assessing decisions about orthodox therapies.

Finally, orthodox medical practitioners are being urged to assess their clients' use of CAMs. This would enable them to more fully understand their clients' health perspectives, recovery and side effects. (Yager et al., 1999).

Chapter 7

Placebo Effects

Research presented in previous chapters suggests that expectations may have a strong influence on many health-related decisions, including those related to compliance. The preponderance of research suggests that compliance is enhanced by positive effects of treatment. Given the importance to compliance of both treatment expectancies and treatment outcomes, it is appropriate to include some discussion of placebo effects.

DEFINITIONS AND EXPLANATIONS

Placebo effects are often defined as the non-specific effects of a treatment for any condition. They are those aspects of a treatment which are not known to have any active influence on a particular disorder, but which nonetheless produce some positive outcome for the person being treated (Miller, 1989). Miller points out that a placebo effect can be produced in two ways. First, it could be a positive (unexpected or neglected) effect of a genuine placebo treatment (that is, one designed to have no particular effect on the disorder). Second, a placebo effect could be an additional expectancy effect of a genuine treatment. For example, in a 1970 study by Luparello, Leist, Lourie and Sweet (cited in Hahn, 1999), participants who were given a genuine asthma drug responded differently according to what effect they were told it would have on them. Accurate information increased the drug's normal effectiveness, while misinformation had the opposite result.

A placebo may be either active or inactive (Kirsch & Sapirstein, 1998). Active placebos are genuine medications or procedures without any known effect on the condition under investigation, but which have pharmacological side effects to which change may be attributable, or which may signal a treatment effect to the person taking it (Kirsch & Sapirstein, 1998). That is, because of some side effect of the

active placebo, the client or participant may either experience some side effect as a beneficial outcome or believe the treatment must be “real” because it produces side effects. Inactive placebos have no pharmacological effects at all. For example, aspirin would be an active placebo if used as a control treatment in a study into the effectiveness of antipsychotic medications, while sugar pills would be an inactive placebo.

Placebo effects have been discovered in both physical and psychological medicine. Reports have been provided of placebo medication and surgery (Miller, 1989), and placebo psychotherapies (Frank, 1989). Thus, many disciplines, including psychology, have an interest in placebo effects (Harrington, 1997a).

Harrington (1997a) succinctly sums up the contradictions and confusions created by the acknowledgement of placebo effects:

Placebos are the ghosts that haunt our house of biomedical objectivity, the creatures that rise up from the dark and expose the paradoxes and fissures in our own self-created definitions of the real and active factors in treatment. On the one hand, we acknowledge the power and ubiquity of placebo responses by our requirement that all new drugs be tested in double-blind placebo-controlled situations; however, we then define those same responses as “non-specific noise” in the treatment to be subtracted out of the picture. We often fail to notice that these factors are not inherently non-specific but are only so because insufficient energy and attention has been spent on specifying them. (p.1-2.)

From this viewpoint, defining placebo effects as non-specific aspects of treatment may be unhelpful or indeed misleading. It may be more beneficial to look at the total effect, including any placebo effects, of a treatment package. These may include the chemical effects of medication or dietary intervention, non-chemical aspects of the primary treatment such as taste or colour, presence and personality of the clinician or researcher, appointment regularity and location. Indeed, researchers should also consider naturally occurring remission or symptom abatement, and regression as

possible causes of a response to treatment, be it active or placebo. It may be that the so-called “noise” elements in fact have consistent and quite specific effects on treatment outcome.

Placebo conditions may be more “effective” if participants are more compliant. Compliant participants in placebo control conditions have been found to have better treatment outcomes than non-compliant participants in placebo conditions (Horwitz and Horwitz, 1993, cited in Myers and Midence, 1998). Myers and Midence postulated that such outcomes may be because compliant placebo responders may also make efforts to engage in other health behaviours that will impact positively on their health outcomes, because of raised expectations of treatment effects.

PLACEBO EFFECTS IN DEPRESSION

Placebo Effects and Antidepressants

In their meta-analysis of effect sizes for responses to antidepressant medication versus placebo control, Kirsch and Sapirstein (1998) concluded that, in the 19 studies they examined, which included 2,318 participants, 75% of the total drug response was in fact a consistent placebo response. They stated that “This does not mean that only 25% of patients are likely to respond to the pharmacological properties of the drug. Rather, it means that for a typical patient, 75% of the benefit obtained from the active drug would also have [been] obtained from an inactive placebo” (Effect sizes section, ¶ 1). Kirsch and Sapirstein also highlight the possibility that the remaining 25% of the effect size may in fact be attributable to an active placebo effect rather than to antidepressants per se.

There are three important points to note here. First, Kirsch and Sapirstein (1998) distinguished between drug *response* (change which happens after a drug is administered) and drug *effect* (that portion of change that results from the drug’s chemical components). Second, they similarly distinguished a placebo *response* (change after a placebo has been administered) from a placebo *effect* (the difference

between change after administering a placebo, and change which would occur without administering a placebo). Third, the size of the placebo *effect* is not apparent from the observation that 75% of the drug response is a placebo response. The authors were unable to measure this adequately, because few of the studies in the meta-analysis included a 'no-treatment' control group.

To investigate the size of the placebo effect, Kirsch and Sapirstein (1998) conducted a meta-analysis of psychotherapy studies involving assignment of participants to either an active treatment group, or wait-list/no treatment group. Change in the 'no-treatment' groups (attributed to natural history) was then used to estimate the placebo effect size in the medication meta-analysis. The groups in the psychotherapy studies, and the antidepressant and placebo groups from their earlier meta-analysis, were found to be comparable in terms of both key demographic characteristics and pre-treatment depression scores. The placebo effect (placebo response minus no treatment response) was found to be 0.79.

Overall, Kirsch and Sapirstein (1998) concluded that about one quarter of the 'drug response' is due to active components of antidepressant medication, one quarter to naturally occurring changes (as in the no treatment condition) and the remaining one half to placebo effect. This study was controversial when initially published, and Kirsch's continued denunciation of the specific effects of antidepressants remains a contentious topic of debate (Kirsch, Moore, Scoboria, & Nicholls, 2002; Thase, 2002).

A recent study that investigated functional brain correlates of placebo versus Prozac effects in depression using positron emission tomography to map changes in the glucose metabolism in different parts of the brain of 15 hospitalised men (Mayberg et al., 2002). Favourable response to treatment (fluoxetine or placebo, both delivered in the context of an in-patient therapeutic milieu, but without interpersonal or cognitive behaviour therapy) was defined as at least a 50% reduction in baseline Hamilton Depression Rating Scale scores after six weeks of treatment. It was found that four men from each of the fluoxetine and placebo groups met the criteria for treatment responders. Both groups of responders showed changes in glucose metabolism in the

same specific areas of the brain, while non-responders did not change in similar ways. Changes included increases in the glucose metabolism in the cortical region of the brain, and decreases in the limbic-paralimbic areas. However, responders in the fluoxetine group exhibited additional subcortical and limbic glucose metabolism shifts.

Mayberg et al. (2002) suggested that for depression to be successfully treated by any modality it must encourage these common changes in the brain's glucose metabolism. Thus, medication, psychotherapy and dietary interventions may all facilitate remission from depression if they can 'spark' the appropriate areas of the brain. In the reported study, change in placebo responders was attributed to the therapeutic environment associated with the study.

As many before them have emphasised, Mayberg et al. (2002) noted, "...the administration of a placebo is not absence of treatment, just the absence of active medication." (p732). These researchers believe that the additional changes that occurred in the brains of the fluoxetine responder group demonstrate increased efficacy of medication over placebo, rather than a mere side effect of medication, as these effects were not demonstrated in the fluoxetine non-responder group. They suggested that active medication effects may be associated with a longer-term remission.

Placebo Effects and Psychotherapy

It is well recognised that different forms of psychotherapy have common components that enhance the clinical effectiveness of all treatments for most disorders (Bergin & Garfield, 1994). It has been hypothesised that such non-specific aspects of psychotherapy act to reduce the demoralisation experienced by people who seek psychotherapeutic intervention (Frank, 1989). This alone may be curative for many people.

Frank lists four elements common to all forms of talk therapy, which help to reduce demoralisation. First is an emotionally charged relationship with a therapist who is

there to help. This is often sufficient by itself to begin to alleviate demoralisation. Second, the context of a healing setting, which engenders a sense of safety and expectations that healing will occur. Third, a rationale, scheme or myth that explains symptoms and prescribes a way to alleviate them. Finally, a ritual requiring both the patient and therapist to have an active involvement in treatment. Frank emphasised that while non-specific therapeutic elements are necessary and at times sufficient for healing in psychotherapy, the specific aspects of particular forms of psychotherapy will add to increased effectiveness for particular disorders in particular individuals. Additionally, the more severe the problem for which psychotherapy is sought, the more specific therapeutic elements will be required to enhance the outcome. Bergin and Garfield (1994) provided a comprehensive review of studies into the effectiveness of different types of psychotherapies for depression, including those that controlled for common non-specific elements. This research has confirmed the added value generated by cognitive behavioural therapy and interpersonal psychotherapy for depression.

Placebo Effects in Non-Traditional Therapies for Depression

History is replete with examples of placebo effects in what would now be described as non-orthodox medical and psychological treatments, across all cultures and treatment modalities (Shapiro & Shapiro, 1997). One of the more outlandish cures, by Western psychology standards, may be a West African cure for depression. This is based on driving out unwanted spirits (Solomon, 2002). Solomon experiences depression himself. He took part in a *ndeup* ceremony, which involves animal sacrifice, music, dance, ritual and, in his case, hundreds of participants and observers. His reflections on the event described elements that instil hope that success has been achieved in those with mental illness:

The *ndeup* impressed me more than many forms of group therapy currently practised in the United States. It provided a way of thinking about the affliction of depression – as a thing external to and separate from the person who suffers. It jolted the system, which could certainly throw one's brain chemistry into overdrive – a kind of unplugged ECT. It entailed an intimate

experience of community. It included close physical contact with others. It put one in mind of death and at the same time affirmed that one was oneself alive and warm and pulsating. It forced a great deal of physical improvement on the sufferer. It introduced the comfort of a specific procedure to follow in the event of a recurrence. And it was bracingly energetic – an absolute tour de force of movement and sound. Finally, it was a ritual, and the effect of any ritual – being covered in the mixed blood of a ram and a cockerel or telling a professional what your mother did when you were small – is not to be underestimated. The mix of mystery and specificity is always enormously powerful (p.170).

If it can be accepted that, for some people in some circumstances, an experience such as the *ndeup* may alleviate depression, it is then easier to understand how treatments and experiences, which make sense in terms of an individual's values, beliefs and education, can be beneficial even if objectively there seems no reason for them to work. However, following from arguments already cited (Harrington, 1997b), it may be that some *specific* aspect of the *ndeup*, such as involvement of the community or faith in the practitioner, is curative.

Solomon's (2002) account of his non-traditional treatment experience is a reminder that a placebo response may involve some of the very mechanisms that constitute good therapy; offering hope, forming a working alliance, and inducing expectations that the therapy will work (Bergin & Garfield, 1994; Frank, 1989).

Placebo Effects in Depressed Research Participants

People who respond to invitations to participate in research trials may also be differentially susceptible to placebo effects. One study found that depressed participants differed in their responsiveness to treatment in the placebo condition depending upon whether they were recruited through consultation or advertising (Miller, Hooper, & Bakish, 1997). More specifically, it was found that those recruited by advertising were more likely to be early responders to placebo conditions in the first, second, fourth and fifth weeks in five 6-8 week clinical trials

for pharmacological treatments for depression. Advertisement recruits were also more likely than consultation recruits to be in remission at weeks two and four of the trials. Note that advertising- and consultation-recruited groups did not differ on most demographic variables or mental health history, but advertisement recruits in the placebo condition had significantly lower baseline scores on the Hamilton Depression Rating Scale (17 item version) than those from the consultant recruits in the placebo condition. The authors said this supported earlier findings that advertisement recruits are less depressed than other recruits in depression research studies (Lecrubier, 1996, cited in Miller et al, 1997). The authors also stated that overall, advertisement recruits were more likely to have received no treatment for their current episode of depression than consultation recruits, and were thus more treatment naïve than the latter group. Perhaps the fact of someone taking an interest in them and their condition (where no treatment options existed previously) was sufficient to trigger the treatment response. Finally, Miller et al. noted that placebo responses dropped off after week six, suggesting longer trials would help differentiate treatment effects from placebo effects. No significant differences were found between the two placebo groups in terms of either dropout rate or reasons given for early discontinuation.

SUMMARY

Placebo effects are the non-specific aspects of a treatment or experiment that impact on a disorder. They may occur as a result of genuine effects of the supposed placebo condition, or from an expectancy in the individual being treated. Harrington (1997a) pointed out that defining placebos as non-specific aspects of a treatment may be misleading, or at least a failure to acknowledge important aspects of a treatment package which deserve attention in their own right.

Placebos may be active, in that they produce side effects that may be attributed to a genuine treatment, or inactive, meaning that no known pharmacological effects are present.

There is a healthy, ongoing debate about the degree to which antidepressant medications produce real or placebo effects. In their meta-analysis of antidepressant trials, Kirsch and Sapirstein (1998) were able to tease apart data to show that what was previously thought to be an antidepressant drug response was 75% attributable to either placebo effects or changes that occur naturally over time. Only 25% was attributable to active ingredients in the medication itself. Their conclusions are by no means universally accepted. Mayberg et al. (2002) have advanced the debate on placebo responses to antidepressants by postulating that neuroanatomic changes necessary to relieve depression may be triggered by both non-specific aspects of treatment, and by medication. Antidepressants may have some additional action on specific aspects of the brain's glucose metabolism that produces an enhanced effect.

Both studies above give a timely reminder that a placebo condition is not the same as an absence of treatment. The specific elements at work may be harder to disentangle in psychotherapy. By their very nature, placebo components are intricately intertwined with specific aspects of psychotherapy, and valued for their effectiveness as tools to treat mental distress. Solomon's (2002) account of a treatment from West Africa highlights how effective therapy may come in many packages, but seems to always contain certain essential elements, not least among them being hope and trust.

Finally, and importantly in the current context, research shows different groups of research participants may respond differently from others to placebo conditions. For instance, Miller et al. (1997) found that people recruited through advertisements were more prone to placebo effects early in the course of placebo controlled antidepressant drug trials. These participants could also be distinguished from consultation recruits in that they were more treatment naïve, and possibly less unwell overall.

PART 3

THE PRESENT STUDY

Chapter 8

Methodology

This chapter discusses the rationale for using grounded theory methodology in the Compliance Study. In doing so, grounded theory methodology and data analyses are introduced. In this thesis, analysis was conducted using both quantitative and qualitative data collected in the Compliance Study. The chapter concludes with a discussion of criteria used for assessing the quality of qualitative research generally, and grounded theory in particular.

RATIONALE

The primary consideration when choosing a research method is how the research questions might best be answered. Ontological assumptions of what it is possible to know, or what constitutes knowledge, inform epistemological, pragmatic and ethical considerations relevant to the research area. In the Compliance Study, the ways in which people's beliefs influence behaviour were explored. To carry out this research, it was necessary to acknowledge that beliefs are shaped by contexts that cannot be predicted or controlled for. Beliefs are constructed by individuals within the circumstances of their own lives and vicarious experiences, and are not universally held. Thus, a relativist ontological stance informs the research approach.

Relativism views reality as socially constructed by and for individuals, and as being amenable to change. In other words, relativism holds that there is no objective reality (Guba & Lincoln, 1994). In the Compliance Study, realities are seen as relativistic; it is acknowledged that there is no "objective" or "true" method for measuring compliance. Participants' perceptions of their compliance experiences becomes central to the research process. However, the qualitative data used is also seen as producing an approximation of reality for the participants. This may seem anomalous, but can be accommodated by grounded theory methodology selected for

this research (Strauss & Corbin, 1994). Quantitative data here were not treated as objective truth or the only truth. Even if its use is considered an anomaly, ontological and epistemological irregularities are common in social science research, and should be acknowledged rather than hidden from view (Becker, 1993).

Epistemology

Epistemology is the theory of how things may be known (Ezzy, 2002). Arising from a relativist ontological perspective, the epistemological approach to this research is constructivist. Meaning is set in context, with interpretation occurring in a dialogue between the researcher and participants (Guba & Lincoln, 1994). This approach is appropriate given the exploratory nature of the Compliance Study, and the research questions, which revolve around the nature of meaning, and how it gives rise to compliance behaviour.

Many would disagree with the use of quantifiable measures with a constructivist epistemology. Guba and Lincoln (1994) argued that postpositivist and constructivist paradigms cannot coexist because of oppositional assumptions about the nature of reality and objectivity in research. They stated that “resolution of this dilemma will necessarily await the emergence of a meta-paradigm that renders the older, accommodated paradigms not less true, but simply irrelevant” (p.116).

This thesis asserts that the quantitative measures in the Compliance Study are measures of a subjective reality of how participants viewed their mood states, treatment decisions and compliance behaviour. Although certain aspects of these constructions *are* measurable, they cannot be objectively verified as either true or false, even if that were a desirable outcome. Nonetheless, they provide some data for comparing where participants see themselves at a given point in time.

The Compliance Study attempted to clarify what factors were important for the participants when deciding *how* to undertake a treatment regimen. In doing so, the meanings that women attributed to the treatment and outcomes were important. Their meanings may differ from what the literature *says* any particular regimen

should mean and achieve, or how it should be received. This was acknowledged even though theories of health behaviour helped inform that questions were asked of participants. Additionally, results from both the quantitative and qualitative parts of the Compliance Study were scrutinised for how well they “fitted” and made sense of each other, rather than simply evaluating either set of results in terms of the existing literature.

Pragmatic Considerations

The Compliance Study sought to explore two related but potentially independent questions. First, what drives women to be compliant or non-compliant with treatments for depression generally, and second, what makes women compliant or non-compliant specifically with the nutritional supplement regimen used in the Dietary Intervention Study (DIS).

Very little research has been conducted on compliance with medication for depression, and none at all was found dealing with compliance with alternative or nutritional therapies for depression. The Compliance Study has, accordingly, looked at a new area of research. As such, it was appropriate to begin with an exploratory study, acknowledging existing theories and empirical findings in relation to compliance generally, but not limiting conclusions to the verification or falsification of existing theories or findings.

A pragmatic decision was made at the outset to make use of all resources available within the framework of the DIS as investigative tools in the Compliance Study. These resources included blood analyses and questionnaires that would provide quantifiable measures of participants’ compliance and mood progress over the course of the 12-week DIS trial, as well as information that could be used more qualitatively.

Knowing that theories exist which may explain compliance decisions, it was decided to assess the fit of one of these theories to the Compliance Study research. The Health Belief Model assumes there is a link between perceived threat, benefits,

barriers to health behaviour and decisions to act. This linkage was explored in the current study. However, hypothesis testing through manipulation of compliance behaviours and beliefs was not possible, given the constraints of the DIS (in which taking the supplements as instructed was intrinsic to the outcome of the nutritional study). Moreover, it was undesirable given both the Compliance Study's objective of finding out what factors influence the compliance of women with depression, and a commitment to transparency in the research process (discussed later). Thus, a purely quantitative approach would potentially have yielded little information of practical value

As well as blood and questionnaire data, the DIS offered the Compliance Study researcher the opportunity to interact with the women participants during the data collection period. This period was three months if the participant completed the full term of the DIS. A qualitative approach allowed the Compliance Study to explore more fully what factors might drive compliance, especially with regard to the new supplement treatment. New factors could be missed if reliance was placed solely on asking questions derived from existing literature.

Time spent with the compliance Study participants also threw up demand and experimenter characteristics, which may have been seen as "contaminants" in a positivist mode of working (Banister, Burman, Parker, Taylor, & Tindall, 1994). Five meetings and periodic reminder telephone calls over 12 weeks generated a working relationship between the researcher and participants. Many participants viewed the interviews as *de facto* therapy, with even the act of filling out mood and other questionnaires leading participants to make evaluations of their progress and growth over their time in study. It would have been impossible to "control" for participants' interactions with either the researcher or the measures used. A better approach seemed to be to ask about such issues: was compliance affected by the presence and/or personality of the researcher, or by being involved in a research study?

Ethical Considerations

The approach to the Compliance Study was also driven in part by the researcher's personal view that research should be conducted from an ethical basis. A constructivist view fits well with this position, in that ethics are viewed as intrinsic to the research process, with priorities given to confidentiality and anonymity, the avoidance of deception, and respect for the values of participants (Guba & Lincoln, 1994). The researcher's own prior background in law and continuing training in clinical psychology informed this view.

Ethical considerations were not merely met by simply obtaining approval for the research from the various human ethics committees to which the DIS and Compliance Study protocols were submitted. Ethical research was also promulgated by a conscious decision to be open about my research objectives (without compromising the objectives of the DIS research), and by sharing information (such as transcripts and emergent theories) with participants at the end of their time in the research and at subsequent follow-up interviews (not reported in this thesis). Additionally, all participants were sent newsletters during the course of the DIS research project. The newsletters gave updates on the research progress, and profiled the research team, including the "faceless" researchers operating behind the scenes. This was part of an attempt by the research team to ensure transparency and treat participants as contributing members of the research project, who were entitled to be as informed much as possible. Participants continued to receive newsletters even after their own involvement in the research had ceased, until the entire data collection phase ended. These steps were seen as part of the commitment to ensure reciprocity in the research process (Marshall & Rossman, 1989).

COMBINING QUANTITATIVE RESEARCH METHODS AND GROUNDED THEORY

Grounded theory offered an approach that was both compatible with a constructivist epistemology and encouraged the collection of data using a broad range of sources and methods (Chamberlain, 1999; Strauss & Corbin, 1994). In grounded theory

“data” are broadly defined, and may include quantitative data. It is the way that data is analysed, to elicit meaning and enhance theory development, that is the critical point (Strauss, 1987).

GROUNDING THEORY METHODOLOGY AND DATA ANALYSIS

Grounded theory is a general research methodology first developed in the 1960s as a reaction against the trend towards theory verification that had swept into sociology (Glaser & Strauss, 1967). Since then it has been used widely in all areas of social science research (Chamberlain, Stephens, & Lyons, 1997) (Strauss & Corbin, 1997). Its basis is in symbolic interactionism (Clarke, 1997), which considers that the meanings given to self and events are created through social interaction, leading to action, consequences and resultant reinterpretation for the individual concerned (Chenitz & Swanson, 1986). Over time, the original grounded theorists have taken divergent paths on the purposes and practice of their theory. Given the constructivist framework adopted by the Compliance Study, the “Straussian” grounded theory variant rather than the “Glaserian” variant (which has a perspective more in line with a realist ontology and postpositivist epistemology) (Chamberlain, 1999) was favoured.

Grounded theory allows the meanings given to social phenomena by others to be uncovered or “discovered” by the researcher from data without imposing an existing meaning or interpretation. In this sense, the findings emerge from, or are “grounded” in, the data, rather than the data being subsumed by prior findings in a process of theory verification or negation (Strauss & Corbin, 1990).

Grounded theory emphasises the generation of theory rather than description of phenomena (Glaser & Strauss, 1967). It aims to explain how and why social phenomena occur, and emphasises inductive analysis to move from the specifics of the data to more general and abstract premises about the issues under investigation (Strauss & Corbin, 1990). In doing so, concepts and their properties, contingencies,

contexts and interrelationships are clarified to explain the phenomenon comprehensively (Chamberlain et al., 1997).

Chamberlain (1999) argued that although the central core of grounded theory is inductive analysis, to call it pure inductive analysis would be an oversimplification. As theory development proceeds, further data is collected to deductively test tentative hypotheses that emerge from the data. Thus, Chamberlain (1999) sees grounded theory as requiring the application of both inductive and deductive logic when formulating a theory.

GROUNDED THEORY PRACTICE

How does grounded theory achieve the generation of theory grounded in the data? By a process of applying certain key interlinked processes or strategies to data collection, analysis and theory generation. Making constant comparisons between data and categories of data to look for similarities, differences and relationships is key among these, and has led grounded theory to be called “the constant comparative method” (Mertens, 1998). This is a constant in the research process, questioning at every stage and at every level of theory development.

Grounded theory also uses a coding paradigm to create an analytical framework for the emergent theory. Essentially, this has three interwoven parts: open, axial and selective coding (Strauss & Corbin, 1990). The paradigm, and research tools of memoing and diagramming, are described in detail by Strauss and Corbin.

Originally, grounded theory proponents argued that the researcher is sensitised to the subject of study through their own professional and personal experience and should avoid contaminating emergent theory through an early literature review on their topic (Glaser & Strauss, 1967). However, it is now recognised that it is unrealistic, and perhaps counterproductive, to ignore or avoid existing theory or findings, and better to use existing literature as a resource, in a critical and selective manner (Chamberlain, 1999). Strauss and Corbin (1994) acknowledged that grounded theory

has evolved in this respect since its 1967 introductory text was published, but noted that “many people still get their conceptions of grounded theory from the original book, and have missed the later more realistic and balanced modifications of that book’s purposeful rhetoric” (p.277).

CRITERIA FOR ASSESSING QUALITATIVE RESEARCH

There is some debate as to what constitutes good qualitative research, driven in part by ontological and epistemological differences among researchers (Altheide & Johnson, 1994). While objectivity, reliability and validity criteria are appropriate assessment criteria for positivist research, they are neither appropriate nor at times possible to apply as originally formulated to qualitative research (Henwood & Pidgeon, 1992). Both Henwood and Pidgeon and Stiles (1990) suggested criteria for judging the quality of qualitative research. Several of the key guidelines put forward by Stiles for assessing the veracity of qualitative research generally are outlined as follows:

- *Triangulation* is the verification of data from multiple sources and multiple methods to assess convergence of fit and minimise the possibilities of misinterpretation.
- *Testimonial validity* refers to seeking validation for an interpretation from those whom the theory or findings are supposed to fit or represent.
- *Consistency* refers to the quality and comprehensiveness of the interpretation, including fit with prior findings. Poor fit with existing theory does not necessarily denote poor quality research, but any differences must be accounted for in a reasoned manner. This may include illuminating a different set of assumptions and biases, or correcting earlier faulty research.

- *Catalytic validity* is the extent to which “ the research process re-orient, focuses, and energises participants” (Stiles, 1990) (p.33). It moves them forward or changes their perceptions of themselves.

Strauss and Corbin (1990) provide a number of guidelines for judging the quality of a grounded theory, of which Chamberlain et al. (1997) see four as critical. First, the theory must fit the phenomenon of interest. It must not be based on pre-conception about the phenomenon, but emerge from the data. There should be obvious, coherent relationships between theoretical concepts throughout, and the theory should fit the reality of the phenomenon as it naturally occurs. Second, the grounded theory should be meaningful and understandable to both researchers and the researched. The theory should explain how the phenomenon comes about and be sufficiently general to explain the variation found within the phenomenon. This has been referred to as credibility, and parallels internal validity in positivist research in the paradigm (Guba & Lincoln, 1994). Third, the theory should be able to be generalised across a number of contexts, given that it is based on comprehensive data, broad conceptual interpretation and accounts for variation within the phenomenon of interest. Fourth, the theory should provide control. That is, it should state the conditions under which it holds and enable meaningful intervention to occur.

Additional criteria set out by other researchers include ensuring adequate record keeping to enable a comprehensive audit of the study and its findings (Sandelowski, 1986; Henwood & Pidgeon, 1992), relevant and comprehensive sampling to ensure goodness of fit between the theory and the actuality of the phenomenon in its rich diversity (Henwood & Pidgeon, 1992), and that the researcher should acknowledge how they have impacted on the research study and build this into the theory explicitly (Henwood & Pidgeon, 1992).

SUMMARY

This chapter has outlined the philosophical assumptions and pragmatic considerations that led to the use of grounded theory research, incorporating

statistical analysis, in the Compliance Study. A relativist ontology and constructivist epistemology underpinned the decision to use a qualitative research paradigm. Pragmatic and ethical considerations drove the decision to use grounded theory methodology using both quantitative and qualitative data.

The advantages of using grounded theory in the Compliance Study include its suitability for exploratory studies in new areas of research, its ability to generate a dense, richly detailed theory from a broad range of data, and the flexibility allowed to incorporate multiple methods of inquiry.

Grounded theory provides a guiding framework for analysis through its constant comparative method and well explicated coding paradigm. Open coding splits the data into discrete events and instances, labels it conceptually and rebuilds it into categories based on their properties and dimensions. Axial coding uses theoretical codes to confirm or disconfirm tentative hypotheses, refine categories, and relate categories in meaningful ways. In selective coding, a core category that subsumes and accounts for all others within the grounded theory emerges, and is related to all other categories based upon the conditions, contingencies and consequences associated with each. The theory is complete only when theoretical saturation is reached, meaning that no new information is revealed from additional data collection. Grounded theory is dynamic and flexible enough to accommodate a variety of research questions, data and disciplines. Variations in the application of the coding model are acceptable.

There is a lack of universal agreement within the social science community as to what constitutes qualitative research adequacy. However, general criteria have been described by Stiles (1990) and others that are applicable in the present research. Chamberlain et al.'s (1997) list of criteria for judging grounded theory, derived from Strauss and Corbin's (1990) discussion, include its fit with the phenomenon of interest, its ability to be understood by those whom it affects, its generalisability, and its provision of control.

Chapter 9

Method

DESIGN

The Compliance Study utilised both quantitative and qualitative data collected in the course of the Dietary Intervention Study (DIS), as well as in-depth, semi-structured audiotaped interviews with a subset of participants, conducted at the end of the DIS trial. The DIS was a randomised double-blind placebo-controlled trial to assess the effect of omega-3 (n-3) fatty acid dietary supplements as an adjunct to usual treatment for depression in a community sample.

PARTICIPANTS

The 41 women participants who were accepted into the DIS took part in the Compliance Study. All participants had a confirmed DSM-IV diagnosis of unipolar depression and current depressive symptoms. Participants ranged in age from 18 to 47 years.

