Body Image and Psychological Adjustment;  
An Exploratory Study with Individuals  
with Cystic Fibrosis  

by  

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VOLUME ONE – CONTENTS

Academic Dossier ................................................................. 1

Adult Mental Health Essay ..................................................... 2

  Critically Discuss Two Therapeutic Interventions for Major
  Recurrent Depressive Episode

People with Learning Disabilities Essay .......................... 25

  Parenting Skills can be Assessed and Taught to People with
  Learning Disabilities. Discuss

Child and Family Essay ......................................................... 48

  Children who have been Abused are more Likely to become
  Abusers themselves in Adulthood. Discuss with Reference to
  Assessing and Intervening with such Children

Older Adults Essay ............................................................... 70

  What is the Role of the Clinical Psychologist in Services for
  People with Dementia and their Families? How can we Evaluate
  our Contribution as Psychologists?

Clinical Dossier ................................................................. 94

Summary of Clinical Experience .......................................... 95

Clinical Case Report Summaries ....................................... 105

  Adult Mental Health Case Report Summary .................... 106

    Cognitive Behavioural Group Intervention for Individuals with
    Panic Attacks
People with Learning Disabilities Case Report Summary...... 109
Extended Assessment of a 14 year old boy with Down Syndrome

Child and Family Case Report Summary......................... 114
Behavioural Sleep Intervention Using Some Techniques from Narrative Therapy with a Six Year Old Boy with a Bedtime Settling Problem

Older Adults Case Report Summary................................. 118
Neuropsychological Assessment with an 83 Year Old Man Presenting With Memory Problems: Dementia? ...Or Something Else?

Specialist Placement (Paediatrics) Case Report Summary... 123
Cognitive Behavioural Therapy with a 15 Year Old Girl with Chronic Pain. Was an Intrapersonal Conceptualisation ‘Good Enough?’

Research Dossier.......................................................... 127

Service Related Research Project................................. 128
An Audit of General Practitioner Referrals and the Standards of a Duty Team in a Community Mental Health Team (CMHT)

Major Research Project................................................. 156
Body Image and Psychological Adjustment; An Exploratory Study with Individuals with Cystic Fibrosis

Research Log Book...................................................... 332
ACADEMIC DOSSIER

This section comprises of four essays written over the three-year course. Each essay covers a topic pertaining to the four core client groups – Adult Mental Health, People with Learning Disabilities, Child and Family, and Older Adults.
Adult Mental Health Essay

Critically Discuss Two Therapeutic Interventions For Major Recurrent Depressive Episode.

January 2003

Year 1
INTRODUCTION

In a recent World Health Organisation review it was concluded that major unipolar depressive disorder (MDD) is the fourth most important cause of worldwide burden of disease in terms of both death and disability. Projections indicate that by 2020 it is likely to be the second most costly cause of global disability (Murray & Lopez 1990, cited in Clinical Standards Advisory Group [CSAG], 1999; Murray & Lopez 1990, cited in Reynolds et al., 1999). Emphasis on finding effective strategies to alleviate the suffering of millions of individuals is therefore of great relevance and priority.

Estimates suggest that there is a 17% chance of suffering with depressive symptoms during a lifetime (Blazer, Kessler, McGonagle & Swartz, 1994) and a psychiatric morbidity survey found that during a week 2.3% of the population in the United Kingdom suffer with a major depressive episode (Jenkins et al., 1997). Studies have shown that depression frequently recurs, with a conservative figure of 25% of patients experiencing a new episode of depression within a year of the first (Piccinelli & Wilkinson, 1994). For individuals who have received psychiatric care for an episode of MDD the median number of episodes experienced during a lifetime is four, with 80% experiencing at least one more episode (Judd, 1997). Angst (1997) commented that many patients get little or no follow-up after their first episode of depression. A review of the literature suggested that prophylaxis of pharmacotherapy and psychotherapy is beneficial and can delay onset of a new episode (Angst 1997). Angst (1997) highlights the concept of maintenance treatment, which is especially indicated for highly recurrent episodes, particularly if the illness cycle is less than three years in length.

Studies have indicated that past depression is the best predictor of future depressive episodes (e.g. Gotlib & Hammen, 1992; Jarrett et al., 2001) and that younger adults are significantly more likely to have more recurrences than adults over 40 years old (Coryell, Endicott & Keller, 1991). No clear gender differences have been observed (Coryell et al., 1991) but psychosocial factors such as stressful life events and lack of supportive relationships have been found to correlate with additional episodes of
depression (e.g. Gotlib & Hammen, 1992). Residual symptoms also predict higher and shorter relapse rates (Judd, Paulus & Zeller, 1999; Paykel, 2001).

This essay will discuss two of the most common psychotherapies used in the treatment of major recurrent depression. These are Cognitive Behavioural Therapy (CBT) (Beck, Rush, Shaw, Emery, 1979) which is based on Beck’s cognitive theory of depression (Beck, 1967, cited in Beck et al., 1979) and Interpersonal Psychotherapy (IPT) (Klerman, Weissman, Rounsaville & Chevron, 1984) which is based on a mixture of psychodynamic and psychobiological theories of psychiatric illness. Both CBT and IPT have been recommended as the psychotherapies of choice for the treatment of depression in a recent Department of Health document (DOH, 2001). A description of both therapies will be outlined with the corresponding theory which supports it. The evidence of their effectiveness in the treatment of recurrent major unipolar depression will also be presented. This will involve examining studies which have used maintenance treatments in particular. Next the findings from the influential Elkin et al. (1989) National Institute of Mental Health (NIHM) Treatment of Depression Collaborative Research Program study will be reviewed. Conclusions regarding intervention effectiveness will then be formulated on the basis of the empirical evidence.