Recruitment Procedure

Participants were recruited both through referrals from an adult community mental health centre in Palmerston North, and through advertisements placed in three community newspapers in Palmerston North, Wanganui and Wellington. The objectives and procedures of both the Compliance Study and DIS were explained by telephone to interested respondents, before screening them to ensure the DIS criteria for participation were met. Once suitability was confirmed, potential participants were sent a detailed information sheet prior to obtaining informed consent. The information sheet and consent forms are contained in Appendices A and B

respectively. Four hundred and sixty-two women were screened during the 17 months from May 2000- September 2001. Screening criteria are set out in Table 1.

Table 1 Women's Recruitment Screening Criteria for Participation in the Dietary Intervention Study

| Inclusions if present: | Exclusions if present: |
|---|---|
| Aged 18-50 years | Breast-feeding mother |
| DSM-IV diagnosis of unipolar depression | Any co-morbid psychiatric disorder (other than an anxiety disorder) |
| Currently symptomatic for depression | Diabetes |
| Treatment for depression unchanged for at least the last 3 months | Lack of normal menstrual cycle (for example, due to menopause, hysterectomy, polycystic ovary disease or pregnancy) |
| | Blood clotting disorder |
| | Traumatic brain injury |
| | Other serious medical conditions |
| | Use of anticoagulant medication |
| | Allergies/objections to fish or olive products |
| | Diet high in fish or use of omega-3 fatty acid dietary supplements |

MATERIALS

Nutritional Supplements

The experimental supplement contained tuna oil. The daily dose of 8 capsules delivered a combined total of 8 grams of tuna oil, containing approximately 3.4 grams of n-3 fatty acids. The placebo supplement capsules were identical in appearance, packaging and labelling but contained olive oil only.

Questionnaires

Personal History Questionnaire (PHQ)

The PHQ was adapted from a longer questionnaire developed by the Massey University Psychology Clinic to obtain demographic and background mental health information about new clients. Item 6 was added specifically for the Compliance Study in order to ascertain participants' views on the causes of their depression. A copy of the PHQ can be found in Appendix C.

Beck Depression Inventory II (BDI-II)

This self-administered 21-item questionnaire assesses the presence and severity of symptoms associated with depression. Each item begins with a statement of a depressive symptom, followed by four response options ranging from low to high severity. Scores for each item may range from 0-3, with the BDI-II total score range being from 0-63. The developers of the BDI-II suggested clinical cut-off scores be set to reduce the probability of identifying false negatives (Beck, Steer, & Brown, 1996). They suggested score ranges of 0-13 (minimal depression), 14-19 (mild depression), 20-28 (moderate depression), and 29-63 (severe depression).

The BDI-II is a development from the 35 year old Beck Depression Inventory (BDI) (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961) and the revised BDI-IA (Beck & Steer, 1993). The BDI-II was developed to reflect changed diagnostic criteria for depressive disorders in the DSM-IV (American Psychiatric Association, 1994). New items in the BDI-II measure agitation, worthlessness, loss of energy and concentration difficulty. Changes to the way sleep and appetite are measured allow both increases and decreases in these areas to be more accurately reported.

The psychometric properties of the BDI-II have been found to be highly comparable to those of the BDI (Dori & Overholser, 2000) and BDI-IA, (Steer, Rissmiller, & Beck, 2000), although scores for the BDI-II are approximately two points higher than those on the BDI-IA (Steer et al., 2000).

Beck et al. (1996) reported good internal consistency for the BDI-II, with coefficient alphas of above .90 for a group of psychiatric outpatients and .93 for a college student sample. Further research has yielded Cronbach's alphas of .89 for a student group (Whisman, Perez, & Ramel, 2000), and .90 in a sample of clinically depressed outpatients (Steer, Ball, Ranieri, & Beck, 1999). Cronbach's alpha in the Compliance Study was between .90 and .96 across five administrations of the questionnaire.

While high test-retest correlation coefficients would not necessarily be expected with repeated administrations of a mood measure before and after a therapeutic intervention, Beck et al. (1996) reported a test-retest correlation of .93 for a subset of their psychiatric outpatient sample, tested two weeks apart. Research has suggested that the original BDI may be subject to testing effects, resulting in significant decreases in depression score between testing sessions, regardless of additional intervention (Sharpe & Gilbert, 1998).

Health Belief Questionnaire (HBQ)

The HBQ (Versions 1 and 2) are 14-item questionnaires developed specifically for the Compliance Study, to investigate whether the Health Belief Model (HBM) has utility in predicting compliance with treatments for depression. It was used to provide both quantitative and qualitative data for analysis. A copy of the HBQ (Version 2) is included in Appendix D.

Although the HBM framework has been widely used in health research, there is a lack of well validated and adaptable measures of its components (Champion, 1984). In the area of mental health research, the situation is even more dire. A review of medication compliance research in mood disorders where HBM constructs were used, found that many researchers used only portions of the HBM (Cohen et al., 2000). Furthermore, no generally applicable measures of the HBM existed. The HBQ was therefore designed to incorporate all core HBM components, plus self-efficacy (operationalised as ratings of compliance confidence in Version 1, and actual compliance in Version 2) as advocated by Rosenstock et al. (1988). While the

HBQ may be used to compare beliefs about different treatments for depression, only findings with respect to the nutritional supplements used in the DIS are reported in this thesis.

Versions 1 and 2 of the HBQ are identical in most respects, except that the wording changes to reflect baseline and post-treatment administrations. Items are answered by checking boxes or marking a series of five-point Likert scales. Ratings are given for respondents' perceptions of severity and susceptibility to depression, and perceived most helpful treatment for depression. Respondents are asked which of four treatments they have already experienced. Treatment choices are psychotherapy, antidepressants, alternative or natural therapies, and prescribed lifestyle changes. Perceived benefits of and perceived barriers to compliance, and self-efficacy, are separately assessed for each of three treatment types: the DIS supplement; antidepressants; and psychotherapy or counselling. A single item is used for each HBM component-by-treatment combination. The HBQ item number relating to each component-by-treatment combination is provided in Table 2. The final item asks respondents have used nutritional supplements in the past, and for what reasons.

Table 2 Health Beliefs Questionnaire Items for each Health Belief Component by Treatment Type

| Health Belief Questionnaire Variables Related to Treatment Types | | | | | |
|--|-------------------|-------------------------|-------------------|-------------------|------------------------|
| Treatment Type | Severity Item No. | Susceptibility Item No. | Benefits Item No. | Barriers Item No. | Self-efficacy Item No. |
| Supplement | 1 | 2 | 5 | 8 | 11 |
| Antidepressants | 1 | 2 | 6 | 9 | 12 |
| Psychotherapy | 1 | 2 | 7 | 10 | 13 |

The HBQ (Version 2) also included a termination questionnaire. Participants provided a global assessment of how compliant they had been with the nutritional

supplement therapy, using a scale from 1 (most compliant) to 5 (least compliant), and their reasons for non-compliance, if applicable. The termination questionnaire was also administered on its own to participants who dropped out of the DIS, if they consented to an exit interview.

The HBQ provides descriptive data on causal attributions, treatment preferences, treatment history and nutritional supplement use. It was also used to produce an overall health beliefs score for the DIS supplement. This total score was arrived at by adding the scores for perceived severity (item 1), perceived susceptibility (item 2), perceived benefits (item 5) and compliance confidence (item 11), and subtracting the score for perceived barriers (item 8). The possible total score range for the HBQ (supplement) is from 3-19. While this scoring method has been criticised, it has been utilised in other instruments designed to measure Health Belief Model components (Janz & Becker, 1984; Champion, 1984).

There was no opportunity to conduct a pilot study of this questionnaire prior to the commencement of the DIS trial. Accordingly, reliability and validity information cannot be reported. However, as it was intended to use the data at least for qualitative analysis, it was decided to include the HBQ as a data collection tool despite the lack of a pilot administration. Face validity was checked by the research supervisor and via administration to a group of non-clinical controls.

Additional Questionnaires

Additional questionnaires were administered as part of the DIS requirements but were not included as part of the Compliance Study. These were as follows:

- Hamilton Depression Inventory–Short Form (HDI-SF) (Kobak & Reynolds, 1999), a reliable and well validated mood measure.
- Food Frequency Questionnaire (FFQ), which was developed for the nutritional analysis component of the DIS. Two versions of the FFQ with slightly different

wording (reflecting the baseline and termination data collection points) were administered.

- SF-36 Health Survey (SF-36) (Ware, Kosinski, & Keller, 1994), an instrument used to assess both physical and emotional health status.
- Perceived Stress Scale-10 (PSS-10) (Cohen, Kamarck, & Mermelstein, 1983), used to measure participants' perceptions of their own stress levels.

Research Records

Comprehensive records of administrative arrangements, participants' questions and comments, telephone conversations with participants, and clinical observations were kept throughout the period of the research project. These records contributed to the grounded theory data analysis.

In-depth Interviews

In-depth, semi-structured, audiotaped interviews, each lasting between 40 and 80 minutes, focused on exploring participants' beliefs about the cause and course of their depression, and their beliefs, attitudes and prior experiences that may have contributed to their decisions about treatment compliance. Special factors that may have contributed to compliance with the nutritional supplement used in the DIS were also explored.

Interview sessions began with an explanation of the nature of the interview, the right of the participant to receive, comment on, and keep a copy of the interview transcript, and their prerogative to decline to answer any question, or to end the interview at any time. Interviews concluded with a debriefing, and an opportunity for the participant to ask questions or make comments about the interview process.

An interview guide was used by the researcher to ensure complete coverage of the topic of women's compliance with treatments for depression. The guide was not

rigidly adhered to, for two reasons. First, it was considered important that the interview format incorporated sufficient flexibility to allow participants to talk freely and comprehensively. To encourage this outcome, the interview protocol was adapted to allow each participant to control the pace and content of the interview as much as possible. Consequently, not every question was asked of every interview participant. Time was spent exploring matters within the interview framework that seemed most pertinent to each interviewee. Second, the interview guide changed from interview to interview, as new issues were raised from the data to that point. New issues were then pursued in later interviews and DIS assessment sessions. Also, some original areas of enquiry became saturated early in the Compliance Study. Some initial avenues of inquiry were found not to be relevant to participants' experiences of treatment compliance. The interview structure was reviewed by a senior clinical psychologist prior to the commencement of the Compliance Study.

PROCEDURE

Participants were randomly assigned to either the fish oil supplement experimental group, or the olive oil supplement control group before their first assessment interview.

There were five DIS assessment interviews and three blood tests during the 12 weeks that each participant was involved in the DIS trial. Assessment interviews were carried out at Massey University's Psychology Clinic in either Palmerston North or Wellington. A clinical psychologist was available for consultation in case any safety concerns arose. This was in accordance with the requirements of the Massey University Human Ethics Committee. Fasting blood samples of 12-15mls were collected at a medical laboratory in either Palmerston North or Wellington by a qualified phlebotomist.

Assessment interviews were scheduled for weeks 0 (baseline), 2, 4, 8, and 12. Each interview session lasted between 30 and 60 minutes, and included the collection of questionnaire data for both the DIS and Compliance Study, the provision of

nutritional supplement capsules, and discussion about the participant's experiences of being involved in the research and complying with the requirements of the DIS and other treatment regimens.

At baseline, participants completed all measures (the PHQ, BDI-II, HBQ Version 1, HDI-SF, PSS-10, SF-36 and FFQ Version 1) and were given one month's supply of either fish or olive oil supplements and instructions for taking them. Four capsules were required to be taken in the morning and again at night, with food. Participants consented in writing to their mental healthcare provider verifying their unipolar depression diagnosis and treatment information. In all cases, a general practitioner was nominated as the appropriate healthcare provider. One participant also nominated a psychologist and both practitioners were asked to verify diagnosis and treatment details. Participants were asked to contact the researcher at any time if they had any questions or concerns about the supplement capsules or were experiencing any side effects. Additionally, the first of the fasting blood samples was arranged.

Participants repeated the BDI-II, HDI-SF and PSS-10 at weeks 2, 4, 8 and 12. The SF-36 was repeated at weeks 4, 8 and 12. Version 2 of both the HBQ and FFQ were administered at week 12. Blood samples were repeated at weeks 2 and 8.

A subset of participants from each treatment group was asked to take part in the in-depth, audiotaped qualitative interviews. These were conducted 1 to 3 weeks after the week 12 assessment. Eleven such interviews were conducted. Where possible, interview participants were chosen based on the principles of theoretical sampling (Strauss & Corbin, 1990). However, a problem arose in accessing participants who dropped out of the DIS early, as most were either not contactable or unavailable to undertake an in-depth interview. One participant who did not complete the study did, however, undertake a qualitative interview.

A professional typist transcribed the interview audiotapes. All identifying material was removed from the transcripts. Transcripts were offered to the participants to

comment on or correct as they wished. Three participants made minor comments, while one chose not to see her transcript.

DATA ANALYSIS

Blood Analysis

Fatty acid levels in participants' blood were used as a biological measure of compliance for the research report in this thesis, as well as being an important measure in the DIS. Fatty acid analysis was carried out on the three blood samples from each participant. Crop & Food Research scientists conducted the analyses. The method of analysis is reported elsewhere (Silvers et al., 2003).

Statistical Data Analysis

The Statistical Package for the Social Sciences (SPSS) for Windows, Release 10.1.3 (2001) was used to analyse the quantitative data. The alpha level for hypothesis testing was $p < .05$ unless otherwise stated. Descriptive statistics were used to summarise the data. Simple correlations, independent samples t-tests, chi squares and repeated measures Multivariate Analysis of Variance (MANOVA) were used to make comparisons between the experimental and control groups, and between DIS completers and dropouts.

Qualitative Data Analysis

Analyses of interviews, portions of the HBQ and research records were conducted according to the paradigm outlined by Strauss and Corbin (1990).

Two or three qualitative interviews were often conducted very closely in time (within 48 hours), due to the participants finishing the DIS in blocks. It therefore was not possible to transcribe and code each individual interview before moving onto the next. However, each audiotape was listened to at least twice before the next

scheduled interview, thus allowing for new areas of enquiry to be explored with each later participant. Each block of interviews was transcribed and initial analysis completed before the commencement of the next subset. There was one exception to this. The sixth interview resulted in a poor quality audiotape, which was difficult to hear. It took considerable time to produce a working copy sufficiently free of background noise to enable transcription. As a result, this was the last interview to be transcribed and analysed.

Open coding of the first four interviews was conducted line by line, using a process of constant comparison of each piece of information within each interview. Questions were asked of the data such as “what is this an example of?” and “what does it represent?”. Each phrase was conceptually labelled to reflect its tentative classification. Labels were written directly onto transcripts and into a separate code list. Patterns that seemed to appear frequently within interviews were grouped together as more abstract categories. The resulting memos of concepts were then compared and contrasted, renamed if appropriate, and negative instances noted. Analysis of later interviews continued in this manner, but with each new piece of data compared with substantive codes in an alphabetical list to see if a previously identified concept label was appropriate. With each subsequent interview fewer new codes emerged.

Concepts were then tentatively grouped into categories, both within and between transcripts. This process occurred several times during the analysis, as old labels seemed inadequate to reflect more abstract ideas. At times categories seemed too broad or too narrow, and needed further division or could be subsumed under other existing categories. At this point, research records were examined for fit with the emergent codes, and considered in light of interview data.

The next step was to formerly delineate properties and dimensions for each category. For example, a category *influential relationships* was found to have the property of *caring*, with dimensions of *extreme care* to *destructiveness*. Some properties had dimensions that did not seem to fit neatly on a continuum, and were more like distinct variables. For example, again within the *influential relationships* category,

the property of *establishment mechanism* had subcategories of *relinquishment of control*, *inability to take control*, *denial of problem*, and *sharing power*. These were treated as dimensions early in the analysis, but were later designated as axial codes.

Categories of “fractured” data were reconnected according to relationships based on conditions, contingencies and consequences of each category. Axial codes changed over time, as data from later interviews was made available for the analysis. Thus, the process was integrated with open coding, or a continuous consequence of it.

Final selective coding was somewhat delayed because of the extended period over which the data was collected, being approximately 20 months. Memoing and diagramming were used to test the fit of each category against all others as theory development progressed. An advantage of a long data collection period was the time it provided to refine questions, re-examine data and ‘sit’ with the data for a considerable period. Several ‘light bulb’ moments occurred as issues were considered and reconsidered, and previously unrelated categories were put together in new ways.

In the thesis write-up period, the final grounded theory was able to be put to four of the in-depth interview participants during follow-up interviews conducted in 2002 for the DIS (not reported here). Overall, their reactions were positive, while their comments helped shape the final form of the grounded theory presented in this thesis.

Chapter 10

Quantitative Results

This chapter presents results from the quantitative portion of the Compliance Study. Participants' demographic and mental health profile data are presented first to provide a context for the quantitative analysis that follows. Frequencies for health beliefs associated with depression, including prior use of dietary supplements, are presented next. Findings on the impact of both treatment effect and health beliefs on compliance are then provided.

For the purposes of the current research, compliance was operationalised in three ways:

- Completing the Dietary Intervention Study (DIS) (completer versus dropout status).
- Increase in levels of omega-3 (n-3) fatty acids in the experimental (fish oil) group.
- Self-rating of compliance from the Health Belief Questionnaire (HBQ) at week 12.

DEMOGRAPHIC PROFILE

Forty-one women enrolled in the DIS, but four failed to complete the necessary baseline measures and dropped out of the study at week zero. The remaining 37 participants were included in the Compliance Study analysis. Twenty participants were randomised to the DIS fish oil (experimental) group and 17 to the olive oil (control) group.

Participants ranged in age from 18-47 years with a mean of 32.24 years ($SD = 9.087$). New Zealand Pakeha/European made up 94.6% of the sample ($n = 35$) with

the remainder being of other European ethnicity (5.4%, $n = 2$). In terms of their marital status, 24.3% ($n = 9$) were single, 46.0% ($n = 17$) were married or living with a partner, and 29.7% ($n = 11$) were separated or divorced. Twenty (54.1%) had children. About two-thirds were in paid employment, and had a family income of \$40,000 or less (67.6%, $n = 25$ for both variables). About one-third ($n = 12$) had completed a tertiary-level degree or diploma, while 24.3% finished their education in or before fifth form, and an additional 40.5% finished in form six or seven. Data on highest educational level completed was missing for one participant. There were no significant differences between dropouts and completers, or between treatment groups, based on age, education or marital status.

MENTAL HEALTH PROFILE

The most frequently reported duration of the current depressive episode was 12 months or more ($n = 21$, 56.8%), followed by 6-12 months ($n = 9$, 24.3%) and less than 6 months ($n = 7$, 18.9%).

Few co-morbid diagnoses were reported by participants. Responding to the question “have you ever been diagnosed with [category of disorder]?”, 28 (75.7%) participants reported no additional diagnoses, 4 (10.8%) reported an anxiety disorder diagnosis, 2 each (5.4% respectively) reported another mood disorder and eating disorder, and 1 (2.7%) a psychotic disorder.

Most participants ($n = 31$, 83.8%) were on antidepressant medications during the DIS trial. Twelve (32.4%) were receiving some form of counselling or psychotherapy. Of the latter group, 8 (21.6%) were also receiving antidepressants. All but one of the participants in this group saw a therapist less than once every two months, and did not see their therapist at all during the course of the DIS. Therefore, impact of psychotherapy was not considered in further statistical analysis. Seven participants (19%) reported having been prescribed lifestyle changes for their depression. Three (8.1% of the total sample) of this group were receiving no other interventions for depression. The nature of the lifestyle changes were not reported and were not

factored into the quantitative analysis. No participants were using any alternative or natural therapies for depression at baseline.

There were no significant differences between DIS completers and dropouts based on any of: medication status $\chi^2(1, N = 37) = .78, p = .38$; duration of current episode $\chi^2(2, N = 37) = .3, p = .68$; or diagnosis of an additional mental health disorder $\chi^2(3, N = 37) = 8.57, p = .07$.

DEPRESSION DATA

The relationship between treatment effectiveness and dropout level was investigated. Scores on the BDI-II were collected to see if there were any significant changes in participants' depression levels over the 12 weeks of the DIS. The mean and standard deviations for BDI-II scores by treatment group separately and combined for the total sample over the trial period are shown in Table 3. The distribution of BDI-II scores at baseline for the whole sample is depicted in Figure 3.

Table 3 BDI-II Scores: Means and Standard Deviations By Treatment Group and for the Total Sample Over the 12-Week DIS Trial

| BDI-II Week | Olive Oil | | | Fish Oil | | | Total | | |
|----------------|-----------|-------|-------|----------|-------|-------|-------|-------|-------|
| | n | M | SD | n | M | SD | n | M | SD |
| 0 | 17 | 24.94 | 11.12 | 20 | 23.15 | 10.10 | 37 | 23.97 | 10.47 |
| 2 | 16 | 17.19 | 10.70 | 18 | 14.06 | 11.20 | 34 | 15.53 | 10.93 |
| 4 | 16 | 15.94 | 13.80 | 17 | 15.12 | 12.30 | 33 | 15.52 | 12.84 |
| 8 | 14 | 11.79 | 10.68 | 15 | 15.27 | 11.24 | 29 | 13.59 | 10.97 |
| 12 | 12 | 8.00 | 6.40 | 15 | 11.07 | 9.70 | 27 | 9.70 | 8.39 |

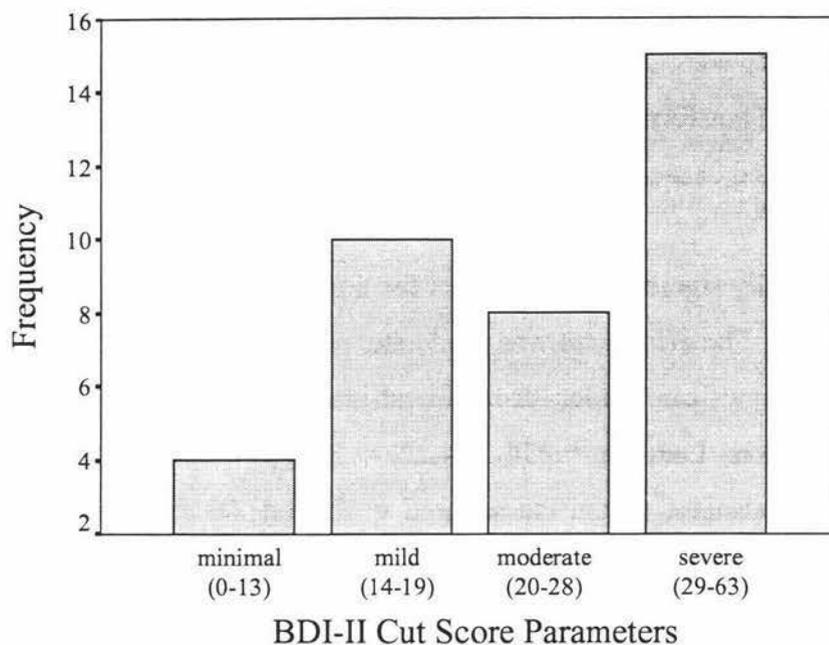


Figure 3 Distribution of Beck Depression Inventory II (BDI-II) Scores at Baseline

At week 0, BDI-II scores ranged from 3 to 47. Four participants (two in each treatment group) had scores in the minimally depressed range as defined by Beck et al. (1996). An independent-samples t-test indicated there was no significant difference in terms of BDI-II score between DIS dropouts ($M=25.10$, $SD = 12.538$) and DIS completers ($M= 23.56$, $SD = 9.827$); $t(37) = -.394$, $p = .11$. The magnitude for the difference in the means was small (eta squared = .02). There was no significant difference between the fish oil group ($M = 23.15$, $SD = 10.10$) and olive oil group ($M = 24.94$, $SD = 11.12$), $t(37) = .513$, $p = .61$, eta squared = .01.

Effect of Treatment and Time

The data showed decreases in BDI-II scores over the course of the DIS for both treatment groups. To assess whether there were statistically significant changes attributable to treatment condition a mixed between-within subjects repeated measures ANOVA was used. Allocation to either the fish oil (experimental) or olive

oil (control) group was the independent variable, with BDI-II scores over time as the dependent variable. Preliminary assumption testing found no violations of linearity, univariate and multivariate outliers, or homogeneity of variances. Only minor violations of normality were found, except for BDI-II scores at week 4, which were positively skewed. Transforming this data did not affect the results significantly, therefore untransformed data are presented.

There was a statistically significant main effect for time, Wilks' Lambda = .382, $F(4, 22) = 8.88$, $p = .001$. The effect size was moderate, partial eta squared = .38. There was no statistically significant effect for treatment group $F(1,25) = 1.27$, $p = .27$, or interaction effect, Wilks' Lambda = .936, $F(4,22) = .377$, $p = .82$, though effect size was small in both instances, partial eta squared = .05 and .06 respectively. These results are presented graphically in Figure 4. These results suggest that there is no significant treatment effect of fish oil over olive oil supplementation for depression in the female sample. However, these results need to be treated with caution as the small sample and effect sizes inhibit analytical power. Accordingly, the relative effects of the dietary supplements on depression are not conclusive. More comprehensive statistical analysis of the larger, combined sample obtained in the DIS is yet to be reported.

Relationship between BDI-II Scores and Dropout Status

The relationship between depression levels and dropout status was assessed at weeks 0, 2, 4, and 8. There was no significant difference in BDI-II scores between dropouts and completers at: baseline, $t(35) = -.39$, $p > .05$; week 2, $t(32) = -1.18$, $p > .05$; or week 8, $t(27) = -1.13$, $p > .05$. Effect sizes were small, partial eta squared $\leq .05$ for each statistic. There was a significant difference between BDI-II score at week 4 by dropout status, $t(31) = -2.064$, $p < .05$. The effect size was moderate, partial eta squared = .12. Women with higher BDI-II scores at week 4 were more likely to drop out of the DIS before week 12 than those with lower BDI-II scores at week 4.

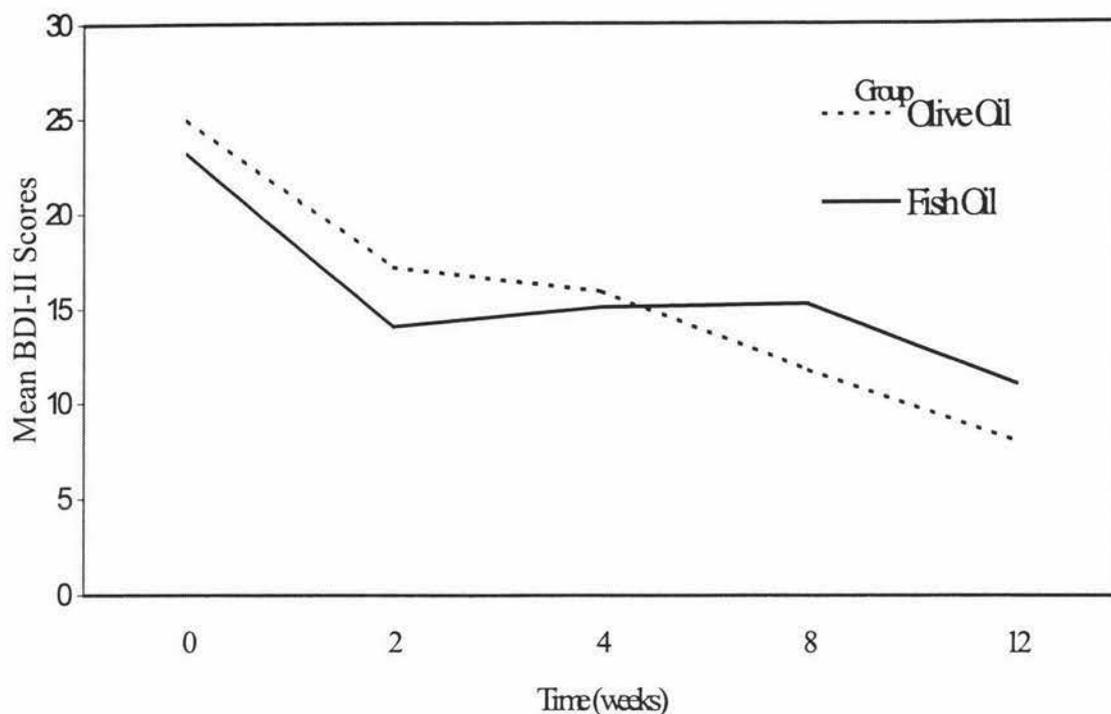


Figure 4 Change in BDI-II Scores By Treatment Group Over the 12-Week Dietary Intervention Study

BLOOD RESULTS AND COMPLIANCE

Omega-3 fatty acid levels from blood samples taken from participants at weeks 0 and 2 were used as a measure of compliance. This measure was available for the fish oil (experimental) group only, as n-3 fatty acid levels are not affected by increasing olive oil consumption as occurred in the control group.

If participants in the experimental group took the fish oil capsules as instructed, an increase in their n-3 fatty acid levels would be expected. In order to assess compliance, participants needed to have submitted blood tests at both baseline and week 2, so that both absolute n-3 fatty acid levels and change in n-3 levels over time could be determined.

For those fish oil group participants who remained in the analysis at week 2 ($n = 18$), absolute levels of n-3 fatty acids for eventual dropouts and completers were compared to determine whether there were any significant differences between these groups at baseline. An independent samples t-test found no significant differences between completers ($M = 5.07$, $SD = 1.55$) and dropouts ($M = 6.57$, $SD = .90$), $t(16) = -1.60$. However, the effect size was very small, partial eta squared = .05. This analysis was repeated using absolute n-3 fatty acid levels at week 2. Again there was no significant difference between completers ($M = 7.01$, $SD = 1.99$) and dropouts ($M = 7.15$, $SD = .86$), $t(16) = -.11$; $p = .9$, partial eta squared = .05.

HEALTH BELIEFS ASSOCIATED WITH DEPRESSION

The Personal History Questionnaire recorded women's causal attributions for depression. Twenty-two participants (59.5%) cited multiple causes for their depression, with stressful life events alone (24.3%, $n = 9$) being second most frequent response. Body chemistry (8.1%, $n = 3$), interpersonal relationships (5.4%, $n = 2$) and childhood issues (2.7%, $n = 1$) were next in rank order of frequency of response.

The Health Belief Questionnaire (HBQ) asked participants to choose between what the most helpful treatment for their depression would be from four categories of treatments. Nine (24.3%) chose psychotherapy, 10 each (27%) chose antidepressants and prescribed lifestyle changes respectively, and seven (18.9%) alternative or natural therapies.

Regarding prior experiences of the four types of treatment listed, 30 participants (81.1%) had experienced some form of psychotherapy or counselling, 10 (27%) had used antidepressants, 12 (32.4%) had been prescribed lifestyle changes, and 13 (35.1%) had tried alternative or natural therapies. The frequency with which participants endorsed different numbers of past treatment options was as follows: 9 did not report any past treatments, 7 reported one past treatment option, 11 reported

two options, 6 reported three, and 4 participants endorsed all four listed treatment options.

Thirty six of the 37 participants had used dietary supplements in the past. Of those, 28 (75.7%) took them to improve their general health, seven (18.9%) for depression, and 12 (32.4%) for other specific health problems.

Due to violations of the expected frequency count in chi-squared analyses, no assessment could be made of differences between dropout and completer groups for the variables discussed in this section.

Relationship Between Health Beliefs and Compliance

There was very little variability in participants' global self-rating of compliance reported in the week 12 assessment interview. Of the 37 participants, 3 (8.1%) rated their compliance as "1" (most compliant), 22 (59.5%) as a "2", 7 (18.9%) as "3", and 5 participants (13.5%) did not respond. Non-responses were recoded as "5" (least compliant)

Nutritional supplement scores from the HBQ were used to operationalise perceived severity, perceived susceptibility, perceived benefits, perceived barriers, and self-efficacy ("compliance confidence"). A total supplement score at week 0 and week 12 was also calculated by adding the scores for the appropriate individual items, as detailed in Chapter 9. Total HBQ supplement scores ranged from 9-16 at baseline and from 7-13 at week 12 (with the possible range being 0-19).

Multiple regression was not available to assess whether the total supplement HBQ score predicted compliance rating for the DIS supplement at week 12, because of the small sample size. Assuming an alpha level of .05 and beta of .20, a sample size of 90 would be the minimum needed to calculate multiple correlations for the five variables required (Tabachnick & Fidell, 2001). Bivariate correlations using the compliance rating at week 12 showed no significant correlation with total supplement HBQ scores at week 0 ($N = 37$), $r = .057$, $p > .05$, or week 12 ($n = 27$), r

= -.238, $p > .05$. Simple correlations between compliance rating and individual elements from the HBQ detected no statistically significant relationships with compliance ratings. These results are presented in Table 4.

Simple correlations were repeated to assess the degree of relationship between survival time in the DIS and total health belief score for the supplement, and its individual components. No significant relationships were found. Results are also presented in Table 4.

Table 4 Simple Correlations Between HBQ Scores for DIS Supplement at Baseline, and Both Compliance Rating at Week 12 and Survival Time.

| Variable | Compliance Rating | Survival Time (weeks) |
|-----------------------|----------------------|--------------------------|
| HBQ total | .06 | .08 |
| Severity | .23 | .01 |
| Future Risk | -.27 | .21 |
| Expected helpfulness | .00 | .09 |
| Expected barriers | -.11 | .05 |
| Compliance confidence | .03 | -.05 |

($N = 37$, $p > .05$ in all cases.)

SUMMARY

No significant differences were found for either dropouts and completers, or fish and olive oil treatment groups, in terms of any demographic or mental health variables. Improvement in depression levels was not associated with treatment group. Although depression scores reduced over time, there was no significant effect of treatment group. However, high BDI-II scores at week 4 were associated with non-compliance operationalised as eventual dropout from the DIS trial.

Blood analyses for the fish oil group found no significant differences in n-3 fatty acid levels either at baseline or week 2 between completers and dropouts. No equivalent measure was available as a biological compliance measure for the olive oil group.

Neither the Health Belief Model (operationalised as the HBQ total supplement score) nor its individual constructs (operationalised by the HBQ components) had any relationship with compliance in the DIS.

The results presented in this chapter were derived from data collected from a small community sample of 37 women with a diagnosis of depression. The DIS results will report on treatment efficacy on a larger sample, including both men and women. Accordingly, no conclusions as to the impact of n-3 fatty acid supplementation on depression should be made solely on the basis of the findings presented here.

Chapter 11

Finding a Treatment that Fits

Although the inductive analysis in grounded theory proceeds from the very specific and individualistic to the more conceptual and general, this first qualitative results chapter presents a “final product” of a core category first. This builds an understanding of the findings, including the linkages between conceptual and contextual elements, and how the selective codes that subsumed by the core category fit together.

The next four chapters provide a detailed examination of the constituent selective and axial codes. The final results chapter discusses how Finding a Treatment that Fits operated on compliance in the Dietary Intervention Study (DIS). A table showing all contributing codes is found in Appendix E.

While research records from all 37 DIS participants informed the generation of the grounded theory presented, the chapter begins by introducing the 11 women who took part in the in-depth interviews. Profiles of these women interviews are provided to give a sense of each as an individual, with an individualised experience of depression and its treatments. All of the 11 women were given a code name to protect their identities.

PROFILES OF QUALITATIVE INTERVIEW PARTICIPANTS

Sally was in her late thirties, unmarried, and living with a family member. She was a beneficiary but undertook some casual work. She first experienced depression in her teens, and had had several major depressive episodes since. There had also been some less depressed times between periods of relative well-being. She had tried a range of medications for depression, but was not on antidepressants at the time of the DIS trial. Sally had seen a psychologist or counsellor through the public health

system at times, and was hospitalised twice for depression some years ago. Sally perceived her treatment as being complicated by an anxiety disorder and competing physical health problems. Sally was in the fish oil group, and completed the 12-week DIS commitment. She did not think she benefited from the supplements.

Ellen was in her mid thirties, married, with children. She had chosen to stay at home with her children, pursue creative endeavours and study. She first became depressed following the birth of her first child, but believed she had experienced depression at times before that. She had tried both antidepressants and counselling with success. She experienced one major relapse, when her GP suggested she stop her medication. She had stayed on antidepressants since then. Ellen was in the fish oil group, and was a DIS completer. She believed she improved somewhat while taking the supplement.

Jane was in her mid forties, divorced, with adult children. At the time of her involvement in the DIS Jane had one child living at home and was on a benefit. Jane had taken medication continuously for many years, and felt her depression was always present to some degree. Her depression was first recognised postnatally but Jane believed she was depressed for some years before that. Her first treatment came several years after her initial diagnosis. Jane was in the olive oil group and was a DIS completer. She reported that she did not benefit from the DIS intervention.

Nicky was in her early twenties, single and a student nurse. She first experienced depression early in her training, and had had two distinct episodes since then. Nicky had tried medications and psychotherapy and found both helpful. She was taking antidepressants during the DIS trial. She was in the olive oil group and a DIS completer. Nicky was ambivalent about the benefits of the supplement for her.

Linda was in her late thirties, married, with children. She operated her own small business. Linda first became depressed in her teens following some dramatic events within her family. However, she was not formally diagnosed with depression until the birth of her first child. Linda's treatments included hypnotherapy, antidepressant medication and psychotherapy. She was receiving antidepressants during the DIS

trial. She was a DIS completer in the olive oil group. She reported feeling “wonderful” taking the supplement.

Abby was 20, and a student with a part-time job. She separated from her partner during her time in the DIS. She became depressed in her mid-teens, and had one major episode since. Abby had tried St John’s wort, counselling and antidepressant medication. She was not receiving any treatment for depression during her time in the DIS. She was a DIS completer, in the fish oil group. Abby felt she may have had some benefits from the DIS supplement.

Helen was in her early thirties, and on a benefit. She had recently separated from her husband and moved to a new town with her children. Helen came from a chaotic and unsupportive family background. She had been depressed for most of her life, but had masked this with alcohol abuse for many years. Helen had tried a range of treatments but never felt anything worked particularly well or met her needs. She was on antidepressants at the time of her involvement in the DIS. Helen was in the fish oil group, but dropped out of the study at week 4.

Mary was in her mid thirties, divorced, with no children. She worked in the health sector in an administrative role. She first became depressed following the break-up of her marriage over ten years ago, and saw her episodes of depression as reactions to stress. Mary found both antidepressants and counselling very helpful in her recovery from depression. She was taking antidepressants during the DIS. Mary was in the olive oil group and completed the DIS programme, but felt any benefits of the trial to her were minimal.

Alison was in her mid forties, married, with children. Alison was made redundant from her professional role part-way through the DIS but found a new job quickly. Her family background was very difficult, and she had relied on alcohol for some years to cope with this. She was first diagnosed with depression in her late twenties. Alison used antidepressants sporadically and reluctantly but recognised their importance for her recovery. Alison was not on any medication during the DIS. She had had one experience of counselling which on balance she found helpful. Alison

felt her depression often abated but never really cleared completely. She was a DIS completer in the fish oil group. She reported experiencing a substantial improvement in her depression during the DIS trial.

Jo was in her mid thirties, married, with several children. She was a full-time mother. Jo first became depressed in her early to mid teens and had been on antidepressants almost continuously since then, with breaks during two of her pregnancies. She found that her depression tended to exacerbate postnatally. Some months before the DIS she had chosen to come off her medication. Jo had had a great deal of counselling but did not find it helpful. She had been hospitalised at least once for depression. She was in the olive oil group and was a DIS completer. At first she reported that the supplements had improved her depression, but later reported that her condition had worsened again.

Mel was in her mid twenties, a single mother of one child and a full-time student. Mel felt she had experienced depression since her early teens, but was first diagnosed when she was 18. She was a sporadic user of antidepressants, and found counselling was very helpful. At the time of this research she had been unable to access any free counselling for some time. She was in the olive oil group and completed the DIS. While she had shown some improvement in her mood during the DIS she was unsure of what to attribute this to, due to simultaneous improvements in other areas of her life.

Table 5 summarises each woman's baseline and final BDI-II scores, and baseline health belief score for the supplement. The final self-rating of compliance with the supplement regimen is also included.

Table 5. Qualitative interview participants' baseline and week 12 BDI-II and HBQ supplement scores, and self-rated compliance score at week 12

| Name | Summary data | | | | |
|--------|------------------|---------------|--------|-----------------------|------------|
| | Week 0 BDI-II | HBQ (sup.) | BDI-II | Week 12 HBQ (sup.) | Compliance |
| Sally | 12 | 12 | 21 | 11 | 2 |
| Ellen | 20 | 14 | 1 | 10 | 2 |
| Jane | 29 | 12 | 26 | 11 | 2 |
| Nicky | 26 | 11 | 8 | 11 | 2 |
| Linda | 41 | 15 | 4 | 12 | 1 |
| Abby | 30 | 15 | 11 | 10 | 2 |
| Helen | 25 | 11 | DNC* | DNC* | DNC* |
| Mary | 15 | 15 | 7 | 10 | 3 |
| Alison | 34 | 11 | 18 | 13 | 2 |
| Jo | 43 | 16 | 7 | 11 | 2 |
| Mel | 38 | 11 | 11 | 10 | 3 |

* DNC = Did Not Complete

THE CORE CATEGORY: FINDING A TREATMENT THAT FITS

Finding a Treatment that Fits was the overarching idea from the qualitative interviews and field notes prepared during the Dietary Intervention Study. Axial codes of Balancing Competing Interests and Getting Good Enough Compliance ran as themes through all of the codes discussed in the next few chapters. Finding a Treatment that Fits provides an image of having to search for a treatment that is appropriate for an individual's diverse needs, rather than accepting unconditionally a "one size fits all" treatment plan. Ultimately, Finding a Treatment that Fits moves a woman from a position of 'compliant' (accepting treatment recommendations and taking action to fulfil them) to 'adherent' (making a decision to maintain her focus on compliance) as she finds the best treatment fit to meet her needs. For some

participants this search was long, frustrating and involved constant reassessment of what constituted treatment that is both feasible and effective. For others, the process was quicker and less convoluted. Some of the women who contributed qualitative interview data had reached a satisfactory end point in their search, while others had not.

Axial Codes in the Core Category

Balancing Competing Interests includes assessing treatment options based on the treatment's effects on depression, as would be expected. But it also requires balancing other disparate elements such as where the treatment fits in terms of the dimensions of one's own illness, its effect on important personal relationships, the meanings one takes from depression, treatment and compliance, and a wider cost-benefit analysis of the treatment under consideration.

Getting Good Enough Compliance refers to women's opinions of what constitutes sufficient compliance to achieve their own well-being aims in the context of their own lives. However 'good enough' compliance may not mean following the rules treatment providers set. Women's opinions about 'good enough' varied from total adherence to making their own rules, and changed over time and according to treatment fit.

These axial codes are treated as thematic overlays in the remaining analysis, and are not separately detailed.

Selection of the Core Category

Eventually, the category of Finding a Treatment that Fits became increasingly more difficult to separate from the other contributing selective codes. Balancing Competing Interests and Getting Good Enough Compliance happened within each remaining category, showing that Finding a Treatment that Fits is all encompassing and intricately related to all other categories. It was felt that its main themes were

present in all other categories. When this point was reached, Finding a Treatment that Fits was selected as the core category.

THE SELECTIVE CODES

The selective codes contain the main conceptual ideas that contribute to and are subsumed by Finding a Treatment that Fits. There are four contributing selective codes:

- Illness Stage
- Influence of a Powerful Other
- Making Sense of Meanings
- Treatment Evaluation

A separate chapter is dedicated to each selective code and its network of axial and substantive codes. The conditions and contingencies that operate on each component are illustrated, as are their consequences, which determine where women “fit” within each element. First, this chapter provides a brief overview of the selective codes and their interrelationships.

Illness Stage

Illness Stage combines depression awareness (recognising depression and how to deal with it), becoming experienced in depression (combining chronological age at onset, and the knowledge that comes with multiple episodes of depression), and assessing depression severity (including episode severity, perceptions of future risks, and whether the women are freed or controlled by treatment).

Illness Stage emerged as influencing compliance in a number of key ways. First, it had a direct effect on how much control over treatment decisions women gave up or had wrested from them. This in turn helped determine how well the treatment fitted with women’s own belief systems. If women were unable or unwilling, due to

Illness Stage, to actively choose how to address depression, then consideration of their own causal attributions and treatment preferences were likely to become casualties. If this piece of the “fit” was missing, women were less likely to comply with a treatment regimen in the long term. Second, Illness Stage incorporated women’s beliefs about their future risk of depression. This risk assessment influenced compliance with maintenance and prevention strategies. Third, women’s level of experience with depression within Illness Stage impacted on Treatment Evaluation in a number of ways. In particular, women’s benchmarking (their assessment against other treatment options) and self-monitoring (women’s own assessments of their coping with compliance and strategies to enhance this) were shaped by prior experience. Illness Stage and Treatment Evaluation interacted in complex ways. For example, more severe symptomatology led to greater vigilance in complying with treatments, but only if benchmarking assessments were favourable.

Influence of a Powerful Other

Influence of a Powerful Other refers to the way women’s treatment compliance was impacted by other important figures in their lives. The “powerful other” could be a family member or healthcare professional. A number of factors were identified as important in these relationships: the mechanism of establishment, ranging from denial of a problem to power sharing; the type of power within the dyad; the degree to which women perceived the powerful other as trustworthy, caring, and competent; and how the women communicated their views and behaviour regarding treatment.

Influence of a Powerful Other interacted with the other selective codes in the process of Finding a Treatment that Fits. First, women experiencing their first episode of depression, or experiencing a depressive crisis, were often unable or unwilling to assess treatment options by themselves. They therefore relied on, or were coerced by, other influential people into accepting treatment. This influence linked directly with both the Illness Stage and later Treatment Evaluation to shape compliance decisions. Data showed that there were circumstances when a more coercive ‘powerful other’ increased immediate treatment compliance. However, the Influence

of a Powerful Other was generally more likely to encourage long-term compliance if the powerful figure was perceived in a favourable light and exercised a supportive or persuasive rather than coercive power.

Second, the mechanism by which the relationship with the powerful other was established also influenced compliance. The women who felt they had chosen to share control over treatment decisions were more compliant in the long-term than women who had had the power relationship forced upon them due to avoiding depression as an issue, or their inability to act for themselves. Illness Stage interacted again here, as earlier or more severe episodes of depression were more likely to lead to the establishment of coercive powerful relationships.

An interaction between Influence of a Powerful Other and Making Sense of Meanings occurred for some women. The powerful other directly (through their recommendations) or indirectly (through the impact of the treatment provided) influenced how the women saw themselves in relation to depression, or changed their attitude towards treatments.

Making Sense of Meanings

Making Sense of Meanings refers to beliefs about depression and treatment, attributions about wellness and symptom change, and beliefs about deferring to the opinions of others. It also encompasses a general health beliefs component. In the context of the Dietary Intervention Study, Making Sense of Meanings also included special factors associated with participating in a “scientific study”, such as altruistic feelings.

To some extent Making Sense of Meanings was driven by women’s histories in the Illness Stage category. It was also influenced by the beliefs and behaviour of powerful others in women’s lives. Meanings contribute to attitudes of hopefulness, helpfulness, and openness to new perspectives and change. In turn, these influence Treatment Evaluation. That is, what a person believes about depression and treatments will colour their view of treatment efficacy and feasibility. Data showed

that if women's personal meanings were ignored, treatments were ultimately doomed to fail, either by a passive choice to let it fall into abeyance, or through an active decision to stop, following an unfavourable Treatment Evaluation.

Treatment Evaluation

Treatment Evaluations are the conscious or subconscious cost-benefits analyses women conducted when considering whether to continue with a treatment for depression. A Treatment Evaluation occurred when the women considered they had given the treatment sufficient opportunity to "work". Within this category the women appraised treatments they tried for efficacy, side effects, indirect effects and barriers to compliance. In Finding a Treatment that Fits, barriers are elements external to the women themselves that were perceived as interfering with compliance.

The women also performed a self-appraisal, incorporating both self-monitoring and self-efficacy aspects. In the self-monitoring mode, women assessed how well they followed the treatment rules. For example, could they continue keeping appointments, remembering to take their medication, performing homework tasks? Self-monitoring included developing strategies to ensure 'good enough' compliance, including making a commitment to compliance. Self-efficacy included both ability to master, and motivation to perform, treatment tasks. For some women, self-appraisal included a move towards treatment self-regulation. This group perceived themselves as having high self-monitoring and self-efficacy, but did not have a good working relationship with their healthcare provider.

Finally in Treatment Evaluation, women evaluated how well the treatment fit with their beliefs about what "should" work, given their current beliefs about depression and its treatments. Interactions with the other three selective codes have been described earlier in this chapter.

THE BASIC SOCIAL PROCESS OF FINDING A TREATMENT THAT FITS

Balancing Competing Interests and Getting Good Enough Compliance occurred continuously in Illness Stage, Influence of a Powerful Other, Making Sense of Meanings, and Treatment Evaluation. The importance of each selective, axial and substantive code waxed and waned differentially as women progressed through their experiences of dealing with depression. In addition, the influence of components was at times historic rather than current. For instance, as the size of Illness Stage increased, so did Influence of a Powerful Other. As the depression abated (and the size of Illness Stage decreased), the impact of the powerful other also abated. Yet the historic powerful relationship often continued to subtly influence ongoing treatment decisions. For example, a strongly positive historic powerful relationship could sway a woman to seek out and comply with similar treatments to those advocated by the powerful other in the past. The powerful relationship might also model the possibilities for future strong therapeutic relationships and power sharing. Alternatively, a strongly negative historic powerful relationship might increase cynicism towards treatments and treatment providers.

The interrelationships between components in Finding a Treatment that Fits are represented diagrammatically in Figure 5.

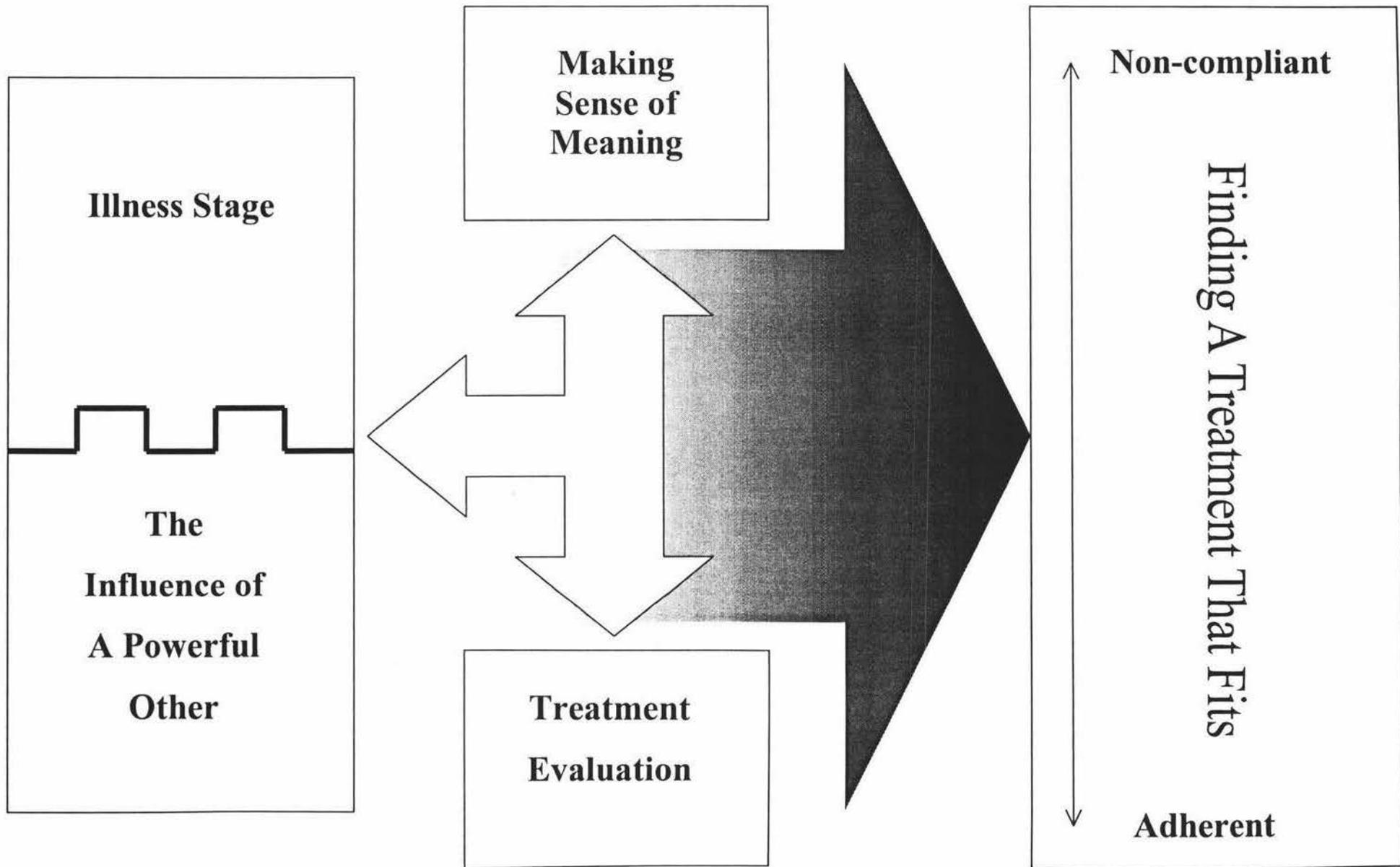


Figure 5 The Basic Social Process of Finding a Treatment That Fits

Finding a Treatment that Fits is not a linear process. It is more like a game of snakes and ladders, with progress and set-backs along the way. The selective codes are mutually influential. Due to a mix of contextual and illness variables, personality, and life experience, some women negotiate this “game” more easily than others.

The Role of Temporal and Socio-Economic Contexts

The temporal context in which depression develops and treatments are tested can also have effects on the process of Finding a Treatment that Fits. Notably, the women who reported experiencing depression for the first time during adolescence perceived the influence of early powerful relationships as having been more negative, or as more coercive, than relationships that arose for other women. The former group evaluated both early and later treatments more negatively, tended to give up on treatments earlier, and tended to have more difficulty in finding a treatment that fitted them, when compared with women who became depressed later in life. However, there could be more than one explanation for this difference. One possibility is that early negative experiences of treatment, or being pushed into particular treatments, made these women more cynical about treatments for depression. Alternatively, perhaps the early onset depressions were more treatment resistant, thus leading women to despair of finding a treatment that fitted the criteria of resolving depressive symptoms with no side effects. It should be noted that most of the women who contributed to the qualitative interviews in the Compliance Study felt that their early treatment experiences coloured their attitudes towards later treatment recommendations. This was not the exclusive realm of those who became depressed as adolescents. The adolescent onset group, however, overwhelmingly experienced early treatments as in some way coercive, unpleasant, unhelpful or at odds with their views of what would have helped. This was despite the efficacy of the treatments themselves.

Another temporal variable was the point in real time at which the women initially experienced depression. Some of the older women had experienced older antidepressants that had either been ineffectual for them or had side effects that were difficult to deal with. They had seen the “valium generation” become over-medicated.

The Compliance Study identified two diametrically opposed compliance responses associated with being an older woman. First, some women expressed reluctance to stay on antidepressant treatments once a crisis had abated, not wishing to become “dependent” on them. Second, others feared sliding into unwellness if they ever stopped medication. One explicitly spoke of her fears of being hospitalised. Younger women did speak of medications as “unnatural”, but did not use the same language around dependency.

Socio-economic context played a role in compliance. If the recommended treatment was expensive, many women finely balanced the costs against the benefits. Some of the women spoke of wanting to try more talk therapy, more nutritional supplements or make radical lifestyle changes, but were unable to pursue these because of financial barriers or family circumstances (such as having to work to earn, therefore being unable to give up a stressful job). Their process of finding a treatment that fitted was limited to those options that presented the fewest financial barriers. Generally, this meant medication and, perhaps, sporadic privately-funded psychotherapy or counselling. Most of the participants did not meet public sector criteria for treatment at community mental health agencies.

SUMMARY

Finding a Treatment that Fits emerged from the data as the core category that best defined the process of deciding whether to comply with a treatment for depression. Optimally, Finding a Treatment that Fits changed the depressed women from merely compliant to fully adherent with treatment as their progress in balancing and achieving “good enough” compliance led to a treatment they could confidently maintain with little support. The process of Finding a Treatment that Fits was complicated for some women, for others relatively simple. Some of the informants in this study were continuing their journey towards Finding a Treatment that Fits.

Four key concepts were involved in the process of Finding a Treatment that Fits: Illness stage, Influence of a Powerful Other, Making Sense of Meanings and Treatment Evaluation. These interlocked, and had differential influences on compliance choices. At different stages, as women progressed in their experience of depression, the selective codes and their elements were balanced in different ways.

In the following four chapters, the selective codes will be discussed. Each chapter breaks the selective code it considers into axial codes, and then substantive codes. Concepts emerged from the totality of data (including research records and questionnaire responses from all 37 DIS participants) though many points were only explored in detail in the 11 in-depth interviews. Illustrative examples are limited to transcript excerpts. In the transcript excerpts, text that is bracketed and italicised indicates the researcher's comments and questions.

In Chapter 16 the grounded theory of Finding a Treatment that Fits will be discussed as it operated within the context of the DIS.

Chapter 12

Illness Stage

Illness stage deals with how the dimensions of depression itself impact on women's compliance decisions, and how these interact with the effects of age and experience. Key elements emerged from the data as three axial codes: Depression Awareness, Becoming Experienced in Depression, and Assessing Depression Severity.

Illness stage provides some of the context in which acts of compliance or non-compliance occur. In a sense it sets the scene in which the concepts and categories in the following chapters are crystallised.

Each axial code below has a number of substantive code components. The substantive code names are listed below each axial code heading.

DEPRESSION AWARENESS

- Seeing it for what it is
- Monitoring what needs to be done

In order to consider whether to comply with a treatment, a person must accept that they have a disorder that would benefit from some kind of intervention. The axial code Depression Awareness arose from the women's stories of becoming aware that what they were experiencing an illness called depression, and that treatments were available to them. Depression awareness also encompasses the monitoring or sensitisation to depression that many of the women mentioned as important in their decisions to start, persist with, stop, or amend a treatment regimen.

Seeing It For What It Is

All the women in the DIS talked at some point about not knowing what was happening to them when they first became depressed. They frequently talked about initially denying they had depression or failing to recognise it:

The very first time was probably when I was, probably about when I was 15 and my parents separated, only I didn't think about it like that then. Everyone else was telling me I was depressed, but I didn't think about it, but I was. Yeah. (Abby)

It's funny but I never ever identified any of it as an illness or even a physiological problem or anything. I just always thought there must be something wrong with me... – there must be something wrong with me – spiritually wrong with me, or whatever. And I always thought it was my fault. (Sally)

Some women recognised that they had moved from a position of unawareness to seeing depression for what it was:

I was like fucked up. I thought I was just a fucked up one of my bunch of friends. And, um, it took a while to realise that it wasn't, that wasn't the case. It was just that I wasn't very well and needed some help. (Nicky)

They described embarrassment, confusion or fear at having to seek treatment. Denial of, or failure to recognise depression meant treatment was delayed, or was initiated by someone else:

I didn't know what was wrong. I didn't really want to go and see my doctor or anything because I was too ashamed... (Linda)

I felt I was a bad mother, I was really like, just absolutely shattered. And that's when [the plunket nurse] said "I think you've got postnatal depression and you need to see someone". (Helen)

Monitoring What Needs To Be Done

Most of the women became good at recognising their depression warning signs. This helped them make treatment decisions:

Um whereas if I'm vigilant and monitoring myself more closely then I am much better at dealing with it. I don't always stave it off completely but I'm better at minimising it and getting on really. (Mary)

I now understand that my depression is a steady build up. So that if I try and ignore it and stand on my own two feet, I'm just going to end up in a worse situation. And I've had three bad crashes and so they say every time that you crash badly you have got the more likelihood of crashing again. (Jane)

A few of the women were not yet experienced enough with depression to fully recognise its onset. This caused them to delay decisions to get back onto treatment or seek a treatment change:

Well I wasn't taking anything but I was, was starting to feel down again. But I didn't know whether, I wasn't sure whether it was depression or whether it was kind of just that I wasn't sure what I was doing. (Abby)

Jo described a catastrophic incident when she was not sufficiently sensitised to depression. This led to her being too scared to terminate treatment again for years:

I spent literally all day and all night in bed, did nothing, the baby got um, [it] was diagnosed with failure to thrive and they eventually - the psychiatrist and the paediatrician decided it was because I was so depressed. [The baby] was put into hospital, into the children's ward for two weeks and basically our lives just fell apart. Um, and I was put onto antidepressants and I've been on them almost ever since. (Jo)

Some of the women were vigilant at monitoring what needed to be done. Jane changed her medication dosage according to her perceptions of her depression, and her own expertise gained from living with it:

I'm taking 10 mg a day and that's enough. And I've worked that out myself, the doctor put me on 20mg a day but when I found it was too high, it was basically up to me to reduce the level. (Jane)

Women who were not adept at monitoring their depression tended to be less likely to stick rigidly to the treatment recommendations of their health professional, and experienced more crises:

I had probably been - with stress in the job and everything - been depressed before that but, you know, you just put it down to stress or whatever. Um, yeah and then after I was pretty upset and going to the doctor, they suggested that I go back on them, antidepressants. (Mel)

BECOMING EXPERIENCED IN DEPRESSION

- Having been there before
- Age at onset

Becoming experienced in depression developed over time, and tended to increase with age. Women who were more experienced in depression were also more experienced at making choices between treatments, dealing with health professionals and family, and knowing what had worked for them in the past. However, for some women, their early depression and treatment experiences seemed to shadow them, and had a marked influence on their perceptions of health providers and treatment modalities.