DEFINITIONS

According to the Diagnostic and Statistical Manual of Mental Disorders the criteria for major depressive disorder, recurrent is the “presence of two or more Major Depressive Episodes [with] an interval of at least two consecutive months in which criteria are not met for a Major Depressive Episode” (APA, 1994). A major depressive episode can vary in its severity, but the individual will typically experience loss of interest and pleasure in activities, feelings of guilt, hopelessness, pessimism, agitation and disturbances in sleep and appetite, all of which will significantly interfere with the person’s ability to function as normal. Suicide and suicidal thoughts are common in the more severe subtype of depression and prevalence of suicide is around 15% in this population (Coryell, Noyes & Clancy, 1982, cited in CSAG, 1999)
Frank et al. (1991b) found inconsistencies with the definitions of change points for depression and suggested that these could be impeding research. In this essay definitions for the term ‘continuation’ therapy will refer to the use of pharmacotherapy or psychotherapy for several months following alleviation of the acute episode symptoms as a strategy to try and prevent ‘relapse’ (defined as the early return of symptoms which indicate return of the original episode) (Weissman, 1994; Paykel, 2001). ‘Maintenance’ refers to longer term treatment (often years) with those deemed at high risk of experiencing ‘recurrence’ (a new episode). This is generally after the patient has been without symptoms for a six month period since the acute episode (Paykel, 2001; Weissman, 1994). In general the term ‘effectiveness’ is used to encompass a number of measures used to determine outcome. The Hamilton Rating Scale (HRS) and Beck Depression Inventory with variable cut off points are the most frequently employed measures to distinguish between recovery, relapse and recurrence.

COGNITIVE BEHAVIOURAL THERAPY

Theory
CBT is based upon Beck’s cognitive theory and is also influenced by behavioural theories, such as reinforcement (Ferster 1973, cited in Rehm, 1990; Lewinsohn, 1974, cited in Rehm, 1990), learned helplessness (Seligman, 1974, cited in Rehm, 1990) and self-control (Rehm, 1977, cited in Rehm, 1990). The main ethos of CBT focuses on the notion that the way an individual thinks impacts on the way they feel and behave. Information about past events is stored in structural units called schemata, these aid to interpret new experiences. In terms of depression, Beck (e.g. 1979) proposed that the individual views the world through depressive schemata that involves the negative interpretation and bias of information, including systematic thinking errors, about the self, the world and the future (cognitive triad). Cognitive distortions are formed which lead to negative automatic thoughts, relating to themes of loss, and cause the person to feel low, helpless and often suicidal. The theory is backed up by empirically derived findings about the nature of depressed individual’s thinking, dysfunctional attitudes, memory bias and presence of negative schema’s (e.g. Gotlib & Hammen, 1992).
Therapy
One of the main aims of CBT is to work with these negative automatic thoughts in a collaborative alliance between the therapist and patient so that the individual becomes able to identify and eventually to challenge the rationality of the thoughts using evidence from everyday life. CBT for depression is a time limited, psychoeducational, short-term therapy that normally lasts about 20 sessions (Gotlib & Hammen, 1992). The focus of therapy is the present day with little attention being paid to past, except in the formulation. Behavioural and verbal techniques such as, goal setting, problem solving, thought recording, behavioural experiments and cognitive and imagery restructuring are utilised. Homework is a vital component to the generalisation of what is learnt during the therapy process into everyday life (Newman & Beck, 1990). CBT used in continuation and maintenance treatments may differ to some degree from the CBT used in the treatment of acute episodes and will often include a focus on relapse, work on prevention of residual symptoms and consolidation of skills (Jarrett et al., 2001).

Effectiveness
CBT is the most widely researched brief therapy for depression (e.g. Scott, 2001). In a meta-analysis by Dobson (1989) evidence was found in ten studies for the superiority of CBT in 98% of cases over either wait list controls or no-treatment. More importantly CBT has been found to be as, or in 70% of cases, more effective than pharmacotherapy (Dobson, 1989). Combination of CBT and drug therapy has sometimes been found to be significantly better than either treatment alone, indicating additive effects of the two interventions (e.g., Blackburn, Bishop, Glen, Whalley & Christie, 1981; Williams, 1997). A mega-analysis of the combination effects of psychotherapy (NB. Both CBT and IPT) and pharmacotherapy has been undertaken by Thase et al., (1997). They found that the equivocal findings from previous investigations may have been due to the failure to distinguish the severity of depression, and ascertained that combination therapy showed a distinct advantage in more severe recurrent depressions over psychotherapy alone with a 41% difference in recovery rates in patients younger than 60 years old (Thase et al., 1997).
For the population of individuals who suffer with recurrent depression continuation and maintenance strategies are now employed routinely (Paykel, 2001). A recent randomised control study by Jarrett et al., (2001) for patients with at least two episodes of MDD compared CBT with a continuation phase (CBT-C) of ten sessions over eight months to CBT without this phase. They found that the CBT-C phase was effective in significantly reducing relapse rates. In those patients at higher risk of recurrence due to predictors of early-onset and unstable remission, with the presence of residual symptoms, the estimates of recurrent episodes was reduced to 37% compared to 62% in controls (Jarrett et al., 2001). The authors suggest that although the study needs replication, CBT-C should be routine regardless of whether medication is being utilised.

There have also been CBT interventions which have been aimed specifically at the treatment of residual symptoms of depression. These are very similar to continuation strategies (Fava, Grandi, Zielezny, Canestrari & Morphy, 1994; Fava, Rafanelli, Grandi, Canestrari & Morphy, 1998a). It has been found that residual symptoms of depression, once the episode has remitted but the individual cannot be said to be fully recovered, such as generalised anxiety, irritability and somatic anxiety, are characteristic of the prodromal symptoms of relapse (e.g. Fava et al., 1994). Results using CBT to target these specific symptoms has shown a trend for effectiveness in preventing relapse although there is little hard evidence. For example, at the six year follow-up, 50% of the patients who had received the ten bimonthly CBT sessions had relapsed compared to a nonsignificant 75% of those in the clinical management group (Fava et al., 1998a). However, improvements on residual symptoms (Fava et al., 1994), a significant protective effect at four year follow-up (Fava, Grandi, Zielezny, Rafanelli, & Canestrari, 1996), and lower number of new episodes by six years (Fava et al., 1998a) were found to be statistically significant using this type of continuation strategy.

Fava, Rafanelli, Grandi, Conti and Belluardo (1998b) tested the CBT continuation treatment for residual symptoms in a population of patients with major recurrent depression (three or more episodes of MDD). They found that at two year follow-up 25% of the CBT group had relapsed compared to 80% of the CM group. They
suggested that this finding could be attributed to the CBT group significantly reducing residual symptoms following completion of the continuation CBT phase. Paykel et al., (1999) found that five months of CBT together with maintenance antidepressant medication compared with pharmacotherapy without psychotherapy continuation in partially remitted individuals significantly reduced relapse rates from 47% to 29% and indicated the benefit of combining the two interventions.

Blackburn and Moore (1997) appear to be only the researchers to have investigated CBT as a true maintenance treatment in recurrent depression. They used a sample of 75 patients with ‘recurrent’ depression (although this definition only included those patients with at least one previous episode of depression) and allocated them to three groups, antidepressant treatment for both the acute and two year maintenance phase, CBT in the acute and maintenance phase and antidepressant medication for the short-term phase of 16 weeks and CBT for the maintenance period. CBT as a maintenance intervention consisted initially of three sessions for the first month, then two sessions for the second month, followed by monthly CBT session thereafter. They found that cognitive therapy and pharmacotherapy had similar prophylactic effects. This research may well be the strongest evidence yet of the viability of CBT (without medication) as a long-term effective intervention for individuals at risk of recurrent episodes of depression.

The process by which CBT is an effective continuation and maintenance strategy is suggested to be due to the patient learning specific skills which they can put into action at times of risk or aversion or the changing in thinking patterns which may also offer protection (Jarrett et al., 2001; Teasdale et al., 2000). CBT in this way helps to prevent reoccurrence of similar thinking and processing styles, which has been shown to be the case without this kind of input (Teasdale, 1997). In a comment to Fava et al.,’s (1998b) study Persaud (2000) suggests that CBT may well have its crucial effect by mediating the effect of the previously depressed individual to generate new adverse (“dependent”) life events, which relate to onset of new episodes.
The issue of effective psychotherapeutic interventions, of any kind, for this population is important because not all individuals are happy remaining on antidepressant medication for long periods of time, particularly as some of the drugs have unpleasant side effects. Between five and ten percent of patients refuse to take antidepressant medication. In addition, some individuals such as pregnant women, the elderly and those who require major surgery will often not be suitable for pharmacotherapy (e.g. Klerman, 1990; Mago, 1999; Williams, 1997). Just with antidepressant medication there remains a large number of individuals who relapse with CBT and it will not be suited to all patients. An alternative empirically validated psychotherapy in the treatment of recurrent unipolar depression is IPT.

**INTERPERSONAL THERAPY**

**Theory**

The ideas of researchers such as Meyer, Sullivan and Bowlby have all contributed the philosophy behind ITP (Weissman & Klerman, 1990). Meyer (1957, cited in Weissman & Klerman, 1990) highlighted the importance of early experiences in the family and the effect of social groups on an individual's ability to adapt to environmental change and cope with the amount of stress which is produced. It is argued that difficulties in these domains ultimately form the basis of psychiatric disorders (Meyer, 1957, cited in Weissman & Klerman, 1990). Sullivan (1953, cited in Weissman & Klerman, 1990) defined psychiatry in terms of interpersonal relations and his work provided the foundation of the interpersonal school (Klerman et al., 1984). Bowlby (1969, cited in e.g. Klerman et al., 1984; Weissman & Klerman, 1990) also influenced the basis of IPT with his findings suggesting the importance of early attachment experiences and the impact of disruption of attachment bonds, at any age, leaving the individual vulnerable to depression. The theory behind IPT has been validated empirically with the work of researchers such as Brown and his colleagues (1977, 1978, 1987 cited in Gotlib & Hammen, 1992) on the relationship between adverse life events (particularly loss events) and depression. In addition, research on lack of social support as well as martial distress, representing a model of intimate interpersonal relations, has been found to correlate with depression (e.g. Gotlib & Hammen, 1992).
Academic Dossier: Adult Mental Health Essay

Therapy

IPT, like CBT, is a time-limited psychotherapy, even when used as a maintenance treatment (Weissman & Klerman, 1990). It is normally carried out weekly with most patients completing between 12 to 16 sessions (e.g. Weissman & Klerman, 1990). It has some parallels with CBT in that it is focused on current issues, and although it acknowledges past difficulties this does not provide the main focus of therapy. In addition, in both CBT and IPT a formulation of the patient's difficulties is constructed and the model of therapy is discussed with the individual. Both use specific techniques to develop skills which it is hoped will generalise to daily life and any change and mastery is accredited to the patient (Teasdale, 1985). IPT and CBT are also interested in the patients distorted cognitions about themselves and others (Klerman et al., 1984). However, in IPT attention is drawn to discrepancies between patient thoughts, attitudes and standards and their behaviour, with no attempt to directly seek these out and develop alternative thoughts (Klerman et al., 1984). Blagys and Hilsenroth (2002) have found that use of homework, direction of session activity, emphasis on specific teaching of behavioural skills, amount of information provided about treatment rational and symptoms, and emphasis placed on intrapersonal (i.e. cognitive) and interpersonal factors differentiate between the two psychotherapies, indicating that they are two distinct interventions. This finding of clear procedural differences was also backed up by DeRubeis, Hollon, Evans & Bemis, 1982).