Having Been There Before

Having had a prior episode of depression influenced women's comparative analyses of treatment (see "Benchmarking" in Chapter 15), and their degree of 'monitoring what needs to be done'.

About half of the women described situations where treatment decisions in earlier depressive episodes were left almost entirely in the hands of their doctor or other health professional, but women participated more in the choice of later treatments.

Not so much [reliance] now. Um I think because I've done a bit of reading, um, and from the medical centre and just I think I'm probably more aware um yeah. [*Right back at the beginning, how much did you rely on your GP?.*] Completely. I had no idea.
(Mary)

Some women talked about taking on a more active advocacy for the treatment of their choice during later episodes of depression:

... I popped along to the old GP again but this time, um, stipulated that I didn't want to be medicated, that I wanted to talk to somebody. (Mary)

Um and I think that there are GPs out there – I've been very lucky but I'm also very outspoken. I'll stick up for myself and if I'm not getting the service or treatment I want, I won't, won't, you know, let it happen. But there's people out there who won't speak up for themselves and will just let it carry on. (Mel)

Age at Onset

Chronological age at onset was entangled with 'having been there before'. Younger women had fewer personal resources to call upon when decisions needed to be made about what to do about depression, and whether to continue with treatment. This, combined with a lack of awareness of having depression, enabled someone else to impose their beliefs about suitable treatments. If no other person stepped in, however,

the young women were left floundering in depression without adequate knowledge of what to do for the best.

Those women who were in their teens when depression first struck described two different patterns of making treatment choices when they were young. In the first, young women were very reliant on a parent or a health professional to make treatment decisions on their behalf:

Um I had to go to some counselling. I found, umm I saw a counsellor that my Mum made me go to. I, she actually made me go to a couple of different ones but I never found one I really liked. And then I had to go to one at school too because my headmistress was worried about me. (Abby)

I had my mother standing over me. [*That's a pretty big incentive to do it.*] Oh, a very big incentive! (Jo)

In the second pattern, young women felt they had no one to lean on to support their treatment choice, and made decisions that in retrospect were unhelpful. Women spoke of variants on this pattern:

I don't know but I didn't take it [antidepressant] for very long, maybe six months. I wasn't told, I didn't know an awful lot about it, I was sort of at that age too, it's like you know, you're not supposed to drink when you're on antidepressants and that interfered with my social life. (Mel, describing her rationale for non-compliance at 15).

Yeah I went to a hypnotist... [*What made you choose that particular path?*] I think I just got um desperateand a hypnotist was somebody anonymous. (Linda talking about her unsupported treatment choice at 15).

By comparison, the women who became depressed for the first time as adults, or who first recognised depression adults, were more likely to try to initiate contact with a health provider themselves, even if they were uncertain or afraid of possible outcomes:

I couldn't see what was happening until one day we had been to see the Plunket Nurse and I was determined that I was going to tell her how I was feeling and then I didn't and yeah, I just remember walking home and just crying all the way home and thinking I've got to do something here. (Ellen)

The narratives of those women who had no real experience of depression until adulthood show that they had been the most successful in finding a treatment that fitted. The data suggest several explanations. First, these women viewed their depression as more reactive than the others:

Um it was as a direct result of a marriage break-up ... um yeah a feeling of hopelessness, that everything you'd dreamt about and planned was no longer going to be a happening thing. (Mary)

This reactive quality was present even if a biological component to their condition was acknowledged:

...it came about postnatally, that was the trigger, but I think for me it was childhood issues. And, I guess I think there must be some biomechanical, I don't know, chemical or something. (Ellen)

Second, this group of women had all developed an assertive commitment to compliance, ensuring they had active strategies in place to help achieve their end goal of living without depression as much as possible. Several of the women who were interviewed in-depth fitted this pattern. They used a combination of medication and psychotherapy to manage their depression, and actively used strategies suggested within therapy to regain a sense of themselves as women without depression.

Third, those women who became depressed as adults all attempted to develop power sharing relationships with their treatment providers. The dynamics of such relationships are discussed in the next chapter.

This contrasted with some of the women who had been adolescents or younger when they became depressed. Many of this group expressed continuing dissatisfaction with their treatment experiences, and often felt unable or unwilling to put in place strategies for change, or felt changes were not “working”:

I sort, I often feel like you're pressured into having therapies and things. Um you often feel like, well it should be working you know so maybe if you keep sticking at it, maybe it will. (Jo)

Sometimes the problem was developing good communication with their treatment provider:

So in the end I just got totally fed up and I just didn't want to, it was better to rely on my own support as limited as it was than to struggle and try and find a professional that was interested. (Jane)

For some of the women, their teenage treatment experiences had left an indelible imprint, which tended to influence treatment evaluations from that point on. For example, Sally had developed a pattern of “knowing what needed to be done” to become well, but felt quite unable to instigate the lifestyle changes she felt were essential to controlling depression. Sally's early depression experiences had been marked by someone else taking responsibility for ensuring she received treatment. Many of her treatments had fallen into abeyance when a valued treatment provider had left. She felt she needed a motivator in her life:

When I'm with my Mum who is the person I'm closest too, I tend to achieve more. You know, she'll just say “we'll just go around the block and do this, it won't matter” – you know. Whereas if I'm by myself I'll just say “forget it, I want to go home”. (Sally)

This pattern tended to be linked to early age of onset. Early ‘age at onset’ was also linked to cynicism about treatment. Some participants spoke of becoming suspicious or pessimistic about treatment providers (see Chapter 13) or the role of different therapies (Chapter 14).

ASSESSING DEPRESSION SEVERITY

- Assessing episode severity
- Assessing where control lies
- Assessing the risk of future episodes

In the context of Finding a Treatment that Fits, Assessing Depression Severity refers to more than just where depression fits for the moment on the continuum from mild to severe. Along with episode severity and duration, it also subsumes expectations about the future risk of depression and the degree of control women feel they have with and without treatment. For example, those women who felt their symptoms were most severe also found that depression lasted longer and/or occurred more frequently. They also tended to perceive a higher risk of future episodes.

Assessing Episode Severity

Compliance with treatment was highest when the women were in crisis, and lowest in the maintenance or preventive phase. Women frequently described taking medication as directed while symptoms were severe, despite the presence of unpleasant side effects:

Um, just the feeling miserable all the time, lots of crying, not mixing with people, um just being incredibly unhappy... [Medication had] um, lots of side effects, lots of dry mouths and um feeling a bit shaky. Didn't like them, didn't like them at all. And it took a long time, it seemed to take about six weeks before I had any benefits. (Jo)

Once the crisis had abated, most of the women began to consider whether the treatment was worthwhile. Early decisions to stop treatment were often accompanied by negative Treatment Evaluations or a degree of wishful thinking:

I don't know, I probably just tried not to think about it. "Oh yeah it's fine, it's fixed now", you know, like taking antibiotics. (Mel)

It was just too hard. I just didn't want to go back there. (Linda, on early counselling experiences)

Well, I went and saw as I said, the counsellor which didn't do anything. I've seen counsellors every year - they don't do anything. (Helen, who had formed a pattern of early treatment termination over approximately 10 years)

Once they considered themselves reasonably well, some of the women decided to "risk it" by stopping treatment because of adverse side effects

I went off the antidepressants....there was a reason for that. I ended up wanting to try a Phenfen drug to help with it, because I'd put on a lot of weight over [that year]... Because of all the weight gain I've had, especially with Prozac. I gained 45 kilos. I mean I might have gained some of it anyway to be fair, but I think a lot was to do with Prozac. (Sally)

Assessing Where Control Lies

For some, an attitudinal shift towards terminating treatment came about because they felt controlled by their treatment, rather than having the treatment control the depression. They became concerned about becoming too dependent on drugs:

[Prozac] Yeah and I can be on it fine. But, and I'm on it for say three months and then I feel I've got to get off this stuff because I'm beginning to be reliant. And its, its basically worse than being depressed because you're in a state of flux I called it, whereas nothing affects you, you could stick a pin in me and I wouldn't feel it.... Yeah. Yeah and I don't think its natural. (Alison)

Assessing Future Risk

Assessing control was linked with assessing the risk of future episodes of depression. Some women decided not to stop treatment once a crisis had passed, based on their experience of having a chronic depression, or of fear of "going down" again. For these

women, 'assessing where control lies' favoured the continuation of treatment, as they perceived that it helped rather than hindered their ability to be themselves in the long term:

So basically I've had 20 years of low-grade depression... I haven't really overcome it. Um, I don't think I ever really am going to be. So it's just learning to live with it, to cope with it... [Medication helps] me to keep in control so that I'm dominant over the depression if the depression isn't taking me over. (Jane).

SUMMARY

The Illness Stage selective code sets the scene for many of the women's later experiences with depression and its treatment. Compliance histories were impacted by both early and continued assessment of depression awareness and depression severity, and through a later development of depression experience. Depression experience enabled the women to make comparisons between their past and current treatments (including who controlled treatments), and contributed to their treatment evaluations (see Chapter 15). To some extent compliance decisions followed a pattern in which the women became more savvy and assertive over time. Alternatively, women became "stuck" by rejecting too many options, or being overly dependent on others to find the treatment that fitted. In Finding a Treatment that Fits, Illness Stage was an ever-present, a "given". Illness Stage elements were balanced within this code, and other selective codes seem to be weighed against it. 'Good enough' compliance was constantly assessed against the severity of depression and experience with the illness.

Chapter 13

Influence of a Powerful Other

This chapter sets out the ways in which the presence, or absence, of significant others can influence compliance at strategic points in women's experiences of depression. The axial codes contributing to this category are: Establishment Mechanism, Type of Power, Perceived Attitude of the Other, and Communication of Treatment Decisions.

Criteria for what constitutes "good enough" compliance may be set by a powerful other. Women respond to those criteria in a variety of ways, depending on how they perceive the stance of the other: is the powerful other taking over unnecessarily, considering the women's perspective, attending to the woman's best interests?

ESTABLISHMENT MECHANISM

- Denial
- Inability to take control
- Relinquishment
- Sharing power

For women in the Compliance Study, powerful relationships arose when they were unable or unwilling to retain control over their own treatment, or when they chose to involve another person. The substantive codes listed above specify the mechanism by which a 'powerful other' can influence treatment decisions.

Denial

Denial of depression, when it occurred, was generally associated with a first episode of depression, and lack of experience with the illness. Where a woman denied having

depression, or did not sense any decline in her mood, the responsibility for treatment initiation was passed to another person. Women who described this were generally women who had become depressed initially as teenagers. The following transcript extract is representative of the experiences of this group:

Um, just the, feeling miserable all the time, lots of crying, not mixing with people, um just being incredibly unhappy. *[Okay. And did you realise at the time what was happening to you?]* No because I'd felt like that for years. *[Did the people around you realise what was going on?]* Um I think my mother knew and got medical advice
(Jo)

Key features of the denial mechanism included withdrawal from family, appearing sad and isolated, expressing concerns about physical illness, but not wanting to talk about feelings. The 'powerful other' for those with early onset depression was always her mother at first instance. Mothers initiated treatment, using persuasive or coercive power to ensure their daughters at least received a preliminary assessment. Several women described their mother making early treatment decisions on their behalf:

Um, oh eventually my Mum made me take St Johns wort which was horrible. (Abby)

Inability to Take Control

The women described how at times they had become overwhelmed by depression, usually when they considered it to be "severe":

I just went into the bedroom for three months, I just stayed in the bedroom, didn't come out. (Alison)

Some women described simply being unable to take control of their treatment decisions:

I think it is [too much when in crisis to seek information or help myself]. And, and it's not knowing where to go.....Oh I said something to [my husband] yesterday about it, it [depression] stops you being able to do those sorts of things you know. (Alison)

In such cases, the women had to rely on a trusted family member, friend or treatment provider to ensure treatment was initiated or stepped up, and that opportunities for both wellness and compliance were increased. This occurred when the powerful other gave reminders of the need to take medication, arranged doctor's appointments, or took the participant to therapy sessions:

I just woke up in the middle of the night and was highly anxious and thinking of things that happened to me when I was 18....And it was terrible. So my auntie took me back to see the doctor. (Sally)

Relinquishment

Relinquishing power involved making an active choice to allow someone else to direct treatment decisions. That person was given responsibility for ensuring compliance, if possible:

You want them just to sort of take your load on to their shoulders so that you can get rid of it for a while. (Jane)

Note that women who were unable to take control generally tried to make their own decisions, but found they could not. In relinquishing control, women did not want that responsibility, or perhaps recognised that someone else was better able to "take care of things". All of the women described occasions when they had relinquished power to a health professional, usually their doctor. Generally the relinquishment came when they were too tired to battle depression any longer. Relinquishment sometimes came after having successfully been in control for a time, but then 'going back down'. Therefore, it was associated with disappointment or being in crisis. Helen described relinquishing control and accepting medication, even though this was not congruent with her beliefs about finding a treatment that 'fitted':

Yeah, I mean, he put me back on I because I had a panic attack and I said "I'm not living with this shit". It was like the last straw. I said "I'm not doing it [taking Prozac]". And he said "what do you want to do?" And I said "I don't know". He said "do you want to

try Prozac?" and I said "whatever". I wasn't happy about going back on it because I hadn't had it for about two or three years, whatever it was. But I wasn't going to live like that. (Helen)

Sharing Power

Many of the women felt they had now reached a point where they were able to make active and discerning choices between treatment options. They had also decided to allow a treatment provider to share in their decisions about how and when to treat, and when to terminate their treatment.

I've been to see my GP and, um, it's up to me whether I stay on that or finish with it now. (Nicky)

The issue for these women was less to do with compliance, and were more about *adherence* to a treatment they had approved of following the recommendation of a treatment provider. They did not associate decisions to stop or adjust their treatment with being non-compliant, but with a re-evaluation of their treatment needs. The underlying idea was of being part of a team that managed the problem:

[The GP] knows I've got it. I can walk in there tomorrow and I could have Prozac and there would be no problem. I wouldn't have to go through history or anything with him because he knows what I am and he knows I'm not stupid. He knows when I need it and just gives me Prozac. He says "we treat it like measles, it needs to be managed, it's like a disease, if you had a cold you'd take" - I don't know - "Coldrex. Okay so you've got depression, if you need Prozac take it for as long as you want and then go off it". And that's the way we - me and him - deal with it. (Alison)

The establishment mechanism code does not represent a continuum, in a true sense, along which women progressed. Women did not progress through all types of establishment mechanism. Some moved from either being in denial or unable to take control of treatment decisions in an early episode, towards sharing power later. Often no mid-point mechanism was invoked. More unusually, Mary described instances of

inability to take control, power sharing, relinquishment, and then sharing power again. In the following extract, she moved from inability to take control, to relinquishment, once a friend had pointed out that her self-management strategies were not enough any more. This allowed her to see her situation as becoming more subsumed by depression, and decide to relinquish control for a while by asking her doctor to take over:

And I fought it long and hard this time, I fought going to GP long and hard. And then in the end it was a very good friend of mine who said to me “what are you worried about”. She said “would you rather not be well and doing something about it than continue to be as miserable and ill as you are?” and I thought hmmm, very wise lady. (Mary, who then put treatment decisions in her GPs hands for a time)

TYPE OF POWER

- Coercive power
- Persuasive power
- Supportive power

When control was taken over by the powerful other, there were variations in how it was exercised. Substantive codes were developed around three types of power: coercive, persuasive, and supportive.

Coercive Power

Some of the women felt pressured into treatment that they were unhappy with, or could not see the justification for:

I know it's from my childhood, so what good are drugs going to be, you know. But you feel, well, I'd better give it a try. (Helen)

Some women felt they had been coerced into counselling by their partners or doctors. These women cited inconvenience to the family or financial barriers (see Chapter 15) as reasons for discontinuing treatment early. Interestingly, during recruitment for DIS participants, several men answered the newspaper advertisements on behalf of their wives or partners. It soon became obvious that the women themselves were not keen to join the study.

Conversely, sometimes a powerful other terminated treatment in what the women saw as quite an arbitrary way:

I guess it was the doctor just throwing his weight around and assumed that he knew what was best for me. He was insulting, actually, yeah... I just accepted that it was okay, but I knew inside that that wasn't the right thing. But I guess I wasn't strong enough to do anything about it. (Ellen)

Examples were also given where family members used coercive power to ensure treatment and compliance, though the motives of concern for the participant's well-being were generally acknowledged with hindsight:

I, she actually made me go to a couple of different ones [counsellors] but I never found one I really liked. I see why she was worried but I wasn't happy at the time. (Abby)

And then nothing changed until about, Mum made an appointment for me because I was so bad, made me go. I was really, really bad at Easter time – just terrible.... And she made an appointment for me and I saw [the community psychiatrist] then. I was a bit annoyed then, but she was probably right. (Sally)

Persuasive Power

Encouraging or recommending a treatment, or compliance with a treatment, was classified as persuasive power. While the effect of persuasive power was often the same as with the exercise of coercive power, the women talked in subtly different terms about

the two. Women recognised the intention behind the exercise of persuasive power at the time it occurred, rather than with hindsight:

So, only when things got extremely bad I had a friend actually found me counselling and says "Well I've made the appointment, you turn up". And this last time I've gone for counselling it's been the same thing, somebody else has intervened, seen that I'm bad and done the groundwork for me. It's nice to know they're watching out for you. (Jane)

Supportive Power

The use of supportive power consisted of low-key actions to encourage women's efforts to get well. About half of the women placed considerable value on these 'interventions'. Early in treatment, supportive power was often crucial in assisting women to put up with side effects and persist to the point where their symptoms were alleviated.

Um, I think Mum helped a lot and, and I mean after I'd started taking them, and I got to think "oh, you know, it's not too bad apart from the you know side effects". But um, yeah, no it does help to have people, you know, telling you that ... its good that you're doing something. (Abby)

To summarise to this point, immediate compliance was enhanced when a powerful relationship was established during a crisis. Often the women needed someone else to set treatment in motion or help them through its difficult early stages. Coercion did not enhance long term compliance if the women's own belief system did not support the treatment choice of the powerful other, or if her treatment evaluation is overwhelmingly negative. However short term compliance was at times improved by coercion.

Both ongoing compliance and a willingness to revisit treatments later was enhanced when the power changed from a more arbitrary (coercive/persuasive) to a less arbitrary power (persuasive/supportive) once a crisis had abated. The depressed person was able to take back control and consider the merits of treatment options. For example, Alison described her husband, Mark, using persuasion to encourage her to take medication when she is really down, even though she felt uncomfortable about doing so. Alison

recounted how Mark would cite their daughter as a reason to use medication, and she would reluctantly agree. However, Alison “can always talk to Mark” when things get better and he always supported her decisions regarding medication at that point. In this way, she can reserve medication for when she needs it, but she doesn’t have a constant pressure to take antidepressants. Some women found themselves “stuck” in a position where their family or doctor favoured continuous treatment, even though the women recognised that this pressure probably resulted from concern.

PERCEIVED ATTITUDE OF THE OTHER

- Caring
- Trustworthy
- Competent

The women assessed of three properties of the powerful other: being caring and trustworthy, and being competent to make treatment recommendations.

Caring

Generally, the women considered that family members acted from a more caring perspective than healthcare providers. In Abby’s case, her mother’s caring approach overcame Abby’s scepticism of some of the treatments her mother wanted her to try:

Mum was really helpful, she - you know - was trying to do everything she could and giving all different ways to do things. (Abby)

However, a few women directly acknowledged a caring element to the professionalism of their healthcare provider. One woman spoke of a counsellor who helped her through a difficult time adjusting to a new antidepressant, which helped her to comply with that treatment:

So it was really good to have one constant person that was there and helping throughout that time. (Nicky)

Even in hindsight, it was not always possible for some of the women to view particular powerful others as caring or acting out of their best interests. The earliest powerful other in Jane's depression experience was her stepmother:

...and just after your last interview I just suddenly picked up that as a child my stepmother always used to say to me "Oh if you carry on this way you're going to end up in Porirua". So that's why I think I've always not wanted to acknowledge that I was having problems, I tried to bury it because you had that scary thought that, you know, of mental asylums and electric shock treatment and really horrible things going on. (Jane)

Trustworthy

Trust arose explicitly in two of the in-depth interviews. Linda implicitly trusted the advice of her doctor regarding medication. She did not seek further information or question the advice given:

You know I just kept taking it because you're supposed to, they recommended I do and, um, yeah I don't want to go how I was without them. (Linda)

In the second piece of discourse, Nicky raised trustworthiness with respect to the Dietary Intervention Study:

...my partner didn't like me taking them [the DIS supplements] because, um, just it looked like a lot and he didn't really trust that it was a dietary supplement, he thought "oh no they've put something in that you know. They haven't you know, they're doing it in secret, they haven't informed you properly of things". But I didn't agree with that...It would be pretty bad. <laughs>. (Nicky)

While not commented on explicitly by the other women, it seemed that it was important to trust the person directing treatment, though the criteria for trust were not standardised.

Some of the women based trust on competence and reputation, others on caring and rapport. Jo terminated treatment early based on rapport:

I mean with the last one I just didn't like him at all so I just didn't, didn't listen to him I guess. (Jo)

Competent

Competence generally arose when the powerful other was a healthcare provider. It involved feeling that the provider was both informed and in tune with the women's individual needs and desires.

The women considered provider competence to be a crucial attribute, and discounted recommendations or advice of those healthcare providers they felt were incompetent to treat them:

I got a new doctor and everything and he was just useless and told me that I'd been on this medication for long enough and it was time to come off it and so being the good girl that I am that's what I did and just spiralled again. (Ellen)

Probably 90% [reliance on health professional for guidance]... Um it depends on the psychiatrist as well. Um I guess a lot of it depends on how, how good I think they are. (Jo)

In instances where the provider was not viewed as competent, the women either did not comply with the treatment prescribed, or resolved not to see the provider again. This held as much for counsellors and psychologists as it did for GPs and psychiatrists:

I mean coz I know the woman I went to see at school she asked all the wrong kind of questions. And every question she asked I just, I exaggerated everything just to, just to see how far I could push her. That's just because she annoyed me. (Abby)

I had to write down whether I salivated or if I'm thinking about food – blah blah. But it was so obvious to me even then, hey the issue isn't food here. Come on! I'm using food as something. (Helen)

Both Abby and Helen discontinued their work with their therapist concerned as soon as possible after they began to feel the therapist was not competent. In Abby's case, her age and the power relationship established with her mother prevented her from ending therapy for some time. These examples contrast sharply with the discourse of women who felt they had been in the care of a competent healthcare provider:

I found a new GP who was wonderful and started me back on Prozac and that was really good. (Ellen)

I mean at the moment I'd really like to go and see the psychiatrist that [my son] saw because I really felt that I talked to her, she understood, you know she just seemed to really have a grasp of what was going on. (Jo)

COMMUNICATION OF TREATMENT DECISIONS

- Being straight
- Choosing non-disclosure
- Avoiding hurting people
- Implicit messages

The data showed that the mechanism, type of power and perceived attitude of the powerful other had considerable impact on how women communicated treatment decisions with those involved in their recovery from depression.

Being Straight

Women who felt secure in the relationship with their powerful other, and shared power with them, would discuss with the powerful other their views on how treatment should continue, or to make it known that they had decided to stop treatment:

And I would never have said I wasn't going to take them or something. I would have been straight about it I think. I would have said to them – I wouldn't have got involved in deceit or anything over them. (Sally)

Those women who had more success in controlling depression acknowledged the need for good communication. They made treatment decisions with emphasis on 'technical advice' from their healthcare provider, with whom they had established a good working relationship.

I mean [I] would not do anything without talking to her, anything substantial...I mean I can't expect her to know what's going on with me if I don't tell her. (Mary)

Choosing Non-Disclosure

Other women were more cautious in disclosing their chosen treatment path. Jane was locked into a relationship with her GP because she needed continuing scripts for medication, but no longer discussed her pattern of compliance with him and, according to Jane, he no longer asked:

The doctor doesn't really know what I'm taking. It's up to me that if I'm going through a bad patch that I know that I can increase the medication. (Jane)

But this strategy did have down sides for Jane. Her medication was not always easy to self-regulate, but she was unwilling to discuss management strategies with her GP:

You know when I came off them – um, cold turkey because I got the flu - I had a really bad reaction to them. And not, not having an understanding doctor and not

understanding myself, not taking medication very often, it's very difficult to find the right level. And at times you can feel good but you just feel like you're totally zonked out as if you're not in control of yourself. But you can't say that to them. (Jane)

Avoiding Hurting People

Women generally expressed greater reticence about communicating reasons for stopping psychotherapy than at wanting to stop medication. Many women who felt they would tell a treatment provider about problems with, or deciding to stop, medication but would not divulge their qualms about psychotherapy. This was often explained as not wanting to hurt the powerful other or treatment provider, or not wanting to appear ungrateful:

No, I didn't want to hurt them. I didn't want to offend them by saying its not helping....In the end I [stopped making appointments]. One of them moved away. She got shifted to over in the Hutt, so I said "no, I'll be right now". (Helen)

Probably not. No....especially if they really think its helping (Jo, on not communicating with her counsellor about her dissatisfaction with the treatment)

This 'passive' communication style was also evident when communicating with powerful family members:

Oh I kept on with it for a while then just stopped when Mum seemed to think things were okay. Yeah. (Abby)

Implicit Messages

For women who were less able to take control, felt more coerced, or less happy about the attitude of the healthcare provider, communication was seldom explicit and direct. For example, in one instance Jo stopped seeing her psychiatrist by failing to make further appointments. By doing so, Jo wanted to send a message that she did not like the psychiatrist or his methods. This 'message' was qualitatively different from 'avoiding

hurting people'. The intention was not to protect the therapist or avoid embarrassment at having to own up to feelings of dissatisfaction with treatment. In the example below, Sally disagreed with a plan to stop in-patient treatment:

And I don't think the Charge Nurse liked me and she came round and said "you're leaving today" or something – and, I'm like "oh, ok". Anyway, so the next day I attempted suicide....I thought, "I'm going to" so I took an overdose of my antidepressant actually....And I don't remember much but I went to hospital and had my stomach cleaned out. Woke up in hospital on Saturday. (Sally)

SUMMARY

Many women experienced a powerful other taking charge of their treatment during their early episodes of depression. Often this was a family member, but sometimes a healthcare provider filled the role. The establishment mechanism and type of power exercised could lead to more or less control being given or taken away. The less power the women had, the less likelihood that others would recognise their views on what treatments would be appropriate. Women tended to eventually abandon treatments that they felt they had little control over.

Powerful others also appeared at later points in the women's experience of depression. Later relationships could involve more power sharing, though some women remained 'stuck', repeating earlier patterns.

The qualities of the powerful other, as perceived by the women, influenced women's treatment choices and maintenance of compliant behaviours. In some cases, pivotal relationships changed women's depression beliefs in ways that made the treatment experience either more positive or negative. Qualities such as care, trust and competence also influenced how communicative participants were about their decisions around compliance. The esteem in which the powerful other is held could make or break opportunities for second chances at treatment provision.

Chapter 14

Making Sense of Meanings

This chapter outlines how women's attitudes and beliefs inform compliance with treatments for depression. The axial codes are: Beliefs about Depression, General Medication Beliefs, Beliefs about Treatment, and Being a Good Girl.

BELIEFS ABOUT DEPRESSION

- Causal attributions
- What depression means about me

All of the women were able to identify what they thought had led to them becoming depressed, and what they thought experiencing depression meant about them. Causal attributions influenced compliance via acceptance or rejection of treatment choices that either fitted or were divergent from their belief systems. What depression meant about the women influenced compliance via both an aversion to treatments that might be stigmatising, and an exploration of areas of the self that they had previously not acknowledged.

Causal Attributions

Causal attributions ranged from the highly biological/genetic to the highly environmental, but with most of the women acknowledging more than one factor in their susceptibility to depression. For some women, causal attributions had been influenced by the beliefs or recommendations of powerful others in their lives, or had changed somewhat over time as a direct result of a positive or negative treatment experience.