The aim of IPT is to improve the individual's current interpersonal functioning intervening in the first two depression processes. This involves making connections in the components of symptom formation and social functioning but not with personality, the third hypothesised process (Weissman & Klerman, 1990). Tasks of treatment focus on problem areas of unresolved grief, interpersonal disputes, role transition and interpersonal deficits (e.g. Klerman et al., 1984; Markowitz, 1999; Weissman, 1994). Maintenance IPT (IPT-M) differs from acute IPT in its broader focus than just the four defined problems areas. Its emphasis is on the enhancing the skills achieved in acute IPT to deal with interpersonal life events and its focus is on preventing recurrence rather than reducing symptoms. Frequency of sessions is also generally reduced to one a month (e.g. Harkness et al., 2002).
Effectiveness

IPT has been found to be effective in the treatment of MDD for both single and recurrent episodes (e.g. Weissman, 1994). Much like CBT it has been evaluated in comparison to antidepressant medication and placebo’s and against CM interventions. It has been used in the treatment of acute episodes and also as maintenance treatment (e.g. Elkin et al., 1989; Frank et al., 1990; Weissman et al., 1979). It was found that there were no differences in symptom reduction between IPT and amitriptyline at the end of the 16 week treatment but that combined intervention was more effective than either treatment alone (Weissman et al., 1979). At a one year follow-up those patients who had been randomised to the IPT group, whether or not they had received medication, were found to have significantly better psychosocial functioning (Weissman, Klerman, Prusoff, Sholomskas & Padian, 1981).

IPT has also been studied with respect to its efficacy in preventing relapse and recurrence. In an early study, which would constitute a continuation intervention, IPT was not found to have any effect on relapse rates although it had a positive effect on social adjustment and interpersonal relationships (Paykel, DiMascio, Haskell & Prusoff 1975, cited in Weissman, 1994). Continuation pharmacotherapy was found to reduce relapse rate by half in comparison to the placebo and the combination of IPT and medication was considered the best outcome due to the differential effects of the treatments with no negative interactions (Weissman, Klerman, Paykel, Prusoff & Hanson, 1974, cited in Paykel, 2001).

A small number of maintenance studies have been carried out mainly with individuals vulnerable to recurrent episodes. Frank, Kupfer and Perel (1989) found that 50% of patients who experienced a recurrence during their 18 month intervention had a survival time of 40 weeks more if they received monthly IPT-M compared with the clinical management group. Frank et al., (1990) conducted a study with 128 patients who were experiencing their third (or greater) episode of unipolar depression. They were originally treated with imipramine and IPT in the acute phase, then, following 17 weeks of continuation treatment, they were randomised to either IPT-M and active imipramine, IPT-M and placebo, IPT-M alone, medication clinic and active imipramine and medication clinic and placebo. The results showed that active
imipramine was the most effective with 20% of patients experiencing recurrence. IPT was not found to add further benefit by the end of three years, although at one year 18% of active imipramine patients had relapsed compared to eight percent in the combined group. IPT-M alone was not as effective medication but significantly increased survival time to a mean of 82 weeks. It has therefore been suggested this time period is long enough to keep a woman well through pregnancy and nursing and is a clinically relevant finding with positive implications for future treatment options (Weissman & Markowitz, 1994). In an analysis of the quality of the IPT patients received Frank, Kupfer, Wagner, McEachran and Comes (1991a) found that median survival times were significantly longer (18 weeks compared to 102 weeks) if the focus of IPT was rated more specifically interpersonal. There were no differences between therapist efficacy and it has therefore been suggested that it may be useful to try and determine which patient-therapist dyads are likely to be able to stick with an interpersonal focus and any patient personality characteristics which may be related to this (Frank et al., 1991a).

Harkness et al., (2002) have suggested that IPT may have its effect by reducing the potency of negative life events as they found no evidence of a relationship between life events experienced in the IPT-M maintenance treatment phase and recurrence, but a significant effect of life events and the onset of the index episode. Rounsaville, Weissman & Prusoff (1981) found that IPT seemed to be effective through non-specific aspects of treatment rather than factors such as increased reflectiveness, directive techniques and a high amount of time spent on agreed problem areas.

NATIONAL INSTITUTE FOR MENTAL HEALTH TREATMENT FOR DEPRESSION COLLABORATIVE RESEARCH PROGRAM

Elkin et al’s., (1989) multi centre study involving both CBT and IPT as well as pharmacotherapy and control measures is the only published investigation which directly compares the effectiveness of both CBT and IPT. This widely reported research involved 250 patients at three different treatment sites with MDD; 64% had experienced one or more previous episodes of depression. The individuals were randomly allocated to one of four treatments: imipramine with clinical management,
IPT, CBT and placebo-CM. The results showed that overall “there was no evidence that either of the psychotherapies was significantly less (or more) effective than imipramine-CM” (Elkin et al., 1989, p.977). Although a number of analyses did show that medication and IPT, but not CBT, were more effective than the pill-placebo. When the sample was split in terms of severity of initial illness a slightly different picture emerged with evidence of the placebo-CM in the more severely depressed patients being statistically less effective than either imipramine-CM or IPT (HRS only). For the less severely depressed individuals none of the interventions were found to significantly different from one another in terms of their success. At 18 month naturalistic follow-up there was no significant difference found between relapse rates, although at 12 months relapse rates for CBT were nine percent, IPT 24%, imipramine-CM 28% and placebo-CM 25%. CBT also had the lowest rates of receiving additional treatment during the follow-up (Shea et al., 1992)

The results, however, have been complicated by a number of factors. The primary difficulty being that the placebo condition did unusually well. The authors suggested this may have been due to the clinical management intervention being almost like a supportive therapy with highly trained professionals. In addition, there was no psychotherapy ‘control’ group and the imipramine condition therefore was used as a reference group (Elkin et al., 1989; Williams, 1997). There were also some treatment-site interactions. Scott (2001) emphasised that only 26 severely depressed patients received CBT across the three sites, and that it was more effective than antidepressant medication at two sites, doing particularly well at one centre. IPT also did extremely well at another site (Williams, 1997).

**CONCLUSION**

The findings in the NIMH study (Elkin et al., 1989) suggest that there is no difference between the effectiveness of CBT and IPT from each other and antidepressant medication in the treatment of MDD. Although there was some limited evidence to suggest that IPT was more effective in the treatment of individuals with severe depression (a score on HRS ≥20). However, the study had a number of anomalies particularly regarding the higher than expected effectiveness of the placebo-CM
condition and the treatment-site interactions (Elkin et al., 1989; Scott, 2001). Follow-
up 18 months afterwards also revealed no significant differences between relapse rates
(Shea et al., 1992). It is therefore not possible to draw a conclusion as to which
psychotherapy may be more effective. Although differences in patient characteristics,
for example, low levels of social dysfunction were found to predict superior response
to IPT, whereas low levels of cognitive dysfunction were found to predict superior
response to CBT and findings that those with more severe depression and with higher
impaired functioning responded best to IPT and imipramine, may help to delineate
which patients are likely to respond best to the different types of psychotherapy
(Sotsky et al., 1991). What it is possible to conclude, on the basis of this research, is
that both CBT and IPT represent a viable treatment option for people with MDD.