All but one of the women felt that their depression had at least some biological component. Often this was expressed as both a genetic diathesis, and a perception of a hormonal trigger. Five of the qualitative interview participants had experienced postnatal depression:

Well for me its genetic, it is in our family. But then I think too your personality, whereas some of them, the more extrovert ones in our family have got the lesser degree of depression.... But the thing that would have triggered me off was my second pregnancy. (Jane)

Two women raised additional hormonal trigger points:

I have, have a feeling it stems from puberty. You know the hormonal changes that happened to me then and the situation with my family combined. (Mel)

So I had a couple of years there of sort of like pre-menopause symptoms, which they now tell me are far worse than going through menopause itself. I had the night sweats, the fatigue, ah - just irritable, hot flushes, and being just absolutely tired. So a lot of that I think was also depression. (Jane)

Women with strong biological causal attributions for depression tended to have faith in medication, having seen clear benefits to taking antidepressants:

I mean I suppose I'm seeing depression more now as a physical illness because if - I mean it's a mental illness but caused by a physical cause, caused by the chemical imbalance. Otherwise why would you have taken antidepressants to correct it? (Mel)

Mel had changed her causal attribution over time to incorporate a biochemical component as a result of a GP's explanation of depression as a "medical" problem that would improve with the use of antidepressants. For her, a biological diathesis presented an alternative to thinking of herself as a bad person, or a bad mother.

Most of the women saw antidepressants as a necessary but insufficient element in their recovery. In fact, some women saw medication as a crisis management tool, reserved for when their chemical imbalance was at its most severe:

I'm just not sure that they can really help me at this point. I think if you were just sat in a corner and couldn't move and were just so depressed, I think okay fair enough try some drugs. (Sally)

A few, like Linda, feared that relinquishing medication would send them spiralling down into a deep depression again. Compliance was easy to achieve:

I know how bad I have been and I don't want to go back there. And I, I'm just too scared....sort of, they're a bit of a crutch I think. (Linda)

The women who proposed that their depression was reactive, or due to unhelpful responses to stress, were more ambivalent about the place of medication in managing their depression:

Um if it's a choice between the Prothiaden and the counselling then I would say the counselling hands down. The Prothiaden was there when I needed it and I don't think I could have talked to anybody back then. Um the Prothiaden enabled me to get up in the morning. (Mary)

It's really hard to tell because I always think about, you know, when you're taking things and you feel better, is it 'do you feel better because you're taking something', so you feel like you're making a difference, or 'do you actually feel better because of the things that are in the, in whatever you're taking'. So I don't know. (Abby)

What Depression Means About Me

Several of the women felt that depression had defeated them, and that accepting treatment was an acknowledgement of that defeat. This view worked counter to compliance:

But then I went to the doctor and they told me I had depression and I felt really really depressed. <laughs> Because they told me I was depressed and I was really upset about that....I just, I just guess maybe it just freaked me out because they wanted me to go on antidepressants and I didn't want to. I don't know, I think its kind of like admitting that you really do have a problem which I hadn't had to do until then. (Abby, who did not sustain treatment into a maintenance phase)

While ostensibly not having a direct effect on compliance for women who were very unwell, stigma was a factor in decisions to discontinue medication early rather than follow longer-term treatment recommendations. Several women described dealing with stigma around taking antidepressants:

The stigma. I always make a joke of it. I leave it out in the open. People see it and I, you know, I say, if someone comes home and I'm taking it I'll say, "oh shit I forgot my Prozac, I better take one – turn round and kill you". You know, make a joke of it. (Helen)

Alison described fears that a medication would cause side effects that were visible to others:

You, you wouldn't even think about it [trying a treatment with obvious side effects]. You couldn't because you, um I do believe people still will not accept mental illness as just an everyday thing that people have to live with, you know, learn to live with. And I mean there's hundreds of people out there with all sorts of forms of mental illness. (Alison)

Some of the women were able to use their diagnosis and treatment of depression as a route into a personal exploration of aspects of themselves that had previously been hidden from view. They saw depression as representing a vulnerability, which they had taken steps to overcome. These women knew that deep depression could reappear in their lives, but felt confident that with their new strength and understanding of themselves, they would overcome it. Generally, the medium for this transformation was some form of counselling. For these women psychotherapy was not only easy to attend and relate to, but often anticipated as a periodic time of self-discovery:

Just feel like I'm uncovering layers and just sort of this losing this weight inside me just above it. (Ellen)

Because I think I reached a stage where I didn't want the rest of my life to be this small, narrow, miserable person. I wanted yeah I wanted to be somebody different I guess. Um and so maybe I was just ready? (Mary)

GENERAL MEDICATION BELIEFS

- Medication as a management tool
- Medication as a negative

General beliefs about medication were mentioned by some of the women, and could have either a positive or negative impact on compliance with antidepressants.

Medication as a Management Tool

Some women saw medication generally as useful in managing illness and were not averse to considering antidepressants in the same light. Mary found it a relief to be able to think of depression medication as a management tool after a rationale was provided by her doctor:

...um, when I was talking to her about this one and she said some people are diabetics and take medication for it... she said depression is really no different, she said you, you know, "you just live with it everyday". (Mary)

Medication as a negative

Others found the idea of taking any medication unacceptable:

Yeah when it comes to doctors and stuff I mean you know I just don't like it...I think its because, you know a fix, when you have to take something like that it means you really have a huge problem. (Abby)

I see it as a chemical and I see it affecting you in some way. I think it's not good, I don't like it, I don't want to be on it. (Alison)

BELIEFS ABOUT TREATMENT

- Openness towards treatment possibilities
- Attributions for wellness

Openness Towards Treatment Possibilities

Whether the women were open to different treatment possibilities influenced not only their willingness to accept or select a treatment choice, but also how long they "stuck it out".

Women's attitudes towards the orthodox treatments of antidepressants and counselling ranged from very open to cynical. Those who could rationalise the treatment mode as being in line with their causal beliefs were more likely to try the treatment and "stick it out" for more than a few months. While the women differed in their attitudes towards alternative therapies, the gap between them was less than it was with conventional therapies. Those women who were more cautious about the value of a treatment type

were more likely to give up early, or to consider it wasn't working for them. Findings from the data on particular treatment types are outlined below.

Positive attitudes towards antidepressants were associated with biological causal beliefs. Degree of positivity was often influenced by actual treatment experiences. Trial and error approaches to prescribing medication were aversive:

I just, I mean that ..., you know, you go in and they say you've got depression and then they can't just go "well this is the right one". And they say "well take this one and if it doesn't work we'll give you this one, and if it doesn't work we'll give you this one" and "you've got to wait" It's like, you know, the first one, like two months to see if it even starts to work and then you've got to stay on it for how many months? And then if it doesn't work out you stop that and you've got to start all over again and in the meantime you're not getting better at all. (Abby)

Some women had positive experiences with antidepressants despite having initial reservations. Linda "believed in" psychotherapy, but had opened up to the idea of medication because it was easy:

Whereas medication is, I felt like a failure for having to take it and that I should be able to cope, I shouldn't need this. But that was easier to just take it....Yeah. And it didn't require as much effort to go [to a psychologist]. (Linda)

Acknowledging the usefulness of psychotherapy was associated with a belief in a more stress-related depression, or in having dysfunctional responses to the world.

I needed to learn different ways of thinking, different thought processes....to think the right way rather than think yourself into a hole. (Mel)

However, even where women accepted that talk therapy could be useful, they were not necessarily completely "sold on it":

I'm a bit cynical about [psychotherapy]... And I think sometimes while I was with that one with Adult Children of Alcoholics, I don't think they realised what it's all about. And all they are doing is sitting and asking you the right questions. So what I found is that they do these prompter type things that, and I can't see how that's going to help my depression. (Alison, who also had positive experiences of psychotherapy)

Helen, who had found little satisfaction from any of the treatments she tried, had initially been excited by the idea of psychotherapy, but always felt let down by it. Her vision of what therapy should look like did not match her real life experiences, and consequently her time in therapy was invariably short:

Well, I went and saw, as I said, the counsellor, which didn't do anything. I've seen counsellors every year – they don't do anything. Well, I don't know. It was funny like – I suppose as you see on TV, like you go to see a shrink and you should be lying on a couch and they can say “oh, this is because you're mother, you know didn't breast feed you.” You know. And it wasn't like that. It was like – it was just like talking – and shit – I've got people I can talk to, you know – I want some answers. I wanted, like, this is what you've got to do. But they didn't do that. They just asked questions, they didn't connect things. (Helen)

Many of the women expressed an interest in complementary and alternative medicines (CAMs). Linda was the most open and positive about the idea of CAMs:

I like finding out things, I like knowing what's out there. I'm open to suggestions just because, I don't know, there might be something better out there that I don't know about. (Linda)

However, few were willing to try “just anything”, especially where their prior best treatment option fitted reasonably well:

I had been to see an iridologist and she recommended that I try [St John's wort] but I was a bit dubious. [*What made you dubious?*] Well the medication I was on seemed to be, it has made a difference and I was dubious to stop taking that to try the St John's wort. (Linda)

Some CAMs or dietary changes were almost universally more acceptable than others:

So something like that [supplements], that I can understand. Where you're sort of, like, just taking little tablets and just balancing what the body is, I could do that. But the alternative ones where you've got to eat strange sorts of foods and they probably taste horrible, um, I'd rather put up with the depression. (Jane)

Helen, who had yet to 'find a treatment that fitted', had become more circumspect about most therapies for depression, including the use of supplements and non-traditional therapies:

Well, back then it was, I was wanting to do anything and everything. But things have changed in the past few years and I'm a bit more, I'm more aware that I've got to be a bit more careful. (Helen)

None of the women had tried any physical or spiritually-based therapies for depression. Few had used any provider-delivered CAMs. Nicky had tried Reiki for general relaxation, and Abby had tried homeopathic remedies for minor physical ailments. Nicky thought Reiki might offer some benefits to people with depression. However, her reasoning centred on its client focus, rather than on any empirically supportable benefits of Reiki's specific components:

I think even the fact that someone's sitting there focussing on you for half an hour, um, to someone whose in a really bad state of depression, would really make them feel sort of a bit special and worthwhile and all those sort of things as well. (Nicky)

Some women could see specific benefits for some disorders, from some CAMs, though not necessarily for depression. Abby's openness to homeopathy was limited, and seemed to preclude possible benefits for depression. She had tried these treatments at the behest of her mother, her 'powerful other' in terms of the theoretical framework of this analysis. Abby attributed some of the benefits of homeopathy to a medication effect, and some to the patient's belief system:

It was good. I mean because it was just for like, um, I had a bee sting, I had an allergic reaction to bee stings...It works well for things like that. Just like, I don't know, she had all sorts of pills. <laughs> "Take this".*[Okay. So you, you don't have very strong beliefs yourself?]* Um. I think it works for different people... I do believe that if you do think something is going to work it tends to work better than what it would if you don't believe it's going to work. (Abby)

Most participants were open to the idea of dietary supplementation as a measure to prevent the onset of depression, but more sceptical as to the benefits of supplements as a remedy once depression had taken hold:

Yeah I sort of I understand I actually would have liked to have had a chance to use more herbal remedies like St John's wort or something. Um, but I let it go too far and really needed proper medication. (Jane)

It was apparent from the women's discourse that, with respect to CAMs, compliance was a somewhat inappropriate term. Only one DIS participant had ever had any CAMs prescribed or recommended by a healthcare provider of any type (Linda, see earlier). If women chose to use any self-help dietary supplement then the only treatment recommendations were those provided on the container. Dosage recommendations were often quite wide ranging as well, so almost any dosage taken was within the recommended range. Therefore, the concept of 'compliance' was not germane, and 'adherence' barely so. The women themselves simply chose when to start and stop treatment:

I'd tried different things sort of like when I wasn't too bad. I was on, just sort of took extra Vitamin B and took [herbal supplements], which to me is easier than sort of trying to change your diet and your lifestyle. Just for a while, as I can afford them. (Jane)

...but I haven't always been very consistent in taking them unfortunately...I think specifically I've taken B vitamins to help my moods and depression. Because I've read that there's quite a strong link there. *[How long would you have taken those for – the B*

vitamins?] Well I remember taking the B vitamins for probably only about 2 months. Probably only about one bottle. (Sally)

Attributions for Wellness

Beliefs about what had actually relieved depression were also mentioned by many of the women. Where benefits were attributed to treatments received, the women were more likely to comply with those treatments in the longer term. However, sometimes women did not attribute recovery to the treatment they were receiving, or were unsure what had caused an improvement in their mood. Abby was a case in point. Several pieces of her interview indicated that she was cautious of attributing positive outcomes to any treatment modality:

I mean it's not long enough really to say that that was definitely what was making a difference or whether it was just that I felt like I was doing something. (Abby, on her experiences with antidepressants)

I saw one guy, he was okay. But I kind of thought I was better, felt better after that anyway, so I didn't feel like I needed to go back. (Abby, on seeing a counsellor)

And, regarding her perceptions that she had "got better" during the DIS, but did not know what to put that down to:

I don't know. I think maybe I'm just, I might be just sick of being, you know, a doormat. So I'm changing. But you know I do definitely think I'm more confident and it's easier to make decisions. (Abby)

This pattern, though often in less extreme versions, was also apparent for about one third of the study participants. The uncertainty of where to attribute change (to their own growth, natural remission or therapy) led to termination of treatments when women felt in control of depression; there was no maintenance phase. Of the women who completed in-depth interviews, Mel (regarding antidepressants), Linda (psychotherapy) and Alison (the DIS supplement) were ambivalent about attributing gains to treatment.

Both Mel and Linda also found compliance with some treatments difficult because of barriers (see Chapter 15). Alison's supplement experience is mentioned in Chapter 16.

In summary, treatments were continued for longer if the recipients were clear that their moods had improved as a result of those treatments. If not, they were more inclined to discontinue, especially if the treatment modality was a poor fit with what they considered should work, or there were too many barriers to compliance.

For some of the women, negative outcomes were attributed to treatment, regardless of whether these outcomes were empirically supported as treatment side effects. This contributed to termination of treatment if there was no compensatory recovery from depression:

I saw psychiatrist after psychiatrist, the GP sent me in for tests and stuff, um, and in the end I just decided that I would stop. The side effects, it just wasn't worth it. (Jo, on an undiagnosed condition she developed while on one antidepressant)

Helen experienced difficulties with the nutritional supplement trialled during the DIS. Some of her side effects were known possible side effects of the supplement, but others had no known association with the supplement she was taking. However, she felt the signs were that she should drop out of the study before the week four interview:

My skin. It got really, really bad. For a while there I had a bit of the shakes on. You know.... just wondered, I just wondered. It just said in the thingy [instruction sheet] if anything came up just to let you know. Anything that's out of the ordinary for me. Whether it was coincidence or, you know. (Helen)

BEING A GOOD GIRL

- Doing as I'm told
- Making a contribution

The axial code Being a Good Girl emerged in two distinct parts. The first, 'doing as I'm told' applied to a subset of the women across most treatment modalities. The second, 'making a contribution', was important to most of the women who completed the DIS, and arose in the special circumstances of taking part in a research study.

Doing as I'm told

Some of the women who considered themselves to be highly compliant with all therapies saw themselves as "doing as I was told" or "being a good girl", at least in relation to some of their treatment experiences. For some of this group, compliance became self-directed over time, for others following instructions reflected their investment in a powerful relationship or the need for an external motivator.

The data revealed several of the qualitative interview participants as 'good girls' who had 'done as they were told'. Their experiences show both similarities and differences. Ellen, Mary and Linda had all benefited from most of their depression treatments. They acknowledged that their experience of treatments had either been without major side effects or barriers (so following instructions was easy) or that they had persisted in spite of side effects or barriers until the benefits were apparent. All considered themselves to be inclined to try to please authority figures in their lives, and to avoid confrontation when they could. Their differences showed three distinctive patterns of 'doing as I'm told':

- Mary reported no aversive treatment incidents, so had not experienced any dissonance between 'being good' and finding a treatment that fitted.

- Linda persisted with psychotherapy for two years beyond the point at which she felt it was useful. Also, while she felt reasonably happy with her doctor's treatment of her, Linda wanted more information about her medication but felt unable to ask:

I have a few questions that probably I would like to ask, you know, regarding the taking of it... Um I don't sort of feel like I can just go to the GP to ask him that. Um, yeah, just again - purely just to put it in the back of my mind and carry on. (Linda)

Her inability to assert herself with healthcare providers made her slightly uncomfortable, but not so much that she considered changing her behaviour.

- Ellen had moved from 'doing as I'm told' as a result of an aversive experience with depression. Ellen's doctor terminated her medication before she felt ready. She accepted that decision, even though she felt it was not right for her. Ellen relapsed into depression. Her reaction was to find another GP with whom she developed a power sharing, more assertive relationship. Consequently, she had moved on from "doing as I'm told".

These data suggested that, for women who generally acknowledge authority and/or value the good opinion of others, an internal pressure in favour of 'doing as I'm told' increased compliance. It may be that 'doing as I'm told' helps maintain compliance for this group of women unless and until some *sufficiently* aversive treatment experience causes them to reconsider their pattern of behaviour. Alternatively, their personal growth may cause them to re-evaluate their responses to others.

Making a Contribution

This arose only in relation to compliance with the requirements of the DIS: taking the supplements, attendance at interviews, and having blood tests. The emergence of this code led to an exploration of the literature on placebo effects and special conditions affecting participants in research trials.

Responses from the Personal History Questionnaire (Appendix C) showed that most of the women in the DIS trial wanted to help others with depression, or help with the progress of depression research, by participating in the DIS. Sometimes altruistic reasons were the primary motivator for joining the study, and sometimes the prospect of being involved in a scientific study was enticing:

Well it was funny really, it was not for me at all, it was I can be part of a study that will help some other people. (Ellen)

Oh I just found it really exciting. When I read the article in the newspaper about it I just, oh I just wanted to be a part of it, I wanted to, to be in on it. (Linda)

For others, the feeling of ‘making a contribution’ was on an equal footing with or secondary to benefiting personally from the DIS:

Um I’m always willing to try something new if I think it might help. Um, and also I mean if it benefits anyone else then you know that’s good. (Jo)

Coz I thought, I just thought I may as well give it a shot, number one. You know, try anything. It might just work. Um, and other than that I just kept thinking you know “well these people are trying to do something to help people with depression and anything that can help anybody out with depression is a good thing”. Because I just, I mean you know it’s bad enough feeling like this yourself, when you think about there’s other people out there feeling exactly the same as you and you know there’s got to be something that can fix it, you just have to find it. (Abby)

The women who gave altruistic motives more weight for joining the DIS found compliance easier than those who joined more to help themselves. For example, Mel perceived herself as compliant with the study, despite not attributing change in her mood to the DIS supplement. She was asked why she persisted:

Um because I’m not a quitter. That’s just, I don’t quit and it’s like well, well how silly is that, “oh well I don’t notice a difference I’ll just give up”, well how does that help

anybody else? You know I could have been in the control group and not, you know, have anything at all. So how does that help the other people that it might actually really work for? (Mel)

Several of the women who felt that they had improved on the DIS supplements stated that they would not have reneged on their commitment to the study, even if they'd thought they were on the placebo:

It didn't make any difference, because I knew that it was the job to be done. (Ellen)

I would have carried on because I'm like that. I see things through. If I say okay I'm going to do something, I'll do it. (Linda)

Of the 11 women who completed in-depth interviews, only Helen, who pulled out of the DIS early, did not mention making a contribution at all when asked about her reasons for joining the research:

I can't remember. I've got such a shocking memory. I'd sort of just moved up here, and I'd just been separated from my husband and stuff so everything was like – I was quite really stressed. You know. Because what got me [was] the diet connection: I could see the old food thing coming back and that's when I thought it was going to be about. Food. (Helen)

In summary, making a contribution only arose in the special circumstances of participating in a research study, and increased compliance via a commitment to assisting others with depression, or to advancing research into depression. In the context of the DIS, making a contribution was sometimes intertwined with 'doing as I'm told' to preserve or enhance the relationships between participants and the researcher. These issues are explored further in Chapter 16.

SUMMARY

Women used their belief systems to select (or reject) treatment options, and as reasons for not complying once a treatment regimen was initiated. Strongly biological causal beliefs meant that antidepressant treatments made more sense, whereas strongly environmental causal attributions for depression led to psychotherapy being the preferred treatment. However, most women had a multi-factorial attribution system, sometimes developed or adjusted to accommodate the influence of other powerful people.

Openness to different types of treatment meant that women were more likely to try a range of treatments, and give them longer to work. While most of the women were "open" to the idea of the less extreme CAMs to improve their depression, few had specifically tried any CAMs measure other than self-help dietary supplements for depression.

Data suggested that if a treatment was not a good fit with an individual's belief system, attribution of any positive change in depression could be made to non-treatment factors. Similarly, negative effects were more likely to be attributed to the treatment itself.

Being a Good Girl was an important feature of the compliance behaviour for some, but not all, of the DIS participants. When it arose in usual treatment settings, 'being a good girl' was associated with a general characteristic of the women concerned to follow instructions, and seemed to abate if 'doing as I'm told' led to a sufficiently negative experience following compliance, or perhaps after a period of personal growth. In the special circumstances of a research study, a sense of altruism was an important contributor to forming a commitment to compliance.

Chapter 15

Treatment Evaluation

At some point in their treatment programmes, women make a conscious or subconscious evaluation of the treatment they are receiving. Some of the issues they consider are quite obvious, such as the treatment's impact on depression, its cost and side effects. However, other issues are also important. Five axial codes were identified relating to Treatment Evaluation: Impact of Treatment, Benchmarking, Self-Appraisal, Barriers, and Fit with Belief System.

The cost-benefits analysis process discussed here is a complex one. Impact of Treatment overall received a higher weighting than the other components. However, exactly which substantive issues among the remaining axial codes were most pertinent for women did vary, from individual to individual, from time to time, and as the women's circumstances changed.

IMPACT OF TREATMENT

- Assessing treatment efficacy
- Indirect positive effects
- Side effects
- Indirect negative effects

The primary issue for the women in their assessment of any treatment was how it impacted on them and those around them. Four distinct parts of this category were important: assessing treatment efficacy, indirect positive effects, side effects, and indirect negative effects.

Assessing Treatment Efficacy

The women assigned the highest weighting to the effect their treatment had on reducing their symptoms:

Um, well it's your mood really, I mean if my mood is picking up then I'm likely to stick at it. (Jo)

This feeling going away...It's a, you know the feeling that 'what is the point of getting up tomorrow'. If that would go away you would know [if treatment was worth continuing]. <tearful>. (Alison)

Some of the women said they would "know" immediately if a treatment was working. However, for others this was more nebulous:

I don't know that I noticed myself at all I mean that [depression had improved]. That 18 months is a real black gap but I remember a lady that I worked with saying to me... "you've turned a corner" ... it was my demeanour...and I was just lighter really, lighter and brighter um yeah I don't know that I actually remember, yeah I mean I don't really remember much of that at all. (Mary)

Women who had improved on antidepressants talked about the gradual shift in mood almost sneaking up on them:

...it's a bit like giving up smoking. You think you're going to feel better the next day and it's such a gradual thing that it's not until you look back kind of, you know a few weeks or whatever later, that you think, oh yeah that is better. So, yeah, it wasn't immediate, but... (Ellen)

Women who did not improve, or attributed improvement to non-treatment factors, were less likely to continue. However, some women also reported stopping antidepressants when they began to feel better, rather than continuing to use them through a maintenance phase. This could create a yo-yo pattern of usage:

Um, I started taking them, but after about three months I felt so much better so I stopped. But then I went back down quite quickly, so started again. I must have taken those ones for about, oh I don't know, five months? And I was off again for maybe six months, then went back to the doctor. (Mel)

With talk therapies, treatment efficacy was assessed as being a more gradual build-up of returns, with the returns for some women diminishing with time.

Ah initially I think it helped. Long term I'm not sure. I, um, don't know that the counselling that I had was very effective. I didn't feel that it was going anywhere. (Linda)

Despite her reservations, Linda continued counselling sporadically for two years. Other women who felt psychotherapy was not working simply ceased to make appointments, without advising their therapist. However, it may have been that some therapists would have agreed that it was a good time to end therapy, thus changing their clients' status from 'non-compliant therapy dropouts' to successful 'completers'.

The women for whom psychotherapy improved their depression were keen to continue with a psychotherapy regimen or to try counselling again:

I think my treatment of choice would be counselling...Because I have tried drug therapy and that was really useful but I just knew that that wasn't the whole answer. And that I needed to have some form of counselling and therapy to get to the bottom of everything. I would definitely continue. (Ellen)

Indirect Positive Effects

Many of the women noted that not only did they themselves feel better when a treatment was working, but there were also indirect benefits. They considered these indirect positive effects in their overall Treatment Evaluation. Generally, indirect positive effects related to family life being less conflicted or more relaxed:

Well, I think I noticed it in [the children] because of the changes in me. When I was really angry and yelling and they were quite, well, especially my eldest one, was quite nervous... just he was, yeah becoming quite anxious about things and now he's a lot more relaxed about life. (Ellen).

I can tell by how family life is. Whether it's worth sticking to it... I mean if its something that's, that's helping but I'm so exhausted from side effects or, you know, the side effects are making me really agitated or whatever then its probably not worth it. Um, but if its helping and things [are] going smoothly then yeah I'll stick at it. (Jo)

Side Effects

Adverse side effects were noted by about half of the women as a factor in their stopping use of antidepressants at some point in their illness. However, unless side effects were very bad, they were usually insufficient by themselves to cause the discontinuation of a treatment that was alleviating depression. The main impact of less severe side effects was in making women wary of trying the same thing on a later occasion, or in leading to treatment self-regulation:

Probably because of that weight gain issue I would be terribly...I would be terribly suspect, very careful and monitor it really, really carefully that I didn't put on weight. (Sally, considering the hypothetical possibility of using antidepressants again)

...if I take a normal dose for an adult I go on a complete high and I'm just, I'm like a happy drunk, I'm just totally relaxed and not functioning. I could just walk underneath a bus and wouldn't even notice if it hit me. (Jane, who regulates her own medication dosage)

For those women badly affected by side effects, there was a point at which they considered if positive effects of treatment outweighed the negative effects:

Mmm, it got to be worse than the depression. I mean it wasn't too bad in the start but then it just, just really, got really bad. (Abby)

Um, I think the realisation that if I don't, you know, keep taking them, then things would get worse. That they are actually helping. You know, despite the side effects. The side effects are actually not as bad as the depression. (Jo)

This balancing of side effects versus treatment effects is an ongoing process. Jo's assessment of where this balance lay was "tipped" towards non-compliance when her medication (and consequent side effect pattern) was changed by a new psychiatrist trying to alleviate her existing side effects:

Um, and on top of that he reduced my dose right down, I mean I was on something like four tablets a day and he took me down to one. Um I feel that I still had the side effects. But I wasn't getting very much benefit at all and after a couple of months I just decided "well", <pause> "I'll stop taking them". (Jo).

Women undertaking other forms of therapy did not discuss side effects.

Indirect Negative Effects

Indirect negative effects included any negative change attributed to the *fact* of undertaking a treatment for depression, rather than to either a side effect or a "treatment that went wrong". When mentioned, indirect negative effects were generally effects on their relationships with significant others. Whether indirect negative effects contributed to a discontinuation of treatment depended on whether the pros of treatment (direct and indirect benefits) outweighed the cons (side effects, indirect negative effects and barriers) of the regimen. For example, in Helen's case, negative comments from her husband were not a decisive factor in her compliance decisions, but added to the list of reasons for dissatisfaction with medication. For Jo, her perception that she could be a better mother on antidepressants usually outweighed the negative impact that antidepressants had on her relationships with her husband and mother:

...my husband, he tends to make pretty derogatory comments about the, the drugs and things... He implies quite constantly that it's not a good idea to be taking them. My mother is very anti taking anything. [*So how do you respond to those kind of*

comments? Or do you?] I don't. I mean it's all in, obviously I do inside when I think about it but I don't respond to them. *[Okay, and does it effect your ... taking your medications?]* No. Its better for the children. (Jo)

For one woman, effects attributed to medication withdrawal were weighed as an indirect negative effect:

I saw a doctor then ... and actually had a short course of antidepressants but I came off them cold turkey and got to the stage where I had panic attacks and that frightened me off using medication again. (Jane)

BENCHMARKING

- Comparison with prior treatments
- Comparison with other possibilities
- Giving it time to work

Benchmarking refers to the women's comparison of their current treatment against other treatment options. Positive impacts, side effects and barriers could be assessed in the benchmarking process.

Comparison with Prior Treatments

Most of the comments relating to benchmarking referred to direct comparisons of current treatments with that had been tried already. Some comments presented in previous chapters showed how the women favoured one treatment modality over another. Comparisons were also made between specific treatments within modalities. An excerpt from Nicky's in-depth interview is illustrative of women's making comparisons between different types of antidepressants:

I had some [antidepressants] that I couldn't sleep. Um, [then] I was on clomipramine and that wasn't very nice. Um, but the one I'm on now I sort of don't feel any side effects at all. I just sort of generally feel like a well person. (Nicky)

Comparison with Other Possibilities

Some benchmarking involved the women assessing their treatment against possible options that they had heard of from other people, or had read about. Magazine articles and friends were used as sources of information, though women relied most heavily on their doctors for information. Abby eventually tried an antidepressant for the first time following a bad experience on St John's wort, concluding that antidepressants "couldn't be any worse":

...and there was no way I was going back on St John's wort, so um it was kind of like learn to give it a shot. (Abby)

Giving It Time to Work

The most common theme in the benchmarking discourses was 'giving it time to work'. This related to the time it took to feel *any* effect from a treatment, or the time it took for a woman to feel she had benefited *sufficiently* from a treatment:

No I think I sort of gave up on alternative therapies ... Yeah I'd rather not wait, I mean you have to wait a couple of weeks as it was for like, you know, the chemical antidepressants to work. Um, let alone waiting for something that might not work. (Helen)

Some of the women had concrete views on how much time was long enough to try a new treatment:

Um about a month. (Jo)

Two weeks. I mean if you're feeling bad, I mean it's usually when you go to seek treatment if you're feeling bad. Anything longer than that, and that's ridiculous, you just, yeah...Pinning your hopes on something that may not work. (Mel)

Three months. 'Coz that's how Prozac works. Within three months you feel you could - I don't know - kick a football over a goal. (Alison)

Despite the previous comment, Alison responded to a hypothetical six-month wait for real benefits positively, as long as there was a high chance of success "because you've got the rest of your life".

There were various outcomes of benchmarking. Those women who were more compliant generally, and had better relationships with their treatment provider, would discuss any negative assessments with that healthcare provider, and perhaps revert to a former treatment, or try a new strategy. However, those women who were typically less compliant, prone to early termination, or had a poor relationship with their treatment provider were more likely to end treatment early if benchmarking did not favour the current remedy.