Depression has become to be recognised as a recurrent and chronic illness with the
cost to individuals and the economy, enormous. The importance of effective,
empirically validated and cost effective treatment strategies is therefore crucial. CBT
has been found to be an effective continuation and maintenance intervention for
reducing relapse rates in those individuals who are vulnerable to recurrence (e.g.
Blackburn & Moore, 1997; Fava et al., 1996; Jarrett et al., 2001). The effectiveness of
CBT as a treatment for residual symptoms is in its early stages and initial results are
fairly promising (e.g. Fava et al., 1998b). Likewise maintenance CBT is also in the
early stages of evaluation but this initial research is particularly encouraging.
Blackburn and Moore (1997) found evidence that maintenance CBT is as effective as
pharmacotherapy, although it has generally accepted that combined psychotherapy
and medication is likely to lead to the best outcome (e.g. Thase et al., 1997).
Psychotherapy does have several benefits over antidepressant medication for example,
lack of side effects, treatment availability throughout pregnancy and not least the fact
that it appears to have durable effects which continue after treatment termination (e.g.
Markowitz, 1999; Scott, 2001).

IPT has also found to be effective as both a continuation and maintenance treatment
for those at risk of recurrent episodes of depression. Research has focused less on
treatment of residual symptoms, and continuation IPT has had somewhat limited
success although this has only been examined in older research (Paykel et al., 1975,
cited in Weissman, 1994; Weissman et al., 1974, cited in Paykel, 2001). IPT-M has had much greater success with the finding that, although not as effective as imipramine, if a highly specific interpersonal focus is able to be preserved then survival time until next recurrence is two years (Frank et al., 1991a).

As with the difficulty reviewing comparative effectiveness of the two psychotherapies in the NIHM study, Scott (2001, p.103) warns that because short-term interventions overlap in their objectives and clinical characteristics “there will be no specific link between the empirical status of a cognitive or interpersonal theory of depression and the respective clinical effectiveness of CT [or] IPT… Furthermore we may not be able to demonstrate differences in the efficacy of CT [or] IPT.”

Another difficulty with reviewing the apparent effectiveness of CBT and IPT interventions is the problems with the differential outcome measures and definitions utilised. In addition, many studies point out the limited generalisability of their findings, those which use a stricter research design protocols are less applicable to clinical populations, whereas those which use more naturalistic designs suffer with the difficulties of numerous extraneous variables, such as, different treatment regimes and attrition rates.

The mechanisms of change in both CBT and IPT in the long term are questions which are starting to be tackled. Teasdale (1997) has suggested that the interacting cognitive subsystem model offers an explanation of how thoughts come to be changed, and may account for the reason that CBT is not more successful in preventing relapse, with lack of effect at the schematic level due to the patient having to actually change their way of ‘being’. In IPT future research has been recommended for not only treatment outcome but for process variables (Markowitz, 1999). It is interesting to note, that it an inconsistency for IPT-M exists, with the patients encouraged to take on a sick role during the acute therapy sessions but then be expected to shift focus concentrating on preventing relapse and the future in maintenance sessions. It could be suggested that the very nature of time-limited therapies may also prevent much more progress being made to reduce recurrence and relapse rates, since for CBT the sessions concentrate
on evoking change at the level of automatic thoughts and far less at the schema level, and for IPT no effort is made to help induce personality changes.

Gotlib and Hammen (1992) have suggested that depression is based upon deficits in functioning in both interpersonal and cognitive domains which have developed due to the presence of phenomenon such as previous adverse life events, negative childhood experiences, diminished interpersonal skills and negative schemas. Recurrence of depressive episodes, it is postulated, occurs due to the presence of these cognitive, interpersonal and environmental vulnerability factors which can be then be activated by potential stressful life events and/or other relevant triggers. Over time the person’s dysfunctional cognitive interpretations and lack of interpersonal skills impact negatively on the way in which they interact with the environment, thus contaminating it and contributing to the depressive spiral (Gotlib & Hammen, 1992). They suggested that clinicians need to develop appropriate treatment, which take both the cognitive and interpersonal areas into account, such as the interpersonal systems approach (Gotlib & Colby, 1987, cited in Gotlib & Hammen, 1992). This approach has received very little attention and has so far only been used for depressed patients and their spouses. It will remain to be seen whether an integration of these approaches will be pursued in the future.

In conclusion, the above research provides evidence for the effectiveness of both CBT and IPT in the treatment of major recurrent depressive episodes with no way, at present, for demonstrating which psychotherapy offers the most superior outcome. Ultimately, however, the importance of recognising that the intervention should be matched to the patient (and not the other way round) should provide the basis of treatment choice, particularly given the evidence that patient preference is reported to be correlated with treatment outcome (Markowitz, 1999).
REFERENCES


Clinical Standards Advisory Group. (1999). *Services for People who have Depression.* London: Department of Health Publications


Academic Dossier: Adult Mental Health Essay


of Mental Health treatment of depression collaborative research program. *Archives of General Psychiatry, 49*, 782-787


People with Learning Disabilities Essay

Parenting Skills can be Assessed and Taught to People with Learning Disabilities. Discuss

August 2003

Year 1
INTRODUCTION

The Human Rights Act 1998 (Great Britain [GB], 1998) and the philosophy of normalisation (Wolfensberger & Tullman, 1982) has helped established the rights of people with learning disabilities (PLD) to ensure they receive the same treatment as all other people and the benefits of the law. In particular, the basic rights to close personal relationships with the right to marry and have a family are pertinent to this population and subject matter. However, it was only around 100 years ago that the eugenics movement and ideas of Social Darwinism were dominant, and only 50 years ago that the compulsory programmes of sterilisation started to be abandoned (Oakes, 2003). Many of the current generation of PLD have spent the majority of their life segregated from others in large institutions where single sex wards, prevention of sexual relationships and unnatural living conditions prevailed (Oakes, 2003).