SELF-APPRAISAL

- Self-monitoring
- Self-efficacy
- Treatment self-regulation

Self-Appraisal concerns the women's assessment of their own ability to comply with the requirements of treatment. It has three component parts: self-monitoring, self-efficacy, and treatment self-regulation.

Self-Monitoring

The women assessed how well they did in complying with the requirements of treatment. Self-monitoring included: being aware of forgetting appointments or doses of antidepressants; developing strategies to increase compliance; and making a commitment to compliance.

Many of the women felt they were generally good at self-monitoring:

Yeah. I mean I'm pretty good at taking pills and stuff anyway. (Mary)

However, some women described times when they were "too far down" to concern themselves with whether they were taking medication as directed:

I just sort of didn't want to think about it. I mean, I just took them straight away. You know, you are meant to take a quarter. I thought "stuff it". I just took them whole. (Helen)

Those who were good at self-monitoring had developed strategies to ensure that treatment requirements were fulfilled. Many strategies involved creating treatment cues by linking treatment events to other events, such as taking other medication:

That is the bit that I find difficult. I have to have it beside me, right beside my bed and if I don't take it first thing in the morning, I have difficulty remembering whether or not that I've actually taken it. So now I've sort of, you have to work out strategies, so now I think "well, okay, I take half a tablet" so I know that Monday, Wednesday, Friday I start a new tablet. So then Tuesday, Thursday, well I've only got a half a one left. (Jane)

Other women used environmental cues:

What I do is I remember to take my multivitamins [with the antidepressants] and then my weeze is green, and then I know I've taken it. Because I know I've got a shocking

memory. Because otherwise I forget to take it. Because I'm not on the pill. When I was on the pill it was easier – real easy. Reach – one, two. (Helen)

One woman described how built-in cues in the packaging of one brand of antidepressant had helped her:

There was one called Serzone and it had the days on it and it had a little sunshine and a little moon so you knew your day ones and your night ones. They were the best designed packet that I'd ever used. (Nicky)

Another woman used her own bodily responses to missed doses to assess whether she had taken her medication:

Sometimes I will find that, um, especially with the last tablets that I was on, I'd find after, I think, about two to three days I would actually get really bad side effects, I'd feel pretty dizzy and sick and awful...- Flushed and I would know...I would take them. (Jo)

Forgetting tended to occur when no links were created as a reminder:

I had trouble taking that because I had to remember to take it twice a day which was a bit more of a stretch than once a day <laughs>. (Abby, who tied her morning antidepressant dose to her contraceptive pill)

Self-monitoring was easier with appointments for therapy or for medication reviews, and none of the women described “forgetting” these. Problems that arose with psychotherapy tended to have a self-efficacy or barriers component. These factors are discussed later in this chapter.

Some of the women had made a determined commitment to compliance. They made a decision to do whatever it took to become well or stay well. For example, as previously noted, Linda at times felt that talk therapy wasn't working for her, yet nonetheless she was compliant with its requirements until her therapist considered her well. Part of her compliance was related to ‘being a good girl’ (see Chapter 14). Despite her desire to be

“good”, she had also made a commitment to herself do what she needed to in order to get well:

So I thought that I had to [continue therapy] you know. [*Yeah? Where was that feeling of “having to” coming from?*] Just in my head. Mentally I felt I’ve got to do this to get better. (Linda)

Women described planning ahead to ensure their treatments were successful. Nicky, Mary and Ellen all used their own information sources (notably magazines and the internet), as well as their healthcare provider to find out in advance about the side effects and advantages of treatment. They could make comparisons and prepare for adverse consequences. Linda valued the advice and information she received from those of her friends and clients who had experienced depression, and adopted their tips on coping with treatment. Mary discussed how she planned with her doctor to ensure success:

I think I’d been warned by the GP both times that it is a gradual thing, that it might be two to three weeks before you start to notice anything. Um, particularly the first time, I was seeing the GP regularly anyway. I think we decided I’d see her once a week or once a fortnight for about three months, um until she was happy that I was past the worst of it. Yeah. (Mary)

By contrast, the women who were generally less compliant, such as Helen and Abby, did not describe making a commitment to persevere with a treatment or planning to overcome obstacles. Their attitude tended to be more cynical about the potential benefits of treatment:

[regarding antidepressants] I guess I had barriers against, I mean I don’t like taking drugs anyway yeah, I just, yeah.... I had so much trouble just, you know, actually managing to take them just coz I had a resistance to it. Which I’m not sure, quite really sure why, I just didn’t like the idea of it. (Abby)

I don’t know [what would be the best treatment option] because there’s nothing out there. (Helen)

Self-Efficacy

Self-efficacy in Finding a Treatment that Fits included confidence that the various components of treatment could be fulfilled, and motivation to continue to comply with the regimen.

Being able to fulfil requirements of treatment was mentioned most often in relation to psychotherapy. This was especially relevant to homework assignments for women who had received cognitive behaviour therapy. At times, an inability to perform these assignments as required was tied to a perception of pressure to put other family members first:

I think I did try and make the effort but I didn't always...Too many other things. Putting myself on the back burner, too many other things, too many other people to have to worry about before I could find the time and the space just to do that myself. (Linda)

The women sometimes felt that if they weren't able to do the homework or make the suggested lifestyle changes, there was no point in continuing with therapy. Some felt guilty going to therapy without having completed their assigned task. Jo found it hard to make the changes suggested by psychologists and occupational therapists, and had given up on many periods of counselling:

Um, probably because I just don't feel able to put a lot of the steps into place. A lot of them suggest, you know, the main sort of theme seems to be "well its because of the children, its because of your husband, its because nobody does anything around the place", you know, "its just stress, reduce your stress somehow" but I just don't see how. (Jo)

Motivation to make lifestyle changes also featured in the women's discussion of self-efficacy:

I realise now that it's actually my lifestyle that needs changing and because I've been sort of basically negative for 20 years it takes a lot of work to actually change it. They

say it takes three weeks to make a habit but it only takes one day to break it. Um and then you've got another three weeks to sort of build yourself up again....And I don't want the hard work, I would just like a magic answer. (Jane)

But I haven't always been very consistent in taking them unfortunately. Again, it's the internal motivation factor. It's not there. I need external motivation, I think. (Sally, on trying to take nutritional supplements in the past)

Low motivation, as a result of depression itself, was a consistent theme for some women. For Sally, this created a vicious circle. She believed that making lifestyle changes was necessary to resolve her depression, yet "impossible" to achieve at times because of low motivation, caused by her depression:

I think the change in moods make it difficult. Because when you wake up and you feel okay it's easy to do them and then the next day you can feel so different and its all such an effort. (Sally).

Treatment Self-Regulation

A few of the women felt able and motivated enough to regulate their own medication. They tended to be women who had many years of experience with depression, and did not have a close relationship with a treatment provider. For instance, Jane had made a decision to regulate her own dosage some years ago, and combined medication with vitamin supplements when she could afford to. She felt she understood her own body and mind better than her doctor did. She did not consider herself non-compliant:

To me it's more natural. And I feel like I've got more control over it. But that's when I'm understanding now that, okay, there is something lacking in my brain that needs the extra medication. So keeping it on a maintenance level but trying to seek alternative remedies that are more effective.... (Jane)

Thus, treatment self-regulation seemed to be indicative of high self-monitoring, high self-efficacy, and low reliance on a powerful other.

In summary, Self-Appraisal included the ability to monitor compliance and generate strategies to ensure success with treatment. It also included being able to master and motivate compliance actions. The more committed the women were to achieving this end, the more adherent they saw themselves. Treatment self-regulation appeared to be a special aspect to self-appraisal associated with high self-monitoring and self-efficacy, but low reliance on a relationship with a health care provider.

BARRIERS

- Financial burden
- Inconvenience
- Anxieties about risks
- Losing a treatment provider

The axial code of Barriers incorporated environmentally based obstructions to treatment. It included financial and administrative issues, treatment risks and concerns around the loss of treatment providers, especially talk therapists.

Financial Burden

Those women who perceived themselves as most compliant identified fewer financial barriers to trying or maintaining treatments. They were either financially security or they prioritised expensive treatments in their budgets when required:

[on whether cost stopped her trying supplements] No, but I guess that's because we are in a position where that's [money] not an issue. (Ellen)

No I just go and get it [counselling or unsubsidised antidepressants]. If I need it I just go. No, no because I think you have to. (Alison)

Costs prevented some of the women from pursuing certain treatments they had had in the past, or would have liked to try:

Because we were on the one income and yeah that would have been another burden that I would have yeah felt bad about. (Linda, on psychotherapy)

Cost would be a big barrier ... at one stage if my medication was going to cost me \$50.00 a month I would just have to say "well I'm going to have to find an alternative". (Jane)

Inconvenience

For some of the women, the logistics of attending therapy were a considerable barrier. Transport and fitting psychotherapy in with the demands of work were barriers for a few. But the most prominent concern was finding childcare:

...because I had a baby, because I had a child that I had to ask someone to look after, that was a big burden to me too. (Linda)

Though not mentioned in the audiotaped interviews, one DIS participant spoke of being reluctant to ask friends or family to mind her child, in case she was asked where she was going.

Anxieties About Risks

Concerns about the long-term risks of antidepressant treatment were raised as a reason for considering stopping treatment early, or thinking hard about a recommended course of treatment:

Because I mean I'd hate to think you know 20 years on, yeah well antidepressants cause cancer, something like that. (Mel)

Losing a Treatment Provider

Several participants commented on losing impetus when their therapist or doctor changed. For these women, the idea of starting over with a new practitioner was difficult. This was especially if they felt therapy wasn't going well to begin with, or the last therapeutic relationship had taken some time to establish. For Jane, there was also an element of having 'relinquished control' to her therapist, and she felt unable or unwilling to take the reins back:

Mostly it was outside circumstances [that made me stop going], like maybe the counsellor sort of broke off contact and it was just too difficult for me to keep trying. It's better, okay I don't mind if an appointment is changed but it's easier for me if the counsellor makes the changes and, and follows through with me. (Jane)

To sum up, there were several environmental factors which could cause women to let treatment fall into abeyance, and thereby become 'non-compliant'. None, except financial barriers, were enough in themselves to terminate treatment, but did add weight to the "against treatment" side of the evaluation balance.

FIT WITH BELIEF SYSTEM

- Assessing whether treatment makes sense
- Accommodating a treatment that's working

The final component of the Treatment Evaluation was Fit with Belief System. This was intertwined with the beliefs discussed in Chapter 14.

Assessing Whether Treatment Makes Sense

The women considered how well the treatment regimen matched what they considered should work to cure or alleviate their depression:

[on what wouldn't work] Getting psychoanalysis...Okay, I can understand that I've had problems in my childhood but I don't really want to go back and regress to that time [to find what caused] how I am today. And a lot of it is just so completely buried that I wouldn't remember it. (Jane)

Thus, for a woman who had a strong belief in a biochemical diathesis for depression, it would make sense that antidepressants should work to cure depression, and come as no surprise if depressive symptoms improved when taking medication. However, psychotherapies might be viewed more dubiously.

While not raised by most participants, one of the women also had strong views on why different treatments worked for different people:

Beliefs. I think that they actually do think that's a big thing. That's probably part of the reason why I had problems with antidepressants Because I was so against it ... I mean and if you told someone that acupuncture or whatever was going to work and they did try it and they didn't think it was going to work, there's no point doing it. Because they don't, like you know, they're doing it but their heads not behind it kind of thing. Because I always, I think things work better if you believe they're going to. (Abby)

Accommodating a Treatment That's Working

Obtaining a positive effect on depression from a treatment that did not match with a woman's own causal attributions for depression could call into question what the woman "knew" about the cause of her condition and appropriate treatments for it. Several women had experienced the dilemma of whether to integrate a treatment that did not fit her belief system, or to cease treatment. The evaluation of "fit" added a dynamic element, in that treatment effects could modify beliefs, and lead to exploration of different treatment options. Lack of belief in a treatment could have a negative impact on compliance.

Some of the women had been "surprised" by the relief they found in talk therapies, and had decided to adjust their belief systems to allow it to work for them. Mary, for

example had been immediately 'won over' by counselling, despite being both doubtful and apprehensive about it before her first appointment:

[it was scary] at first...but yeah there's nothing like talking to a person who really doesn't know you but yet can see inside you. Wow, it's incredible! (Mary)

At the time of her participation in the Compliance Study, Mary saw good quality "occasional" therapy as not only a tool for managing depression, but also as a way of achieving personal growth.

Some of the women who had participated in the DIS, but did not participate in an audiotaped interview for the Compliance Study, had experienced a dissonance between their biological models of depression and experiences of psychotherapy. A few seemed to have adjusted their beliefs to accommodate this treatment modality to a degree, yet for others it remained a treatment of last resort.

Some women felt initially uncomfortable with the idea of antidepressants, but did accommodate them once medication had been at least partially successful at alleviating depression. Some, however, reserved this 'accommodation of a treatment that's working' for times of crisis only. For example, Sally strongly believed that therapy and lifestyle changes would help her most. Over time medication had become reserved for times of extreme crisis only, partly due to her experience of side effects (weight gain) and partly due to her views that natural healing was best, and that she was already overmedicated.

A few participants could not accommodate the necessary change in their belief system. For example, Abby decided that antidepressants were not a good fit with her belief system about depression, despite her condition improving while on a course of medication. She did not "believe in drugs" generally:

I just, I thought you know it's just, just you know I reckon if you don't want to take something it's just going to make you feel bad. (Abby)

SUMMARY

To conclude, Treatment Evaluation included an assessment of direct and indirect, positive and negative effects of the treatment itself, benchmarking against other treatments, external barriers and an appraisal of how well the women were able to fulfil the requirements of the regimen. This final element involved thinking about whether the treatment made sense in terms of the woman's existing beliefs about depression, and if not, whether she was prepared to adjust those beliefs to allow her take advantage of a new tool. Balancing these Treatment Evaluation elements helped the women decide whether it was "worth it" to continue with treatment.

Chapter 16

Compliance and The Dietary Intervention Study

This chapter discusses how Finding a Treatment that Fits operated in the context of the Dietary Intervention Study (DIS).

Some of the components of Finding a Treatment that Fits outlined in Chapters 12 to 15 were only indirectly commented on by the 11 participants who completed qualitative interviews. However, research records have also been used to explore if, and how, the concepts women considered important to their day-to-day attitudes, beliefs and behaviour in relation to compliance with depression treatments generalised to the DIS trial. Where appropriate illustrations are given from the interview transcripts.

Balancing Competing Interests was not a strong theme in the context of the DIS, perhaps because most DIS completers saw few costs or risks to themselves of participating, and their participation was strongly motivated by 'making a contribution'.

However, the theme of Getting Good Enough Compliance deserves some comment here. Amongst the women who completed the self-rating of compliance at the end of the DIS, all but a few rated themselves as a "2". That is to say, they saw themselves as highly (but not 100%) compliant. However, the research records suggest that there was greater variability. Some women returned capsules at the end of the DIS, or commented during the 12-week programme on taking "pill holidays" if they were ill or away from home. Women's assessments of their own compliance may have been based on Getting Good Enough Compliance to achieve their own aims during the research trial. Those aims may have been wider than simply assessing the personal benefits of a nutritional supplement for depression. Aims may also have included finding a safe environment to experiment with supplements generally, taking an opportunity to talk to an interested party about their lives as women with depression, or to make a contribution to science.

What was good enough for these purposes may have influenced the women's self-rating of compliance.

ILLNESS STAGE

In the context of the DIS, Illness Stage appeared to have a largely historic influence. None of the women were in their first episode of depression, and thus had acquired 'depression awareness' and 'become experienced in depression' to some extent. Several had lived with depression for in excess of 20 years. All participants had trialled at least two treatment modalities. The youngest of the participants were at least 18 years of age, therefore all participants made retrospective comments about their adolescent history with depression, and how those experiences had shaped their attitudes towards treatments and perspectives on compliance.

All of the women who participated in the qualitative interviews considered that their depression was operating at a moderate to low level when they joined the DIS. The issue of being in crisis therefore had minimal impact when 'assessing depression severity' in the DIS. Many of the 37 women who took part in the DIS had baseline depression scores in the mild to moderate depression range, with only 15 women scoring in the severely depressed range (29-63 on the BDI-II). Five of the dropouts were in the BDI-II severely depressed range at baseline. Some of the DIS dropouts had noticed their depression worsening through 'monitoring what needed to be done', and decided to withdraw from the DIS to pursue other treatment options. None of the women commented on 'assessing where control lies' in the context of the DIS supplement, perhaps because of the special character of being delivered through a research trial. Also, most women saw the supplements as a natural product, and may have considered that such a treatment gave them more control than taking another drug would. Within the DIS context, Illness Stage was probably most influential in establishing patterns of experience in depression, which in turn influenced expectations for both the Treatment Evaluation, and for the type of relationship that would be established with the researcher.

INFLUENCE OF A POWERFUL OTHER

This category was perhaps the most difficult selective code to assess in relation to the DIS, because it involved the participants talking to the researcher about how they viewed the power dynamic operating in the participant-researcher relationship.

For some women, the researcher took on the role of The Powerful Other. Despite this, since participants had chosen to join the DIS, they were initially characterised by the researcher as choosing to 'share power'. However, when reviewing administrative notes made during the course of the DIS the 'establishment mechanism' operating for some participants appeared to be 'relinquishment' or 'inability to take control'. Several of the participants with patterns of missed appointments and early discontinuance from the DIS may have been signalling that they were unwilling or unable to take control of their own participation in the study. This group was more compliant when the researcher exercised some persuasive power within the relationship. For example, two women were always responsive to reminders to attend sessions, to fast before blood tests and take the supplements, but failed to do so without reminders. They may have relinquished control to the researcher. Two women seemed to fit the pattern of having an inability to take control, and again dropped out of the study. They seemed to constantly try to meet the requirements of the study, but frequently failed to do so, missing blood tests and interviews even when reminded to attend. These women scored in the severely depressed range at baseline, and had somewhat chaotic patterns to their lives. Perhaps they needed a much higher level of intervention than they were receiving (antidepressants and occasional counselling for one woman, and antidepressants only for the other), or a more coercive power operating in their lives. Ethical boundaries were such that the researcher was not able or willing to "take over" in their treatment decisions. A different type of influential other seemed to be required to fill a void for them.

Some of the women were still aware of powerful others operating in their treatment decisions outside the context of the DIS. For example, Sally and Abby felt supported by their mothers, while Alison acknowledged the persuasive power of her husband when

making treatment decisions. At the time of Alison's in-depth interview, she had been off the supplement for a little over a week, and was "going downhill". Her husband had begun to suggest that medication may again be appropriate for her, given she did not know what the supplement was. Some participants had informed their 'powerful other' of their participation in the DIS, and were supported in their decision to join.

Those women who actively commented about power felt they remained in control of or shared in the decisions they made during the DIS. They seemed to perceive an "appropriate" attitude from the research team: sufficiently trustworthy, caring and competent. Women were asked how they perceived the participant-researcher relationship. Comments included "good" "easy" or "fine" However, it needs to be acknowledged that participants may have found it difficult to make comments critical of either the researcher or the DIS design. In addition, most women began with a power sharing attitude towards the study: they chose to be participants, and were able to leave at any time. Choosing compliance was encouraged, but there were no real consequences in terms of diminishing the relationship with the treatment provider, and no chance that further treatment would be withdrawn. Participants were not reliant on the researcher for continued treatment.

For those women who stayed in the DIS, and for a few who dropped out, 'being straight' seemed to be the preferred mode of communication. This was linked with 'making a contribution', which is discussed in the next section of this chapter. What is more difficult to assess is how the "silent" dropouts chose to communicate within the participant-researcher relationship. Was dropping out of the DIS an example of 'avoiding hurting people' (the researcher, by not saying that the supplement wasn't helping, or the study was inconvenient), 'choosing non-disclosure' (because of a poor relationship with the researcher), or 'implicit communication' (perhaps that treatment wasn't working, or that they had concluded that they were taking a placebo and were sending a message of dissatisfaction)? The researcher's perception of the type of communication pattern present varied across the participants. However, these interpretations are necessarily speculative.

MAKING SENSE OF MEANINGS

Women whose causal attributions were more biological seemed more likely to comply with the requirements of the DIS than those whose causal attributions for depression were more reactive in nature. Helen, who had a pattern of early discontinuation from all treatments she had tried, felt unconvinced about supplementation helping her recovery, feeling it did not address the real problem for her, which she thought stemmed from her childhood.

I don't know, to me it's a little bit like just covering the problem....You're not dealing with it. *[For you, the issue is past issues rather than chemical things going on in your head?]* It's a bit of both. I mean the past issues have caused the chemical things in your head but you've still got to deal with the past. Well, that's just what I feel. (Helen, after ending her time in the DIS)

From the general medication beliefs standpoint, women who believed that medication was unsafe or that taking antidepressants was stigmatising tended to express more approval for the DIS. They had a substantial interest in finding out if a supplement might free them from dependence on antidepressants when they were unwell, or could potentially help prevent depression's recurrence. Abby stood out among the 11 qualitative interview participants as highly motivated by negative beliefs around medication. Excerpts from her transcript in earlier chapters show that she was distrustful of medication, had had bad experiences with it, and saw its use for depression as stigmatising. She characterised herself as almost completely compliant with the DIS.

Regarding 'openness towards treatment possibilities', it is likely that women who were completely closed to the idea of CAMs or dietary therapies would not have joined the DIS. Indeed, several women declined an invitation to join once they had read the information sheet introducing the DIS (Appendix A). This decision may have been based on the requirements of the study, or on cynicism about supplements as a treatment for depression. All 37 participants were at least curious about the idea. Some had tried St John's wort or evening primrose oil before, but without much success:

I never actually seem to finish any of these things....I don't know maybe coz its not helping. Maybe there's not the incentive or the feeling that I need to keep taking it...Yeah if I don't feel it's going to help then I definitely won't continue. (Jo)

Of those women who had tried a self-help supplement for depression previously, most completed a jar or less before giving up. They did not see the termination as non-compliance, but rather the end of an experiment. They acknowledged they may not have 'given it time to work'.

After her time in the DIS, Jane began using Bach Flower remedies. She had become more interested in the possibilities of "easy" alternative therapies during her time in the DIS:

...herbal supplements, which to me is easier than sort of trying to change your diet and your lifestyle. But I'm not really into the weird and way out things where you've got to be [taking] pumpkin seeds and ground up seaweed or anything. (Jane)

So, Jane drew a line she would not cross with CAMs. She perceived herself as fully compliant with the DIS.

Being a Good Girl worked in the DIS to increase some women's compliance efforts because they were very motivated to maintain the working relationship with the researcher, or to make a contribution. Sally contrasted taking supplements herself with taking them as part of the DIS:

I think again that its just that I'm not very good often at taking things like that, that I don't have to take. Like, I'm not too bad at taking pills and medication for the study because there was an external factor. Like I was part of the study and I was *reporting to the psychologist*. (Sally, emphasis added)

Making a contribution was a big factor in compliance for all those women who stayed in the DIS for the full 12 weeks. Many commented they were "happy to help", and were

interested in progress with both the DIS and Compliance Study. They liked the idea that the projects might contribute to the world of scientific enquiry.

In-depth interview participants were asked whether compliance in the DIS was the same as compliance with recommendations from a healthcare provider. Most distinguished the two situations:

[The GP/psychiatrist situation] That was just a matter of course. I guess because it was an official prescription rather than a trial, maybe. (Ellen)

Those who were more invested in making a contribution to the research seemed to stay in the DIS longer than those who were less committed to it. As mentioned in Chapter 14, Helen was alone among the interviewees in not stipulating altruistic intent in her decision to join the study, and discontinued early. Reasons for participating were recorded at week 0, in the Personal History Questionnaire (Appendix C).

TREATMENT EVALUATION

Six of the women who completed qualitative interviews were in the fish oil (experimental) group, and five in the olive oil (placebo control) group. A number of women from both groups felt the supplements had improved their depression:

I did have a greater feeling of well-being taking them and I just felt, again, a little bit clearer, that kind of a layer was peeling off kind of thing. Umm, yeah. (Ellen, fish oil group)

Oh just that, ah feeling of being calm and even and, and my husband even noticed you know he said to me "I really think it is the supplement because I feel you've been better in the last, you know, 12 weeks". And just a whole lot of things made into just a better well-being feeling...Yeah and um I just never really went, I mean, since I've stopped taking the supplement I've had a couple of bad days but I remember while I was on them I didn't really go there. (Linda, olive oil group)

Yeah I felt better. I had more, I mean I was going to say now compared to three months ago I had heaps more energy. And I'm not as tired as often and I just, I'm actually not as achy as I used to be which is you know, I don't know. Yeah... Um I am definitely more confident and more assertive with my own needs but I don't know if that has anything to do with it either. (Abby, fish oil group)

Some participants were less convinced about the effect of the supplement they had trialled:

Um initially I thought "well I must be [in the experimental group]" because I felt so much better. Um, then I sort of went through a stage where I didn't take something because I was sick and I couldn't get them down and then I thought oh maybe it's not, you know, I still feel okay. Um and then afterwards I thought I just really don't know, I don't care. (Jo, fish oil group)

No, but unfortunately they don't seem to have really had any good effects because I'm probably having over the last, since October, I've actually probably had more of these little two or three day episodes of the black depression that I used to have. (Sally, fish oil group)

Helen experienced an entirely negative effect from the "treatment":

And it just felt very similar after a while to the antidepressants, I got so despondent and numb. And I had no energy. (Helen, fish oil group)

Those women who left the study early tended to report a lack of efficacy, though not all could be contacted to seek their reasons for withdrawing.

Few of the women noted any indirect positive or negative effects on themselves or their families. A few women felt that aspects of their physical health (energy levels, the condition of nails or skin) had improved. Linda attributed starting a new fitness programme to an energy boost from taking the supplement. Nicky noted that her boyfriend was suspicious of the DIS and was against her being involved. As noted in

Chapter 15, in Nicky's Treatment Evaluation this factor was not sufficiently important to influence her stance on compliance with the supplement prescription.

Impact of Treatment (the supplement) among the women who completed qualitative interviews seems to have been only one factor in their compliance with the requirements of the DIS. These women had, with one exception, made a commitment to stay in the DIS. The group included a number of women who generally made a commitment to treatment, whatever the costs. For women who did not complete the DIS, Impact of Treatment may have been a greater factor in their pattern of compliance.

Those women who found compliance easiest reported fewer side effects to the supplement:

Well there was only one, and that was reflux. But it wasn't a major issue. It wouldn't stop me taking them, put it that way. (Sally, fish oil group)

No I didn't notice any problems at all. (Jane, olive oil group)

Um not that I can recall. There may have been when I first started taking them. But nothing significant. (Nicky, olive oil group)

The one qualitative interviewee who did not complete the DIS experienced major side effects that she attributed to the supplement:

I was just feeling like absolute crap. Like in the end I mean, my sister was saying "I don't think you should take them any more, you're bloody getting worse". (Helen, fish oil group)

Those who rated themselves as most compliant reported few barriers

Not barriers, no...I guess if you're presented with this huge bottle you might think yeah that that's pretty daunting. (Ellen, fish oil group)

It's not really, it hardly intrudes in your life. You just have to remember to take the pills and show up for the blood tests. And the interviews and yeah. No, it wasn't too much of a hassle at all. Didn't know why people weren't doing it. Yeah. (Abby, fish oil group)

Some had suggestions for improving the ability of other people to comply with a supplement regimen:

And the size of the capsules, I don't know if you want me to comment on that but um the four large capsules twice a day was a bit much I think. If it could be compacted more it would be really good....If it could be um down to one of those little round ones it would be really good. (Nicky, olive oil group)

Three women had psychological barriers to overcome to enable them to finish the capsules as required:

I think with me I had no trouble swallowing them apart from the phase I went through. I don't know if its psychological, I wasn't feeling well and just all of a sudden found that I couldn't swallow them, they just wouldn't go down. [It lasted about 10 days]. After that it was every time I put one in my mouth I had this anxious feeling, I had one burst and it didn't taste very nice. (Jo, olive oil group)

And taking so many. I'm not a good pill popper. And it was just – I could just imagine them all in my stomach – too many pills. (Helen, fish oil group)

Well it's the whole sort of having to stand there and - I know it doesn't seem like much - but if you've sort of got 10 minutes to do such and such and get to the station before your train comes, taking those four bloody huge things can be a bit of a deal. (Mel, olive oil group)

Benchmarking consisted mainly of considering whether the supplement being taken was the "real one" or the "placebo". It seemed that the women were considering how they might perhaps feel if the supplement was genuine, versus how they in fact felt. Some

talked about other alternative or natural therapies when considering how well the supplement in the DIS had worked for them:

I've tried evening primrose oil to try and sort of make me feel better, less um moody. [*And how did you find that?*] <pause> Not very helpful I don't think. [*how long did you stick with that?*] Probably not long enough. I think I, probably six to eight weeks... I think this [DIS supplement] was better for a while, I think, but then I got bad again. (Jo, olive oil group).

Of the qualitative interview participants, 10 completed a self-rating of compliance, and nine of those rated themselves as having taken every dose or nearly every dose. Mary rated herself as slightly less compliant, but explained this as meaning she had missed "occasional" doses when she had been out at night. She set quite a high threshold for "good enough" compliance.

The women applied similar strategies for remembering to take the capsules to those used with antidepressants, such as cueing it to taking other medication. A difficulty arose for some, in that the supplement regimen consisted of both a morning and evening dose. Because few of the women took any other medication at night, they found the later dosage harder to remember. Two women discussed novel strategies to overcome this problem. Alison put a whole week's capsules into separate plastic bags, then put a day's worth of capsules beside her bed each night, thus creating a reminder for both the morning and bedtime doses. Jane began putting one extra capsule beside the supplement jar when she took her morning dose, to remind herself to take the evening one.