Even more recently, and despite the advances made by PLD, it is unclear whether society and its attitudes have moved in line with these changes (Aunos & Feldman, 2002). It is frequently reported that misconceptions about the ability of PLD to parent adequately have led to this population being over represented in custody battles (Hayman, 1990 cited in Aunos & Feldman, 2002), losing their children on the basis of IQ assessments alone (Tymchuk & Feldman, 1991) and scrutinized by higher than average standards (Aunos & Feldman, 2002). The question of assessment and teaching of parenting skills is pertinent. Despite the fact that there are currently no firm estimates of the number of parents with LD, with some researchers suggesting that is it possibly unknowable (Booth & Booth, 1994), what is established is that the number of parents within this population is increasing due to their now extended opportunities (Sheerin, 1998).

This essay aims to provide a discussion and integration of issues around assessment and teaching of parenting skills for people with LD. In the first section definitions will be outlined for LD and what constitutes ‘good enough’ parenting. Specific areas

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1 The terminology relating to ‘disabilities’ will be ‘Person/People/Parent/Parents/Mothers/Fathers with learning disabilities’ as recommended by the British Psychological Society (BPS, 2003). The National Health Service (NHS), and well published UK researchers in this field (e.g. Booth & Booth, 1995) also use this language, which is preferred by the UK self-advocacy movement.
Academic Dossier: People with Learning Disabilities Essay

of assessment will then be considered including forms of assessment and how parenting quality has been assessed within the literature. Identification of the influences which impact upon parenting success and models of parenting will be discussed in terms of what skills and which tools are relevant to assessment by professionals in clinical practice. Next, research will be reviewed documenting the outcome of teaching parenting skills in a number of different areas. Limitations in research methodology and parameters for success will discussed, diversity issues will be outlined and conclusions drawn.

DEFINITIONS

Learning Disability (LD)
Within the UK the accepted definition of a LD relates to three core criteria (BPS, 2000). Firstly, a significant impairment of intellectual functioning (IQ below 70); secondly, a significant impairment of adaptive/social functioning and finally age of onset before adulthood (18 years) (BPS, 2000). There are also clinical definitions of LD found in diagnostic manuals such as the ICD-10 (World Health Organisation, 1992) and DSM-IV (American Psychiatric Association, 1994).

Parenting
Despite the growth of the literature within the context of parents with a LD there remains no confirmed and internationally accepted definition of what the concept of ‘good enough’ parenting (Winnicott, 1965) may constitute (Dowdney & Skuse, 1993; Feldman, 1994). This is one of the greatest limitations of research thus far, which makes comparison between the literature particularly difficult. However, there seems to be some consensus around clinical and legal descriptions. Legal definitions have been aided by the introduction of the UK Children Act (GB, 1989) and courts have requested that all individuals including those with LD meet their parenting obligations in four major domains: provision of love and affection in a safe and healthy environment, attention to the child’s physical needs, undertaking household tasks and providing cognitive stimulation (Wald, 1976, cited in Tymchuk, Hamada, Andron & Anderson, 1990a). Clinical and functional definitions have tended to focus on issues
which relate to specific parenting skills, such as provision of physical care, competency with decision-making and child outcomes (Sheerin, 1998).

**ASSESSMENT OF PARENTING SKILLS**

**Methods of Parenting Assessment**

The difficulty with the definition of what constitutes adequate parenting makes the assessment process especially problematic. However, Dowdney and Skuse (1993) have suggested that assessment of the quality of parenting skills has typically fallen under three categories in the literature. Global assessments tend to cover studies that have looked, generally, at whether parents have been able to provide ‘adequate care’ (Mickelson, 1947, 1949, cited in Dowdney & Skuse, 1993), with some occasionally using more specific outcome information, such as the number of children taken into care (Mattison, 1973, cited in Schilling, Schinke, Blythe & Barth, 1982) or behavioural, developmental delay and academic difficulties experienced by their children (Feldman & Walton-Allen, 1997). Results are inconsistent, with some suggesting that these families have poor outcomes (Gillberg & Geijer-Karlsson, 1983), while others draw a more optimistic outlook (Floor, Baxter, Rosen & Zisfein, 1975). Due to significant methodological issues, such as biased and small sample sizes, inadequate definitions and lack of adequate control groups, it is difficult to obtain any unequivocal conclusions. However, recent research acknowledges that these families do require formal supportive services (Llewellyn, McConnell & Bye, 1998)

Observational assessments have compared the performance of intellectually impaired parents to ‘normal’ mothers on specific parenting skills, in particular, play and interactional skills. (Feldman, Case, Towns & Betel, 1985; Peterson, Robinson & Littman, 1983). Findings have shown that parental deficits in these skills place their children at risk for language delay, although mental development was not impaired (Feldman et al., 1986; Feldman, Case, Rincove, Towns & Betel, 1989). Again, the same limitations to the studies apply with additions of short observational periods and relatively few studies.
The third method of assessment involves investigation of the occurrence, and factors associated with, parenting failures leading to child abuse and neglect. Studies centre around three topics: demonstrating prevalence of LD in parents of abused or neglected children; investigating abuse and neglect in children whose parents have a LD; and investigating at-risk populations who have similar psychosocial factors which have been associated with child maltreatment (Dowdney & Skuse, 1993). Unfortunately, it is out the realm of this discussion to present all the findings from this larger body of research. There appears to be agreement that psychosocial elements, such as low socio-economic status, lack of social support networks, parental history of childhood neglect and abuse, parental mental health, child temperament, marital discord, single parenthood, and low IQ are risk factors for abuse, although again, serious methodological flaws confound this literature (Schilling et al., 1982). Dowdney & Skuse (1993, p.33) rightly point out, however, that “even though risk factors… may be found, their presence does not imply that child abuse is inevitable.”