The only other difficulty women encountered was forgetting to take the capsules while away from home:

Oh fine, I only missed once and that was because I think I went away for the night and forgot to take them with me. (Linda)

Yeah they weren't too bad because I'd already had, I had the pre-programming not that it went too well the first time. So yeah it wasn't too bad. I mean I did have a couple of

weeks where I forgot because I left them . I forgot to take them when I went down to see [relative], at his funeral. Other than that it was pretty good. (Abby)

Self-efficacy was less of a problem for the women who stayed in the DIS, possibly because they had committed to assist with a research study. However, the size, number and taste of the capsules caused difficulty for some women. Several of those who withdrew commented on these factors as being among their reasons for discontinuing, as did Helen.

One factor that arose several times, although not mentioned in the qualitative interviews, was motivation for some women to continue taking an oil-filled supplement that they perceived may cause weight increase.

Self-efficacy with respect to early withdrawal was unable to be formally assessed, as five of the dropouts provided no feedback on their time in the research project.

Treatment self-regulation was discussed by women who experienced stomach disturbance, to help them to adjust to the supplement. These women did not consider their actions to constitute non-compliance, but instead saw these measures as assisting them to stay with the intervention in the long term:

To start with I'd take two and then an hour later I'd take another couple. That worked. You know the first one went down no trouble, the second one was a little bit harder and on it went. And once I'd sort of got back into the routine of taking them, taking all four of them it was no trouble. (Jo)

Transcripts showed that supplementation required little adjustment to most of the women's belief systems to allow it to make sense and enable compliance:

Oh, I just you know a lot goes on inside and I'm sure that, that some of these nutritional things can be of good benefit, can be of benefit to um people like me. You can't really put your finger on why you're like that but if there's something out there that can make a difference... (Linda)

Most of the women however saw supplements as either an adjunct to existing treatments, or as a tool to prevent depression rather than for treating it:

[The supplements are] just a part of things not a thing on their own. (Nicky)

Alison encountered difficulties ‘accommodating a treatment that worked’ because she perceived that the supplement had helped her considerably. She was unsure how much faith to put in it. She had never before considered nutrition as a factor in her depression. The positive change was more surprising to her because her life had become more stressful during the DIS, due to losing her job and having to find a new one. Alison also raised fears of being unable to continue with the “mystery capsules” once her time in the trial was completed. She felt her depression had worsened since the end of the DIS:

Yeah since I’ve been off those whatever they are. And I mean I’ve only been off them a week. <tearful>... I don’t know what to think... So I’ve been stuffing myself with um primrose and St John’s wort. <laughs> [on considering links between nutrition and depression]. No never at all. Didn’t even think about it. Yeah, I’ll have to look it out more, I don’t know, about the omegas and that sort of stuff. (Alison)

Many of the women felt that using supplements to treat depression had a reasonable “fit” with at least part of their belief system about depression, even if they had not previously tried this strategy before. Supplements were seen as having the added advantage that they were “natural” and therefore fitted with the prevalent general health belief that natural products cause less harm:

Um your brain needs certain sort of chemicals and balances and if one thing gets out of balance then you can correct it, you can use a certain thing. I mean I’ve sort of thought of it a bit like the antidepressants and things that the doctors prescribe but a natural, a more natural way of doing it. You know like probably some of the same chemicals involved but in a natural form. (Jo)

SUMMARY

Wherever possible, comments made in research records were compared with those made in transcripts to discover whether Finding a Treatment that Fits was applicable within the DIS. In general, the patterns discovered in the interviews were also uncovered in field notes, though the special circumstances of the DIS also had considerable impact. Unfortunately, some elements could not be verified with those women who only completed the quantitative portion of the DIS. This was especially true for those women who withdrew early and could not be contacted for further comments.

To some extent the women in the DIS were a fairly homogenous group, in that they were at similar stages of their illness experience. They had actively chosen to become involved in the DIS, rather than seeing the DIS treatment as coercive. Thus, the meanings they had from depression and about treatments were already conducive to involvement in the DIS. The one non-completer who was able to be interviewed in depth about compliance seemed to have tried the supplement trial out of desperation, and the DIS did not “make sense” in terms of her depression or treatment beliefs.

The particulars of the women’s Treatment Evaluation of the supplements differentiated those who found the treatment more successful from those who felt it did not benefit them. Unlike findings in the quantitative analysis, this sometimes explained the less rigorous compliance of some women when compared to others, and tendency to drop out of the research. However, special factors associated with being in a research study also increased the commitment to compliance of many women who perceived the supplements as having little benefit to them personally. Thus, Finding a Treatment that Fitted in the Compliance Study was a complicated picture.

Chapter 17

Discussion

The final chapter begins by summarising the findings from the qualitative data analysis in the Compliance Study. It then integrates the qualitative and quantitative results. Next, the research findings are considered in terms of the literature reviewed in Part Two of this thesis. Penultimately, the chapter considers the limitations of the Compliance Study. Finally, the implications of the results for both future research and clinical practice are outlined.

SUMMARY OF QUALITATIVE RESULTS

The first aim of the Compliance Study was to explore what factors are important in women's compliance decisions regarding treatments for depression generally. This was achieved through qualitative analysis of in-depth interviews with 11 women from the Dietary Intervention Study (DIS), and analysis of the research records for the entire sample of 37 women.

Finding a Treatment that Fits is the resultant grounded theory account of women's compliance in treatments for depression, named for its core category. This core category represents themes of Balancing Competing Interests and Getting Good Enough Compliance. The grounded theory has four main components: Illness Stage, Influence of a Powerful Other, Making Sense of Meanings, and Treatment Evaluation. Each of these selective code categories has a number of intertwined axial and substantive code elements. The core category themes of "balancing competing interests" and "getting good enough compliance" act as an overlay, and are ever-present through the component parts.

The theory that emerged from the Compliance Study data is complex and dynamic. Its components are mutually influential, and change as women's experiences with depression change. The array of possible relationships within and between the four selective codes is such that it is not possible to state definitively that certain conditions will predict compliance in every case. What differentiated women's compliance levels in this research was how the overall mix of components came together for each individual.

Each of the four selective codes can be considered to have both a size and a shape, based on where an individual woman is located on the dimensional continua of each contributing substantive and axial code. The particular mix of sizes and shapes of the four selective codes (with their 'balancing' and 'good enough compliance' overlays) determine the level of compliance achieved. For instance, for two women for whom Illness Stage is large (due to severe depression, happening when young or for the first time, and with the women being unable to take control), Influence of a Powerful Other would also be expected to be large (as other people use their power to ensure treatment is initiated and followed). Despite these similarities, the women could be distinguishable by the ways they perceive the powerful other's power base and attitude (with one being seen as persuasive and caring, the other as coercive and uncaring). Additionally, the meanings the two women develop around depression might give Making Sense of Meanings different sizes and shapes. The first woman might have strong biological causal attributions for her depression and be comfortable using medication as a disease management tool. By contrast, the second woman might acknowledge a biological component to her depression, but perceive interpersonal factors as being pivotal in its development, and view medication as a negative. Consequent Treatment Evaluations for antidepressants could be different, even if both women experience some benefit from them. The first woman may continue medication through a prolonged maintenance period. The other may withdraw from treatment, complying "well enough" for her depression to abate, but not carrying it through a recommended maintenance phase, because of her feelings about coercive and inappropriate treatments.

The contextual element of time is important in Finding a Treatment that Fits. Different factors receive a higher weighting in women's compliance decisions depending on their ages and stages of experience with depression. The Compliance Study data show that younger women and those experiencing depression for the first time were more influenced by the opinions of others when making compliance decisions, compared to older women and those more experienced in depression. Also, older women who had tried less sophisticated antidepressants (or indeed, less sophisticated psychotherapy) some years ago were more reticent about those forms of treatment than younger women.

The women in the Compliance Study were in a continual process of assessing their treatment goals and how to achieve them. Women worked through this process while at the same time weighing up the concerns of themselves and others, benefits and barriers, mastery and motivation, beliefs and anxieties. Ultimately success in Finding a Treatment that Fits moved women towards 'adherence', not simply towards treatment compliance. To progress in this way women sought an optimal balance of their interests, and then settled on a level of compliance that was "good enough" to meet their own health goals while maintaining that balance. For some of the women, their own treatment goals were congruent with those of their powerful other or treatment provider, for others that fit was less satisfactory.

The women in the Compliance Study who seemed to have moved furthest towards a state of adherence tended to be older when they first became depressed, had fortuitous powerful relationships, and had become experienced with positive depression treatment outcomes. They had also made a firm commitment to compliance, at the level they had assessed as optimal to maintain their "balance". This was manifest in their vigilant monitoring for signs of depression, and in their developing strategies to maximise compliance. The most adherent women tended to experience fewer negative aspects to treatment. Alternatively, they ruminated less upon the side effects, indirect negative effects, or barriers to treatment compliance.

The second aim of the Compliance Study was to investigate whether the same factors that were important in women's compliance with depression treatments generally were

also important in compliance within the DIS. Overall, the pertinent factors seemed to be similar. However, special issues arose from the unique circumstances of the DIS, whereby women were participating in scientific study of the effects of a 'natural' supplement, which also shaped compliance.

Illness Stage did not help discriminate between the compliant and non-compliant participants in the DIS. This may have been because the participants were at similar developmental stages, had broadly similar levels of experience in depression, and generally mild to moderate depression severity. Even in the group of women who were within the severely depressed range of the BDI-II at baseline, no one was towards the top of that range.

Different establishment mechanisms for the participant-researcher relationship may have resulted in different levels of treatment compliance in the DIS. Most participants shared power and managed their own decisions regarding compliance in the DIS. However, several of the women may have relinquished control or have been unable to take control of their treatment compliance. Perhaps those who needed a more proactive 'powerful other' to encourage compliance (by being persistent in checking compliance between assessment sessions), were unable to complete the DIS trial. However, this remains speculative, as the hypothesis could not be discussed with the women concerned once they had left the study.

Overall, Making Sense of Meanings also failed to account for differences in the women's perceptions of their own compliance with the DIS. Again, participants had similar causal attributions for depression, and were open to the treatment possibilities of the DIS supplement. It is assumed that women who were at different points on the dimensional continua for these attitudes and beliefs would not have volunteered to take part in the DIS trial. However, Making Sense of Meanings includes special factors that emerged from the data as contributing to women's compliance within the context of the DIS. Women who completed the trial were generally highly motivated by making a contribution to the research itself. Thus, while some completers felt they had not benefited personally from taking the DIS supplement, they had made a commitment to

the project because of altruistic motives. Therefore, some DIS completers perceived themselves to be selflessly compliant.

For some women who completed the DIS, their assessments of treatment efficacy were favourable, and increased their compliance with the DIS's requirements, regardless of the treatment group they were assigned to. Also, the completers saw few barriers to participating in the research. Cues to action challenged some women, as the DIS nutritional supplements required two doses a day. Many women found it difficult to establish a cue for the second administration.

Individual's perceptions of what 'compliant' meant in the context of the DIS illustrated variations on "good enough" compliance. Most women rated themselves as reasonably compliant, even those women who returned quantities of capsules at the end of the DIS trial, or were forthcoming about periods when they had been unable to take the supplements. These women ostensibly delineated 'good enough' compliance to meet their own goals for participation in the DIS. These goals may or may not have matched the objectives of the DIS researchers.

INTEGRATION OF QUALITATIVE AND QUANTITATIVE RESULTS

The Compliance Study's quantitative findings were looked at in terms of the grounded theory that emerged from the qualitative data. The question asked was: what do these results say about women's compliance with the DIS? In the statistical analysis, no significant differences were found between DIS completers and dropouts, either in terms of any demographic or mental health characteristics at baseline, or in terms of the treatment groups they were assigned to. Measures of relative omega-3 (n-3) fatty acid levels in the blood of eventual dropouts and completers from the fish oil group found no significant differences between them at weeks 0 or 2. Nor were health beliefs as measured by the Health Beliefs Questionnaire (HBQ) associated either dropout status or participants' own ratings of their compliance levels. Only one quantitative finding

helped differentiate DIS completers from dropouts. A plausible explanation for this particular result involves elements from the Treatment Evaluation selective code.

Those women who had higher BDI-II scores at week 4 of the 12-week DIS tended to withdraw early. This result confirms that, unless a treatment reduces depressive symptoms, women are unlikely to persist with it. This result is consistent with the data from the qualitative analysis. Participants in the Compliance Study were clear that assessing treatment efficacy had primacy in their cost-benefit analysis. Benchmarking, in the form of 'giving it time to work', may also have played a part, in that expectations of an early improvement may have been raised by positive experiences with medications such as Prozac, which many women perceived as improving depression very quickly.

Qualitative data did not identify any particular demographic or psychological variable as pivotal to compliance, except for age. While the qualitative findings showed that younger women have more difficulty than older women with treatment compliance overall, this was not reflected in the quantitative findings. However, it should be noted that the mean age of participants was 32 years, with a range from 18-47 years. Very few were younger than 25 years of age. Therefore, the women's accounts of compliance problems when they were young were largely retrospective, and may no longer have been relevant to the personally participants.

It should be noted that the HBQ developed for the Compliance Study was not successful in finding any associations between health beliefs and treatment compliance. It did not adequately operationalise most of the beliefs that transpired to be relevant to compliance for participants in this research. Moreover, single item ratings of perceived benefits and perceived barriers could not tap the rich diversity of the beliefs within Making Sense of Meanings, while at the same time differentiating those beliefs from the cost-benefits analysis in the Treatment Evaluation category.

Regarding the blood results, it is possible that some of the women's blood samples failed to show an increase in n-3 fatty acids after two weeks of treatment because of variations in how they metabolised the supplement. Biological measures of compliance are not

always reliable for this reason (Myers & Midence, 1998). However, the lack of difference between the dropout and completers groups at this early stage may also have reflected that all participants were compliant at week two. As most of the women who failed to complete the DIS saw making a contribution to the study as one reason for joining the supplement trial, it is likely that compliance levels were still high at the relatively early stage at which the blood samples were taken. Lack of treatment efficacy, side effects or inconvenience may have lessened the resolve of the eventual dropouts later, if making a contribution was not their primary reason for joining the DIS.

INTEGRATION OF FINDINGS WITH RELEVANT LITERATURE

This section discusses the four selective codes of Illness Stage, Influence of a Powerful Other, Making Sense of Meanings and Treatment Evaluation in relation to the literature reviewed in Part 2 of this thesis. Results of the Compliance Study are then considered more broadly in terms of the literature on the relationship between treatment efficacy and compliance. The section concludes by reviewing the theories of health behaviour outlined in Chapter 5, in terms of their overall fit with the findings from the Compliance Study.

Illness Stage

Illness Stage tended to confirm Simon et al.'s (cited in Demyttenaere, 2001) finding that adults in their middle years are less likely than young adults to stop using antidepressants in the first weeks of treatment. In the Compliance Study, older women who had more experience in depression tended to assess their future risk of depression as higher than younger women, and therefore were more concerned to continue treatment. However, Demyttenaere et al.'s (2001a) finding that women were at increased risk of early withdrawal from treatment if their family functioning improved was not supported. Women's narratives showed that improved family functioning is an indicator that a treatment has benefits that are worth fostering in the longer term. This is intuitively sensible. Improved family functioning would tip the balance in favour of

compliance by reducing any dissonance between a woman's best interests and the family's best interests when making her treatment decisions.

Comorbid anxiety disorders did not emerge from the Compliance Study as a factor in women's compliance decisions. While the presence of anxiety disorders has been found to increase compliance with treatments for depression (Tai-Seale et al., 2000), too few women in the Compliance Study had a comorbid anxiety disorder, and its impact may therefore have been lost. Stimmel (2001) asserted that the cognitive symptoms of depression reduce both the motivation and ability to comply with medication treatment for depression. The current finding with respect to depression awareness and assessing depression severity tend to support this assertion. In the Compliance Study, women who were unable to see depression for what it was delayed accessing treatment, and were less vigilant at monitoring what needed to be done as symptoms escalated. However, the Compliance Study also found evidence that once women initiate treatment they try to continue with it until their symptoms abate, so in that way are more likely to take medication while their depression is at its worst. In that respect, Illness Stage supported earlier research which found that the use of treatments for depression declines over time (Myers & Branthwaite, 1992), and as symptoms decrease (Demyttenaere et al., 2001b; Whalley & McKenna, 2000).

Illness Stage also had similarities with Schreiber's (1998, 2001) account of women's recovery from depression. Personal growth and experience in depression were factors in women changing their approach to compliance. In particular, personal growth and experience moved women towards making commitments to adherence, and attending less to powerful others. They became more assertive in either expressing or pursuing their own treatment goals and preferences. By contrast, women who became 'stuck' repeated earlier compliance patterns.

The literature was silent on the pivotal interaction found between Illness Stage and Influence of a Powerful Other. That is to say, there was no consideration of how depression severity, age, or treatment experience might correlate with who controls treatment choices. The Compliance Study found that women's compliance is most

heavily impacted by a social norms element when they are most vulnerable. Both the Theories of Reasoned Action (TRA) and Planned Behaviour (TPB) (Ajzen & Fishbein, 1980) postulate that normative beliefs in relation to important other people shape intentions, which lead to behaviours being initiated. However, neither model hints that developmental changes or severity of illness may increase or decrease the degree to which social pressure impacts on behavioural intention. In the Compliance Study, subjective norms tended to become less important over time, although early treatment histories (which were often influenced by powerful others) continued to subtly influence subsequent treatment choices. That is, women's future attitudes towards treatment options could be shaped by the beliefs and actions of an earlier powerful other.

The element denoted as 'assessing where control lies' is most akin to certain aspects of forming an illness representation and illness meaning as set out by the Self-Regulatory Model (SRM) of health behaviour (Horne, 1997). Horne's review suggests that feelings of being in control are important in how illness is perceived, and therefore what treatment plan is followed and how it is appraised. This was confirmed in the Compliance Study. Women's attitudes towards medication dictated whether they felt more or less in control when using antidepressants.

Influence of a Powerful Other

This selective code is perhaps least well traversed in the compliance and health behaviour literature. Normative beliefs and subjective norms from the TRA and TPB are the closest concepts to this selective code overall. However, no TRA or TPB studies directly investigating compliance with treatments for depression could be located.

As discussed in the section on Illness Stage, the TRA and TPB do not adequately address the establishment mechanism by which control over treatment decisions is bestowed. Additionally, while both the TRA and TPB view an interaction between normative beliefs and motivation as determining subjective norms, they do not link that relationship directly to type of power, which in Finding a Treatment that Fits determines both the quality (coerced or willing) and duration (long or short) of compliance with

treatment. The Compliance Study data show that women sometimes comply by accepting a treatment 'for the time being', if that outcome (treatment initiation and compliance) is valued by their powerful other. The TRA's concept of attitude and intention shaping behaviour therefore did not always fit the Compliance Study's findings. While power sharing relationships are explained by the TRA and TPB, a "fit" with these frameworks is harder to achieve when other establishment mechanisms are invoked. In such cases, the TRA framework can be applied, but in a perverse form. That is, as well as the powerful other influencing assessments of normative beliefs and motivation (leading to the subjective norm assessment), the powerful other's views on how treatment should proceed overshadow women's own outcome beliefs/outcome evaluations. This subjugation can lead to an anti-treatment attitude, and an intention simply to comply until the pressure eases. In spite of this, the behaviour of initiating and maintaining treatment occurs. The TPB may account for this perversity by stating that there is a lack of behavioural control in such cases, and that the preferred or intended behaviour (that is, being non-compliant) is out of reach.

The axial code of 'communication of treatment decisions' confirms prior research findings that people with depression may not communicate non-compliance to their healthcare providers. The failure to communicate may be linked either to a desire to avoid hurting the practitioner, or having different perspectives on the desirability of treatment from those thought to be held by treatment providers (Demyttenaere et al., 2001b).

Making Sense of Meanings

The Compliance Study found that causal attributions, 'what depression means about me', general medication beliefs and 'openness towards treatment possibilities' all played roles in shaping women's compliance attitudes and behaviour. Additionally, the women's attributions for both wellness and side effects were important. While beliefs have been a focus in the physical health compliance research, none of the literature specifically dealing with compliance with treatments for depression has focussed on beliefs as an element in people's decision-making. However, Demyttenaere (2001)

noted that medication dropouts cite fears of becoming dependent on drugs as one reason for treatment termination. This factor also emerged from the Compliance Study data.

The Compliance Study found that attitudes towards treatment are linked to women's acceptance or rejection of treatment options, which constitutes one element of compliance. Women's narratives showed that while they had mixed beliefs about orthodox treatments for depression, overall they expressed an openness towards supplements and some alternative therapies for depression. This was true even if they had not tried them before. For the women in the Compliance Study, attitudes towards alternative therapies seemed to be similar to those found by Furnham (2000). The women were amenable to using dietary supplements for both general health issues, and sometimes depression, but were more cautious about the possible benefits of most provider-driven complementary and alternative medicines (CAMS). Similar opinions were found in a large-scale American magazine survey (Mainstreaming of Alternative Medicine, 2000). Most women in the current research had not tried any provider-driven CAM, which contrasts with reports of prevalence of CAMs treatment uptake by people with depression provided by Kessler (2001) and Druss and Rosenheck (2000).

The participants in the current research were self-referred volunteers for the DIS, and may have had different attitudes towards CAMS than other women with depression who did not volunteer. However, over 400 women were screened for inclusion in the project. Most failed to meet screening criteria rather than declining to join the DIS. This large number of enquirers may be indicative of a substantial pool of depressed women who might consider using a nutritional supplement for depression. It is possible that women's openness to trying the DIS supplement reflected a degree of "medicalisation", created by the environment of the DIS. Alternatively, the openness towards the idea of supplements to treat depression may confirm and extend to New Zealand Jorm et al.'s (2002) Australian finding that more people believed that nutritional supplements would help depression than believed that antidepressants would do so. Interestingly, the Compliance Study found that women did not consider 'compliance' an issue in their exploring supplementation for depression; this was 'experimentation'. None of the

discourse considered the possibility that these additions might be perceived as 'non-compliance' with their standard treatments.

The beliefs within Making Sense of Meanings can be fitted into the TRA, TPB, SRM and Health Belief Model (HBM). In the TRA and TPB, openness towards treatment possibilities, attributions for wellness and general medication beliefs all shape attitude towards treatment compliance, while beliefs about depression itself are subsumed under normative beliefs. In the HBM, the various beliefs are weighted as benefits or barriers, depending on the individual's opinions. However, the model that is closest to fully incorporating Making Sense of Meanings may be the SRM. Leventhal's (1980, cited in Horne 1997) model specifically includes a causal attribution component in the formation of an illness representation and illness meaning. The SRM also provides the necessary feedback loops for beliefs to be continuously, rather than discretely, adjusted, as was found in the Compliance Study. No literature could be found in which compliance with depression treatments had been specifically tested using the SRM.

Treatment Evaluation

The Compliance Study results support earlier findings that people with depression terminate antidepressant treatment prematurely both if their symptoms abate and if the treatment is perceived to lack efficacy (Whalley & McKenna, 2000; Stimmel, 2001). However, the Compliance Study extended those findings by attempting to account for *why* women discontinue early. Research has not so far assessed these reasons comprehensively. The Compliance Study findings suggest that, as well as the clinical outcome of treatment, beliefs and attitudes about both treatments and the powerful other (who may be the treatment provider) are important factors in early treatment termination. Additionally, the Compliance Study found that, consistent with the HBM, barriers to treatment may become more pertinent either if treatment is perceived as ineffective (having "given it time to work"), or if the likelihood of additional benefits accruing seems to be marginal.

No research could be located which included benchmarking in a compliance cost-benefit analysis. Benchmarking, while not a decisive factor in compliance decisions, may account for why women who have been previously treated for depression discontinue new treatments.

Again, no studies seem to have investigated the strategies women use to enhance compliance themselves. It emerged from the Compliance Study data that women self-monitor to check their own levels of compliance, and develop strategies to enhance them. However, this was contingent upon the individual believing the treatment was useful in meeting her own goals for treatment. If so, women developed treatment cues to trigger compliance action, as theorised in the expanded HBM (Horne & Weinman, 1998). Cues to action were employed more rigorously by those women who were most determined to succeed in their compliance. Comparatively little research attention has been devoted to cues to action (Harrison et al., 1992).

Results from the current findings support Bandura's (1977) self-efficacy as an important variable in compliance decisions. Self-efficacy was distinguishable from external barriers in Finding a Treatment that Fits, supporting Rosenstock's (1988) position that the HBM would have enhanced specificity if self-efficacy factors were separated from perceived barriers. Donovan and Blake's (1992) variant on self-efficacy found in people with chronic illness ("can I do what's required to meet *my* health objectives?") is congruent with the profile found in the current study of women who self-regulate treatment. In the Compliance Study this group of women tended to have experienced many years of depression, and therefore they may be defined as experiencing a chronic illness. Women who self-regulated treatment considered the goals set by treatment providers to be less imperative than the goals they set themselves in terms of health and well-being. They were generally confident in their ability to set their own treatment protocols to meet those goals. However, such attitudes and behaviour did not emerge in the presence of a good working relationship with a treatment provider. Furthermore, women who had a supportive powerful other, to help them persevere with antidepressants in the initial stages of the regimen reported being more compliant. Together, these findings tend to support Tai-Seale et al.'s (2000) report that combining

supportive therapy with medication regimens increases medication compliance. It may be that support, rather than psychotherapy, is the critical factor in Tai-Seale et al.'s finding.

In the Compliance Study, barriers to treatment compliance included those factors often cited in general compliance research as impediments to action, such as financial burden, inconvenience and anxieties about treatment risks (Rutter & Quine, 2002). However, external barriers did not emerge in the women's compliance stories as being pivotal in their decisions about following treatment recommendations. Barriers, except for financial barriers, were seldom decisive in compliance decisions. This contrasts with the meta-analysis of Janz and Becker (1984), which found that perceived barriers was the HBM component most significantly associated with health decisions, including treatment compliance. Again, this may reflect the inclusion of self-efficacy factors within the barriers construct in the studies assessed by Janz and Becker (1984).

One barrier which has not been mentioned in existing literature, but which played a small role in the treatment decisions of the women in the Compliance Study, was the effect of losing a treatment provider. Women reported giving up on treatment if the provider changed, especially where the regimen was perceived as difficult (for example, if psychotherapy had reached an uncomfortable point), or if the therapeutic relationship had taken some time to establish. As staff changes are common in the public health sector, ways of smoothing these transition points should be investigated.

The final factor in Treatment Evaluation was women's willingness to incorporate a new treatment if it did not "fit" with their beliefs about depression and its management. Horne (1999) and Sutton (2002) emphasised the need for further research to help inform interventions designed to encourage such adjustments. Sutton in particular noted that 'what' to target is becoming increasingly clear in a number of health-related fields, but not 'how' to change pertinent beliefs. In the Compliance Study, treatment efficacy and a positive relationship with the treatment provider helped women accept treatments that did not "fit", but perhaps only when symptoms were severe. Those women who 'accommodated' psychotherapeutic interventions seemed to do so because of persuasive

power generated in a strong therapeutic relationship. The Compliance Study findings do not fully explain why some women failed to make this accommodation. However, if clients leave therapy before a good therapeutic relationship can be established, no opportunity exists to attempt to persuade them of the benefits of accommodating this treatment modality, nor will they reap the benefits of doing so.

Treatment Efficacy and Compliance in the DIS

The third aim of the Compliance Study was to investigate whether women's levels of compliance in the DIS were related to the efficacy of the dietary supplements. Unlike earlier studies into the effects of omega-3 fatty acids on bipolar disorder (Stoll et al., 1999) and unipolar depression (Nemets et al., 2002), there was no clear indication that fish oil supplements were more effective at reducing depression than olive oil supplements. It should be noted that the Compliance Study results lacked statistical power due to the small sample size. Results reported here did not include the entire DIS sample, which included men as well as women. Nor did the Compliance Study incorporate additional measures of mood and overall functioning that were assessed in the DIS. The final results of the DIS are yet to be published. Findings on the treatment efficacy of n-3 supplementation reported here should not be viewed as conclusive.

Accepting the cautions noted above, the results raise some interesting questions concerning the links between treatment efficacy and compliance. Women in both treatment groups tended to report reductions in depressive symptoms early in the DIS trial. As noted in Chapter 9, Sharpe and Gilbert (1998) reported a tendency for scores on the original BDI to reduce with repeated administrations, regardless of the time between the repeated measures. This artefact, if present in the BDI-II, may account for part of the change in scores over time in the current study. However, it is unlikely to be the only reason for the reduction in BDI-II scores.

The Compliance Study results suggest that a number of people responded to non-specific elements of the DIS regimen. Prior research has suggested that such responses are common both in clinical and research environments (Harrington, 1997a). There are

at least two possible factors to consider when assessing why a placebo effect operated in the Compliance Study. First, Miller et al. (1997) found that advertisement recruits were more likely to respond to a placebo condition in an antidepressant drug trial than people recruited through healthcare providers. As almost all female DIS participants were recruited through newspaper advertising, they may have had special characteristics that made them more likely to respond to the placebo condition. Indeed, the DIS participants fitted the profile of Miller et al.'s placebo responders in terms of their moderate depression levels. The current results may not be replicated if the study was repeated with participants recruited solely through healthcare providers.

Second, while recognising a drug effect does contribute to efficacy in most antidepressants, researchers have recently questioned the extent to which any drug effect is responsible for changes in depression levels, and the extent to which placebo effects are responsible (Kirsch & Sapirstein, 1998; Kirsch et al., 2002; Mayberg et al., 2002). Thus, placebo effects may be a wider phenomenon in research into depression treatments than Miller et al. (1997) theorised. Placebo effects in research may arise partly due to expectations for change created simply by participating in research, or through active placebo effects (Kirsch & Sapirstein, 1998). It is possible that some participants in the Compliance Study construed minor stomach upsets or improved skin or hair condition (which were reported as side effects attributed to both DIS supplements) as signs that the treatment was working for them.