Models and Tools for Parenting Assessment
Attempts have been made to unpick some of these many influences upon parenting adequacy and authors have translated these influences into models and tools for assessment to help professionals understand and formulate an individual’s parenting ability (McGaw & Sturmey, 1994; McGaw, Beckley, Connolly & Ball, 1998).

The Parenting Skills Model (PSM; McGaw and Sturmey, 1994) pulls together the researched influences on parenting and prediction of parental adequacy (Tymchuk, 1992) and presents them as a model that provides a useful guide that can form the basis of assessment (McGaw & Sturmey, 1994). It identifies child-care and child development as the primary indicator for ‘good enough’ parenting and three secondary indicators, parent’s life skills, family history and support and resources. The primary indicator overlaps the three equally significant secondary indicators.

Child-Care and Development
Signs of failure in the domain of child-care and development may include poor child health (McGaw, 1998) or language delays (Feldman et al., 1985). There has also been debate on whether there is a specific link between low IQ mothers producing children
Academic Dossier: People with Learning Disabilities Essay

with intellectual impairment. Large scale longitudinal studies, such as the Milwaukee Project (Garber, 1988), have tried to provide substantiation for this, however, methodological problems have prevented convincing evidence of this link (Spitz, 1991). However, recently, a well-controlled study confirmed a risk for intellectual, academic and behavioural problems over and above the effects of poverty, particularly for boys (Feldman & Walton-Allen, 1997). It is therefore important that assessment of child development and specific child-care skills is undertaken (McGaw & Sturmey, 1994). The PSM suggests use of age-appropriate tools as the Bayley Scales of Infant Development (Bayley, 1969) or Wechsler Intelligence Scale for Children-Third Edition (Wechsler, 1991) and checklists to assess attachment, child care and stimulation in the home environment.

Parent’s Life Skills
Assessment of life skills may require examination of parental factors that maybe directly or indirectly related to child-care (McGaw & Sturmey, 1994). Initial screening may often need take place to identify whether mothers or fathers have a LD (McGaw, 1997). IQ assessment is also recommended, even though it is widely agreed that parental IQ is not associated with parenting competency (McGaw, 1997, 1998), unless IQ is below 60 when it is acknowledged that parents show more difficulties (Tymchuk, Andron & Unger, 1987). However, an IQ assessment, such as the Wechsler Adult Intelligence Scale-Third Edition (Wechsler, 1997), can give relevant information on an individual’s cognitive abilities and specific strengths or weaknesses which may help to build up an individualised intervention. Other skills including literacy, numeracy and organisation need to be assessed, as well as the important notion of ‘capacity to learn’ (McGaw, 1997), which involves testing decision-making and problem-solving skills (McGaw, 1997) and ‘judgement’ (Sellars, 2002).

Independent living skills, such as time telling, budgeting, travel and telephone skills need to be assessed using an adaptive-functioning scale, though as McGaw (1998) suggests, in practice, without assessment of homecare, health skills and ability to establish and maintain routines, the adaptive-functioning assessment will be limited in value. Tymchuk et al., (1990a) have produced an instrument for determining parent’s knowledge of common home emergencies and safety.
**Family History**

A variety of sources, including personal accounts, school records, service case-notes, institution files and family interviews need to be obtained to build up an accurate account of the individual’s background history (McGaw, 1997, 1998). Booth and Booth (1994) argue that problems are too often attributed to be the fault of the parent’s LD without taking into account their social context and upbringing. Such factors as, childhood history of abuse and neglect, bereavement, institutionalisation, experience of appropriate models of parenting, familial genetic and mental health issues have all been found to impact on parental competency (Dowdney & Skuse, 1993). The PSM indicates that collection of a comprehensive background history is invaluable and may help identify factors impinging on the repertoire of parenting skills.

**Parental Support and Resources**

Social support has been found to be a crucial factor associated with parental competency and lack of an adult without LD has been found to be one of the main predictors of child removal (Tymchuk, 1992). Research indicates that parents have very limited social networks, with few friends and reciprocal relationships, often relying heavily on professional services (Llewellyn & McConnell, 2002). Satisfaction with social support is associated with positive maternal behaviours; stress is buffered by these helpful social contacts (Feldman, Varghese, Ramsay & Rajska, 2002). Quality of support offered predicts adequate learning (Tymchuk, 1992). Llewellyn et al. (1998) reported that only some support is found to be helpful by parents with LD and parents and professionals place different emphasis on perceived areas of need. Tucker and Johnson (1989, cited in Booth & Booth, 1993) suggest that support divides into two categories. ‘Competence-promoting’ support is valued by recipients, and includes practical help, continuity of support and positive attitudes held by professionals. ‘Competence-inhibiting’ support, such as sporadic input and professionals’ threats of child removal, disempowers individuals (Booth & Booth, 1993).

Resources available to parents with LD are marred by their social difficulties and low socio-economic status (Booth & Booth, 1994). Poverty, poor housing,
unemployment, social isolation, impoverished background histories (often without experience of an ‘ordinary life’), discrimination and victimisation all impact on the ability of individuals to parent successfully (Aunos & Feldman, 2002). Personal resources for coping with parenting may also be diminished with clinically significant levels of stress found in mothers with LD (Feldman et al., 2002). McGaw and Sturmey (1994) suggest that provision of well co-ordinated multidisciplinary and multi-agency support is essential.

Other Factors Affecting Assessment

Other researchers have produced models that are likely to impact on factors important for assessment and can add to the PSM. Gray (2001), for the Department of Health, has produced a model of assessment for children at risk, which enhances some of the important factors incorporated identified by McGaw and Sturmey’s (1994) model. Feldman (2002, cited in Aunos & Feldman, 2002) has produced an interactional model, although it is yet to be empirically validated. However, the model draws attention to the complexity of influences upon parenting and emphasises child characteristics, such as number of children, behaviour problems and hereditary factors, current life circumstances, such as life crises and parent’s physical and psychological health, socio-economic status and social factors. These are not made explicit by the PSM. Dowdney and Skuse (1993) stress that child characteristics and marital relationships remain neglected topics within the literature. Tymchuk and Andron (1994, cited in Young, Young & Ford, 1997) suggest that addition of personality disorder, epilepsy or physical disability, are further complicating factors.