According to the anti-demoralisation hypothesis of psychotherapy (Frank, 1989), it is highly plausible that people with depression would be responsive to placebo conditions, given the role of cognitions in the development and treatment of depression. It is probable that well recognised, non-specific elements of psychotherapy which engender expectations for change (Frank, 1989; Bergin & Garfield, 1994) are at work in clinical trials where regular interactions with a researcher are scheduled. Most participants in the Compliance Study had no psychotherapeutic component operating in their normal treatment regimens, and it is likely that they perceived the researcher as an interested and supportive pseudo-therapist to some extent. The type of longitudinal investigation reported here cannot help but combat demoralisation. Participants had an opportunity to

tell their story over a 12-week period, to reflect upon their mood state, and to receive a treatment that they hoped would be of some benefit in controlling depression.

Additionally, many of the women had strongly altruistic motives for participation, and felt good about themselves for assisting both the science community, and this researcher specifically, to understand more about depression and how to treat it. Even women who did not report reduced depression levels reported maintaining their commitment to the treatment regimen. Compliance for this group seems to have been driven by a commitment to the research process itself. For others there may have been an interaction between placebo effects and known determinants of compliance in clinical trials (Schron & Czajkowski, 2001; Sereika & Davis, 2001; Verheggen et al., 1998).

Prior findings suggest that better compliance is associated with a greater level of health improvement even in placebo condition participants in clinical trials (Horwitz & Horwitz, 1993, cited in Myers and Midence, 1998). While this cannot be confirmed in the case of the Compliance Study participants, it may be that control group participants who were disappointed with their response to the supplement were less compliant in their pattern of supplement dosing, or dropped out. If so, they may not have been subject to a placebo response, either to the supplement itself, or to the therapeutic aspects of the research environment. The lack of an early placebo effect for the fish oil group may have reduced compliance, which in turn may have impacted on any later treatment efficacy. Additionally, altruistic motives may have been less cogent for study dropouts, though this remains speculative.

Theories of Health Behaviour

The fourth and final objective of the Compliance Study was to assess whether existing theories of health behaviour adequately account for women's compliance with treatments for depression. No firm conclusions can be drawn, however, as no theory was fully evaluated. Most were not suitable for the circumstances of this research project. However, some comments are offered on fit between the broad structures of the

health behaviour theories identified in Chapter five, and the grounded theory of women's compliance developed in the Compliance Study.

As has been noted, some aspects of Finding a Treatment that Fits do slot neatly within several of the five theories of health behaviour discussed earlier in this thesis. However, most were inadequate to fully account for the diverse elements revealed in women's narratives of compliance with depression treatments. The Transtheoretical Model (Prochaska & Velicer, 1997) provides a dynamic dimension essential to representing how women's compliance decisions are weighted differentially as their levels of experience in depression change, but it does not provide an explanation for the elements considered important in the compliance process. The TRA and TPB provide a mechanism to include the influence of other people in compliance decisions, though in neither case is the mechanism detailed enough to allow for historic and emotional impacts of the powerful other, nor for the type of power exercised within those relationships, to be considered. The HBM, in its expanded form, may account for most of the non-relationship variables, but must be further divided to separately weight the impact of perceived direct and indirect benefits and barriers. What all the theories mentioned so far lack, or fail to emphasise, is the constant adjustment and balancing of interests and goals that were so evident in the Compliance Study data. The SRM does emphasise the role of constant feedback, so may be the most useful framework for further research in the area of compliance with treatments for depression. An additional benefit is that it specifically attends to the emotional aspects of health decisions, which were important in women's accounts in the Compliance Study. Hope, desperation, confusion and frustration all featured in their narratives. However, in order to incorporate both emotional aspects and continuous feedback on beliefs, intentions and behaviours, the SRM is necessarily less parsimonious than the other models, and may create challenges for researchers interested in understanding compliance in depression.

LIMITATIONS OF THE COMPLIANCE STUDY

There are several factors that may limit the ability of the Compliance Study findings to generalise to other contexts.

The participants in the Compliance Study, while a community sample, were quite homogenous in several respects. First, there was a lack of ethnic diversity, as all participants were of European descent. Women of other ethnic groups may have different beliefs and attitudes towards depression and treatment compliance to those found in the Compliance Study data. Second, many women were excluded from the DIS as they no longer had normal menstrual cycles. Many age appropriate candidates were excluded due to polycystic ovary disorder, hysterectomies or menopause. Additionally, pregnant or breast feeding women were excluded on safety grounds. The exclusion of women in these categories may have slanted the data in ways that would not have occurred had a more diverse sample been available. Third, the depression profiles of the participants were broadly similar, with most falling within the mild to moderately depressed range on the BDI-II. Thus, the findings may not be applicable to women with more severe depression.

There may have been specific characteristics of the women who volunteered for the DIS that would differentiate them from women with depression who did not put themselves forward for the project. The group available to the DIS may have been more open to alternative therapies than other depressed women, or more dissatisfied with their existing treatments. These traits may have also affected their compliance with the DIS, or their historic compliance with other treatment modalities. Verheggen et al.'s (1998) report that people who participate in clinical trials have different values and expectations from people who do not volunteer must be considered as a possible limiting factor.

The use of self-report measures of compliance may be considered a limitation in the Compliance Study. However, the objective was to explore what factors were important in women's compliance with depression treatments, from a constructivist perspective that there is no objective reality. Thus, women's own perceptions of their compliance

were important. While a biological measure of compliance was incorporated into the Compliance Study design, it was available to assess the experimental group only. Biological measurement does not guarantee reliability of compliance measurement (Myers & Midence, 1998). Patterns of compliance remain obscured, and may be affected by the particular metabolic characteristics of individuals in the sample (Urquhart, 2001).

Factors associated with the DIS research environment may have influenced the compliance narratives women presented. While the relationship between researcher and the researched may have encouraged self-revelation about compliance, women may have been reticent about disclosing material non-compliance with the DIS supplement, given their understanding that following instructions was necessary for the success of the supplement trial.

Finally, the grounded theory presented may better account for *compliance* with therapies for depression, than it does for *non-compliance* with such therapies. Difficulties were encountered in getting women who dropped out of the DIS to provide further data, either by completing a termination questionnaire, a telephone exit interview, or an in-depth qualitative interview. While some information was available from some dropouts, only one consented to an in-depth interview. Her comments are enlightening, but cannot necessarily be generalised to all those who discontinued. Therefore, the theoretical sampling requirements of grounded theory could not be fully adhered to. Women who dropped out of the DIS may have had different perspectives or experiences of depression, and compliance with its treatments, to those who completed the DIS. Additionally, it cannot be known whether the 'silent' women who dropped out of the study were generally prone to terminate treatments early, or whether factors particular to the DIS or supplement regimen influenced their decision to withdraw.

RECOMMENDATIONS FOR FURTHER RESEARCH

The findings of the Compliance Study suggest several avenues for further research. First, the current research has highlighted that depressed women's compliance changes both as a result of their developmental stage and experience with depression. It is important to explore compliance more widely with women who are representative of different developmental stages and depression experience levels. Though early treatment experiences continued to influence many women's decision-making, women in the Compliance Study made retrospective reports only of their adolescent compliance experiences. A longitudinal research design with appropriately aged participants and regular assessments of treatment decision-making and mood levels, would assist in generating a clearer picture of exactly how attitudes to treatment develop.

Second, the current grounded theory needs to be verified or refuted by analysis of more data from women who are typically non-compliant with depression therapy options. The challenge here will be to find ways to encourage such women to co-operate in the research process.

Third, Finding a Treatment that Fits suggests options for testing interventions aimed at improving treatment compliance among depressed women. Women's narratives indicated that they tend to be more compliant when their therapy type is congruent with their causal attributions for depression. Research could compare compliance levels in participants receiving a treatment matched to their beliefs, and participants receiving a standard treatment package. Additionally, research could investigate whether regularly scheduled supportive interviews for women in the early stages of a new therapy improve long-term compliance with that therapy.

Fourth, a qualitative study of compliance among women from different ethnic minorities would further increase understanding of whether the beliefs, barriers and behaviours identified in the Compliance Study enhance or impede compliance in depressed women of non-Pakeha/European ethnicity.

Finally, men's experiences of compliance with depression treatments could be explored qualitatively to discover whether Finding a Treatment that Fits can be generalised to all people experiencing depression.

RECOMMENDATIONS FOR CLINICAL PRACTICE

The Compliance Study findings highlighted some ways in which healthcare providers, including clinical psychologists, may be able to improve compliance across all treatment modalities among women with depression.

It is important to understand clients' attributions for the development of their own depression. Exploring these beliefs would provide an opportunity both to match therapy to those attributions as much as possible, and to suggest ways to accommodate any treatment that does not "fit".

Clinicians should ascertain who is driving treatment decisions and, if appropriate, educate those people on the importance of supporting rather than overwhelming the depressed woman's decision-making. Data from the Compliance Study showed that pressure from another person may improve early compliance, but may ultimately be detrimental to long-term compliance, or adherence.

A further recommendation brings together Mundt et al.'s (2001) findings that the benefits of early compliance may not be obvious before individual's withdraw from therapy, and the Compliance Study finding that many women terminate therapy earlier than recommended but return to the same treatment in crisis. These suggest that education on the benefits of compliance is crucial, and that more intensive clinician involvement at critical points may be called for. Critical points include the first stage of treatment regimens, to support clients through any early side effects or indirect negative effects, and to help overcome early barriers to compliance. Helping institute cues to ongoing action, and discussing what is "good enough" compliance to reach personal health goals could also improve compliance. A second critical period identified in the

Compliance Study is when women's symptoms have abated to manageable levels, and barriers or side effects to treatment become more pertinent negative factors in treatment evaluations. Therefore, clinicians should be more active in their monitoring of women being treated for depression at these times.

Strategies to enhance compliance that build on women's desire to 'be a good girl' by cooperating with treatment may be useful in the short term. However, this may be unethical as 'doing as I'm told' may be associated with personality variables and social role expectations that contribute to depression in women (Simonds, 2001). However, retaining women in treatment by creating a placebo-enhancing environment may be worth considering until treatments are given time to work, or clients' doubts about a therapeutic regimen can be overcome. Such an environment would include emphasising the supportive, non-specific aspects of most psychotherapeutic modalities. When rapport is high and the client feels the clinician is caring, competent and trustworthy, specific therapy aspects (such as cognitive restructuring in cognitive behavioural therapy) may be more successful. This has potential to encourage a longer-term commitment to treatment, and more honesty about treatment compliance.

SUMMARY

Finding a Treatment that Fits is a grounded theory account of women's compliance with treatments for depression. Data from the Compliance Study showed that women make compliance decisions by balancing interests and deciding what level of compliance is good enough to reach their goals for their own well-being. In doing so, women consciously or subconsciously consider their illness stage, their relationships with others who have an interest in their treatment, their own beliefs about depression and its treatment, and perform a comprehensive cost-benefits analysis. These elements are mutually dependent, and together create a dynamic process of choosing or rejecting compliance. Women who find a treatment that fits move towards adherence; that is, towards committing to ongoing treatment for themselves, not simply to alleviate immediate symptoms, or at the behest of treatment providers.

This grounded theory was generated using data collected from a small sample of self-referred women who took part in a dietary intervention study of the effect of fish oil supplements on depression. Limitations associated with the sample selected include potential lack of ability to generalise to more representative samples. Moreover, the research environment in which the data was collected may have shaped women's discourses and compliance behaviour.

Despite its limitations, the Compliance Study advanced current understandings of the factors which are relevant to women's compliance with treatments for depression by attending to women's own accounts of how they make compliance decisions. It confirmed some of the findings from earlier research on when women discontinue treatment, but went further in considering why they do so in a more detailed manner than most research to date.

Further research is required to test the theory with a more representative sample, and to check that Finding a Theory That Fits is indeed comprehensive enough to account for non-compliance as well as compliance. Additionally, some of the variables identified need further investigation and specification; for example, to expand understanding of how developmental stage and ongoing experience of depression shape compliance. The grounded theory of Finding a Treatment that Fits could inform the development of interventions aimed at improving compliance with both antidepressant and psychotherapy treatments for depression.

Several recommendations have been made on how clinical practice might take the findings of the Compliance Study into account, including understanding women's causal attributions and treatment beliefs, before setting treatment in place, and attending to critical stages in the compliance process.

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APPENDICES

**Nutritional Supplement Trial:
Information Sheet for Potential Participants**

Who are the Researchers

My name is Frances Hamilton. I am currently undertaking a research project towards a Master of Arts degree in psychology. My supervisors are Cheryl Woolley, who is a senior lecturer and psychologist at the School of Psychology at Massey University, and Dr. Karen Silvers, who is a nutrition scientist at Crop & Food Research in Palmerston North.

What is the study about?

Crop & Food Research has initiated a study investigating whether a particular nutritional supplement has any effect on mood disorders. I have become involved in that project, and have a special interest in women's ideas, attitudes and expectations about this nutritional supplement treatment, and compliance with other treatments available for mood disorders. This study has received ethical approval from the Manawatu-Whanganui Ethics Committee and the Massey University Human Ethics Committee. I am seeking 50 suitable candidates to become involved in this joint research project as unpaid volunteers. It will not cost you anything to become involved in the study.

What will you have to do?

Your health care professional has been asked to provide this information sheet to women diagnosed with a mood disorder who may be interested in participating in this study. You are not in any way obliged to participate, and whatever you decide to do it will not affect the treatment you receive at the clinic you are attending.

The research will involve two groups of volunteers taking a capsule containing either the nutritional supplement being tested or a placebo (a capsule that looks the same but does not contain the

substance being tested), for a period of 12 weeks. Participants will be assigned to the two groups randomly (that is, chosen by chance, not based on any special characteristics). Both are natural substances which have been proven to have a range of health benefits. They have very few side effects, but may not be suitable for people with any problem that prevents their blood from clotting (such as haemophilia or leukaemia, or people taking anti-coagulants). One possible side effect may be an upset stomach, but this is very unlikely because the dosage used is quite low, and it has been used in other studies without any problems for volunteers. If any participant experiences any difficulties, or if the person's doctor feels it is not appropriate to continue, the supplements will be stopped.

Each person who agrees to participate in the study must provide the name of their doctor, so that the doctor can be advised that their patient is involved in the study. However, the doctor will not be given your individual results at the end of the study, just a summary of what the study found overall.

Each participant will be asked to provide three blood samples (which I will organise) during the study: one at the start, one after two weeks, and one at the end. I will ask you for your mental health diagnosis and what antidepressant medicines you are on. I will ask for your consent to confirm these details with your health care professional. Also there will be a number of questionnaires to fill out. These will take up to one hour each time, and I hope to ask each participant to fill most of them out on another four different occasions over the 12 weeks that they are involved. Finally, I would like to interview a small number of women in greater depth about the nutritional supplement and how it affected them, their attitudes towards treatments for mood disorders, and their general attitudes about health and well being. These interviews may be audio taped so that I can transcribe them later, but the tape will not be accessible by anyone other than my supervisor or myself. Anyone who is interviewed will be entitled to listen to their own tape, and make amendments to the written transcription. People who are interviewed can also request that the tape is returned to them at the end of the study. All unwanted tapes will be destroyed once the study is completed.

Your privacy

Some of the issues involved in this research mean that participants are being asked to provide quite sensitive and personal information. For this reason, the information provided by women in this study will be kept strictly confidential. All questionnaires and interviews will be conducted by me with individual participants. No names will appear on the blood samples, the questionnaires or interview tapes or notes; participants will be identified by a special code number. Only my supervisors and I

will have access to the information received. Reports and articles may be written at the end of the research project, but participants will not be identified. When the study is completed, all blood samples, questionnaires and interviews will be destroyed. Even if you agree to participate you can withdraw at any time without providing any reason, and you may refuse to answer any questions. If individual participants are interested, the research team can provide some information about the outcome of the study when all the work has been completed. Also, I will be happy to answer questions about the study at any time.

If you are interested in participating, or would like more information before committing yourself, please let your health care professional know, and I will contact you by telephone. Together we will decide whether participating in the study is right for you. If you agree to participate I will arrange to meet with you, and will ask you to read and sign a consent form. This informs you of your rights as a participant in the study. We will then proceed with the first interview.

Please feel free to contact me through the School of Psychology at Massey University if you have any questions. The contact telephone number is (06) 350 55898. If you leave your name and telephone number and I will get back to you as soon as possible.

My psychology supervisor, Cheryl Woolley, can also be contacted at the School of Psychology by phoning 350 5799 extension 2076. Dr Karen Silvers can be reached at Crop & Food Research Institute in Palmerston North, phone 356 8300.

Thank you very much for taking the time to consider joining this study.

Yours sincerely

Frances Hamilton
Researcher

NUTRITIONAL SUPPLEMENT TRIAL CONSENT FORM

1. Request for an Interpreter

| | | | |
|-------------|---|-----|-------|
| English | I wish to have an interpreter. | Yes | No |
| Maori | E hiahia ana ahau ki tetahi kaiwhakamaori/kaiwhaka pakeha korero. | Ae | Kao |
| Samoan | Oute mana'o ia iai se fa'amatala upu. | loe | Leai |
| Tongan | Oku ou fiema'u ha fakatonulea. | lo | Ikai |
| Cook Island | Ka inangaro au i tetai tangata uri reo. | Ae | Kare |
| Niuean | Fia manako au ke fakaaoga e taha tagata fakahokohoko kupu. | E | Nakai |
| | Other languages to be added following consultation with relevant communities. | | |

2. Consent Conditions

I have read the Information Sheet and have had the details of the study explained to me.

My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I understand I have the right to withdraw from the study at any time and to decline to answer any particular questions.

I understand that as part of this study, I will be asked to take capsules containing either the nutritional supplement being tested, or another natural substance, for a 12 week period. I will not be told which type of capsule I will be taking. I know who to contact if I have any side effects. I know who to contact if I have any questions about the supplement or the study.

I understand that my GP will be informed of my participation in this study.

I agree to provide information to the researcher on the understanding that my name will not be used without my permission. The information will be used only for this research and publications and seminars arising from this research project, and will not identify me.

I agree/ do not agree to take part in an interview, which may be audio taped. I have the right to ask for the audio tape to be turned off at any time during any interview.

I agree/ do not agree to give three blood samples, which will be analysed as part of this research project

I agree/ do not agree to the researcher asking my health care worker to confirm details of my diagnosis and depression medication.

I agree to participate in this study under the conditions set out in the information sheet.

Signed:

Full Name:

Date:

Signature of Researcher

Name of Researcher

Copy of consent form provided to Participant? Y/N

Appendix C

Personal History Questionnaire

This form asks you to provide some information about your background. If you do not want to answer any question, just put an "X" in the space. If you need more space for your answer, use the other side of the page, and indicate the number of the question being answered.

General

1. Are you:

Female

Male

2. How old are you?

18-25

26-35

36-45

46-55

3. Who is your key worker/clinician?

4. Please provide the name and contact details (if known) of your usual GP

Mental Health History

5. About when did your current episode of depression begin?

6. What do you think was the main cause of your current depression?

genetics

body chemistry

childhood issues

interpersonal/relationship problems

stressful life events

alcohol or drug problems

other (please state)

7. In general, how much does your depression bother you?

| | | | | | | | | | | |
|---------------|---|---|---|---|---|---|---|---|---|----------------------|
| Not at All | | | | | | | | | | Couldn't be Worse |
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | |

8. Have you ever attempted suicide?

yes no

If **yes**, when?

9. Have you ever been seen by a mental health professional before now?

yes no

If **yes**, have you ever been diagnosed with:

- an anxiety disorder (e.g. social phobia, obsessive compulsive disorder, panic disorder, agoraphobia, posttraumatic stress disorder)
- any other mood disorder besides depression (e.g. bipolar disorder, dysthymia)
- a psychotic disorder (e.g. schizophrenia)
- a drug or alcohol related disorder
- a personality disorder (e.g. borderline, antisocial personality disorder)
- an eating disorder (e.g. anorexia nervosa, bulimia, binge eating disorder)

10. What do you hope to achieve by seeing a mental health professional?

11. What do you hope to achieve by participating in this research study?

Family

12. What is your marital status?

- never married currently married or living with partner
 separated/ divorced widowed

13. Do you have children?

- yes no

If **yes**, please indicate the gender and age(s) of your child(ren)

14. How many of your children live with you now?

15. Besides your spouse or partner & children, do you live with any other people?

- yes no

If **yes**, please indicate how many people, and their relationship to you.

Other Personal Background

16. Which ethnic group do you most identify with?

- | | |
|---|--|
| <input type="checkbox"/> NZ Maori | <input type="checkbox"/> NZ Pakeha/European |
| <input type="checkbox"/> Other European | <input type="checkbox"/> Polynesian/Pacific Islander |
| <input type="checkbox"/> Asian | <input type="checkbox"/> Other (please state) |

17. What is the highest level of education you completed?

- | | |
|---|---|
| <input type="checkbox"/> primary school | <input type="checkbox"/> up to form 5 |
| <input type="checkbox"/> form 6 or 7 | <input type="checkbox"/> tertiary degree or diploma |
| <input type="checkbox"/> postgraduate degree or diploma | |

18. What is your usual occupation?

19. Are you currently employed?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> yes | <input type="checkbox"/> no |
|------------------------------|-----------------------------|

20. What is your annual income bracket?

If you are living with your spouse or partner, please include their income.

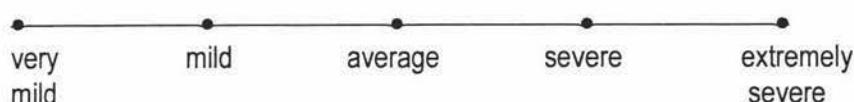
- | | |
|--|--|
| <input type="checkbox"/> less than \$10,000 | <input type="checkbox"/> \$10,000 – \$20,000 |
| <input type="checkbox"/> \$20,000 – \$30,000 | <input type="checkbox"/> \$30,000 – \$40,000 |
| <input type="checkbox"/> \$40,000 - \$50,000 | <input type="checkbox"/> \$50,000-\$60,000 |
| <input type="checkbox"/> more than \$60,000 | |

Appendix D

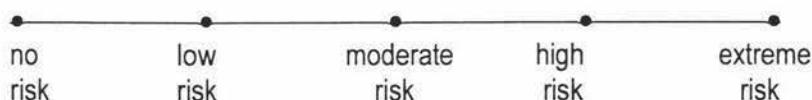
Health Beliefs Questionnaire –(2)

Please answer these questions by either: a) marking an 'X' at the point on the scale which fits you best, or b) ticking the box or boxes which fit you best.

1. How severe is your current depression?



2. How great is your risk of developing depression again in the future?



3. There are different ways of treating depression. What would be the most helpful way of treating your depression? (tick one box only)

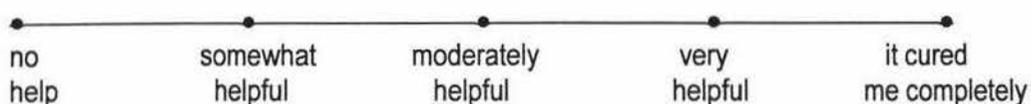
- | | |
|---|---|
| <input type="checkbox"/> Psychotherapy (counselling or talk therapy) | <input type="checkbox"/> Antidepressant drugs |
| <input type="checkbox"/> Lifestyle changes (for example, reducing stress) | <input type="checkbox"/> Alternative or natural therapies |

4. Have you ever received the following treatments for depression:

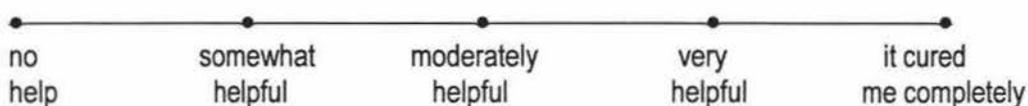
| | Get it now | Had it in the past | Never had it |
|--|--------------------------|--------------------------|--------------------------|
| Psychotherapy (counselling/talk therapy) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Antidepressant drugs | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Prescribed lifestyle changes | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Alternative or natural therapies | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Questions 5-10 ask about your attitudes towards different treatments for depression. If you have not received the treatment mentioned, please consider what you think would have occurred if it had been part of your treatment package.

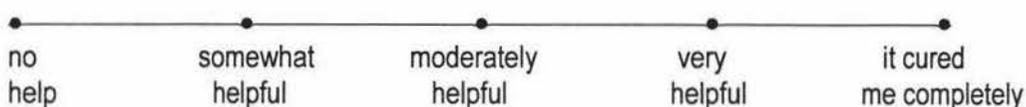
5. How helpful do you think the nutritional supplement examined in this study was in improving your depression?



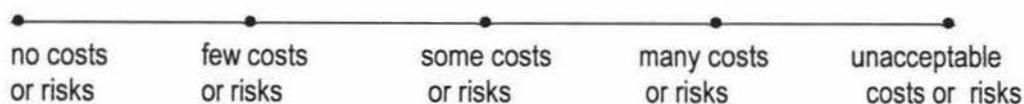
6. How helpful were (or would have been) antidepressant drugs in improving your depression?



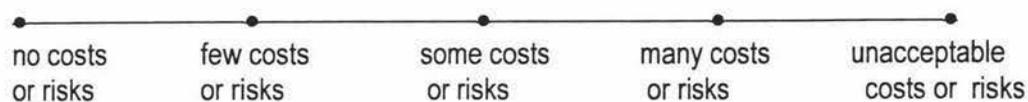
7. How helpful was (or would have been) psychotherapy (sometimes called counselling or talk therapy) in improving your depression?



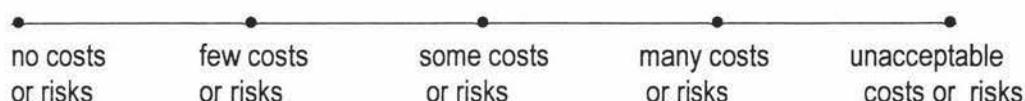
8. How were (or would have been) the physical, financial, emotional or other costs, risks or disadvantages to you of taking the nutritional supplement as directed?



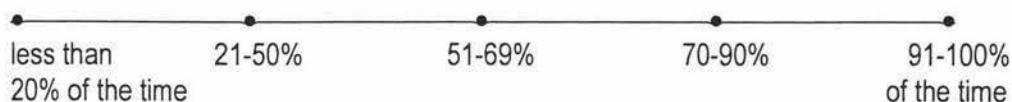
9. How great were (or would have been) the physical, financial, emotional or other costs, risks or disadvantages to you of taking antidepressant drugs?



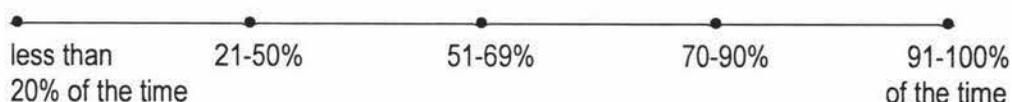
10. How great were (or would have been) the physical, financial, emotional or other costs, risks or disadvantages to you of having psychotherapy (sometimes called counselling or talk therapy) as directed?



11. How often did you take the nutritional supplement as directed for the 12 weeks of this study?



12. If you were receiving antidepressant drugs, how often did you take it as directed for the 12 weeks of this study?



13. If you were receiving psychotherapy, how often did you attend sessions as directed for the 12 weeks of this study?



14. Do you currently take, or have you ever in the past taken, any nutritional supplements?

Yes

No

If **yes**, why do / did you take them?

don't know

to improve my
general health

specifically to help with
my depression

specifically to
help with some other
health problem

Termination Questionnaire

At conclusion of the study (or at exit interview if participant does not complete the trial):

- Ask participants to rate compliance with the nutritional supplement trial (5 point scale from 1 (most compliant) to 5 (least compliant))
- If participant scored a 2 or above, provide list of possible reasons for non-compliance & ask her to tick the one or two items most relevant to her.

The supplement made my depression worse

I developed an upset stomach, indigestion or diarrhoea

My depression improved so I stopped taking the supplement

I developed other physical symptoms which seemed to be due to the supplement

It did not seem to make any difference to my depression

The capsules were hard to swallow

I developed other mental health problems

I did not remember to take the supplement as directed

My family member or friend wanted me to stop taking the supplement

Other (please state)-----

| Substantive Codes | Axial Codes | Selective Codes | Core Category | |
|--|---|--------------------------------------|-------------------------------------|---|
| <ul style="list-style-type: none"> Seeing it for what it is Monitoring what needs to be done | Depression Awareness | ILLNESS STAGE | Balancing Competing Interests | |
| <ul style="list-style-type: none"> Having been there before Age at onset | Becoming Experienced in Depression | | | |
| <ul style="list-style-type: none"> Assessing episode severity Assessing where control lies Assessing future risk | Assessing Depression Severity | | | |
| <ul style="list-style-type: none"> Denial Inability to take control Relinquishment Sharing power | Establishment Mechanism | INFLUENCE OF A POWERFUL OTHER | Finding A Treatment That Fits | |
| <ul style="list-style-type: none"> Coercive power Persuasive power Supportive power | Type of Power | | | |
| <ul style="list-style-type: none"> Caring Trustworthy Competent | Perceived Attitude of the Other | | | |
| <ul style="list-style-type: none"> Being straight Choosing non-disclosure Avoiding hurting people Implicit messages | Communication of Treatment Decisions | | | |
| <ul style="list-style-type: none"> Causal attributions What depression means about me | Beliefs about Depression | MAKING SENSE OF MEANINGS | | |
| <ul style="list-style-type: none"> Medication as a management tool Medication as a negative | General Medication Beliefs | | | |
| <ul style="list-style-type: none"> Openness towards treatment possibilities Attributions for wellness | Beliefs About Treatments | | | |
| <ul style="list-style-type: none"> Doing as I'm told Making a contribution | Being a Good Girl | | | |
| <ul style="list-style-type: none"> Assessing treatment efficacy Indirect positive effects Side effects Indirect negative effects | Impact of Treatment | TREATMENT EVALUATION | | Getting Good Enough Compliance |
| <ul style="list-style-type: none"> Comparison with prior treatments Comparison with new possibilities Giving it time to work | Benchmarking | | | |
| <ul style="list-style-type: none"> Self-monitoring Self-efficacy Treatment self-regulation | Self-Appraisal | | | |
| <ul style="list-style-type: none"> Financial burden Inconvenience Anxieties about risks Losing a treatment provider | Barriers | | | |
| <ul style="list-style-type: none"> Assessing whether treatment makes sense Accommodating a treatment that's working | Fit with Belief System | | | |