Some researchers propose that parents with LD overtax what limited social support is available to them (Booth & Booth, 1995) and that reliance on professionals could potentially lead to burnout (Booth & Booth, 1994). Therefore, it could be suggested that, as is now standard in mental health settings, a carer’s assessment should be incorporated into any comprehensive assessment package. Kroese, Hussein, Clifford & Ahmed (2002) suggest that use of their questionnaire may be beneficial as part of a clinical assessment to establish parents’ psychological well-being, self-esteem, assertiveness, natural support networks, views of parenting and hopes for the future.
Importantly, Sellars (2002) highlights assessment of risk associated with parenting by PLD. She suggests that this should be an ongoing process, ideally starting prior to a definite decision about becoming a parent is made, and growing increasingly important as the child gets older.

Finally, caution must be applied to some of the tools utilised during assessment which have not been validated with a LD population, or not on UK populations, thus affecting their reliability and validity (McGaw, 1998). Sellars (2002), however, argues that this may not be so problematic as the purpose of assessment is to explore whether the individual can function in the parenting role within a ‘normal’ world.

TEACHING PARENTING SKILLS TO PARENTS WITH LEARNING DISABILITIES

Results of a comprehensive assessment, including the capacity to learn new skills, are crucial to inform an appropriate intervention. There is little doubt within the literature that “parents can successfully learn adequate standards of child care through systematic training, provided that factors contributing to generalization and maintenance of skills are taken into consideration” (Kroese et al., 2002, p.325). Feldman (1994) in a review of 20 outcome studies concluded the results were “encouraging”. The evidence suggests that skills can be learnt in a number of different areas, although significant methodological problems with the majority of studies exist and will be discussed at the end of this section.

Basic Child-Care
Feldman et al. (1992) reported that a home-based behavioural programme was effective in training 11 mothers to undertake a variety of child-care tasks, such as cleaning baby bottles, preparing ‘formula’, bathing the child, toilet training, treating cradle cap and nappy rash and sleep-safety. The training was found to maintain performance that was generally higher than the low-to-middle socio-economic status, ‘nonhandicapped’ control group, and may have been aided through the use of reinforcement incentives. There were also anecdotal improvements noted in child
well-being. Feldman, Case & Spark, (1992, cited in Feldman, 1994) report a similar study with a successful outcome. Watson-Perczel, Lutzker, Greene and McGimpsey (1988, cited in Feldman, 1994) found that monitoring, corrective practice, homework and trainer praise was more effective to train household cleaning skills than an education intervention. Sarber, Halasz, Messmer, Bickett and Lutzker (1983) were able to teach menu planning and grocery shopping skills to a mother with an IQ of 57 using behavioural techniques, with success indicated by the return of her child into her custody. Other ‘caretaking studies’ reviewed by Dowdney and Skuse (1993, p.38) report “some impressive gains”.

Safety

Training to enhance awareness and practical skills in the area of home dangers and emergencies has been undertaken. Tymchuk et al. (1990a) used direct teaching in group and individual sessions in a community facility and participant’s home with individualised plans, pictures, prompts, praise, corrective feedback and homework and found that training reduced the number of hazards and increased precautions. Although no accidents were reported during follow-up some mothers forgot most of the trained skills. Tymchuk, Andron and Hagelstein (1992) attempted to address the issue of poor maintenance by involving the mothers’ eldest children in group training at a community centre. Unfortunately, although knowledge of dangers and emergencies improved and was maintained by the mothers, this did not translate into improvement in the home environment or significantly increase their children’s knowledge of such matters and suggests specific modelling and training in the home is required for generalisation.

Decision-Making

Tymchuk, Andron & Rahbar (1988) found that mothers were able to learn a decision-making procedure which improved the quality of their decisions. This was maintained at follow-up and generalised to new theoretical vignettes. Given the known difficulties that some of these mothers have translating knowledge into real-life situations (Bakken, Miltenberger & Schauss, 1993) it is unclear whether such skills would hold up against some of the difficult issues that they face.
Positive Parent-Child Interactions

A number of studies have reported positive adult and child outcomes using behavioural techniques to train parent-child interactions, such as praise, imitation of child vocalisation, physical affection, looking and talking to the child (Feldman et al., 1986; Feldman et al., 1989; Feldman, Sparks & Case, 1993; Peterson et al., 1983). Feldman et al. (1989) found that a behavioural programme, as opposed to verbal instruction alone, produced increases in the target behaviours taught and increases in child vocalisation and development in comparison to a poorly matched control group. The effects were maintained over a three to 18 month follow-up and generalised into a variety of child-care routines. Feldman et al., (1993) confirmed that earlier emergence and increase in child vocalisations were over and above those expected by maturation alone. However, another study highlighted the significant lengths that had to be put in place for generalisation of knowledge of parent-child interactions to translate into positive outcomes and skills in the home (Bakken et al., 1993). These differences could be due to sampling differences and stricter criteria of LD. Another study (Tymchuk & Andron, 1988) found it was possible to make a reasonably positive impact with a mother with an IQ of 74 and three children, aged 18, 63 and 94 months, even though there were significant problems with the logistics of training at home, due to issues of control, finance and housing, and where there was more than one child, the children were older and difficult relationships were ingrained.

Child-Behaviour Management

There appear to be very few studies that have tackled the training of appropriate behaviour management strategies, though problems with appropriate discipline are the highest area of concern reported by professionals (Budd & Greenspan, 1985). Studies seem to focus on creating positive interactions between parent and child (see above) rather than on the more negative and perhaps ethically controversial issue of 'discipline'. However, a study by Tymchuk, Andron and Tymchuk (1990b) using group discussion and written instructions trained eight mothers to make appropriate responses to child behaviour that was at least as good as 23 matched control mothers without LD. Non-corporal discipline was one of a number of skills that ensured maladaptive child behaviour remained low throughout Bakken and colleagues study (1993), although this effect could be influenced by a low baseline of child behavioural
problems. Dowdney and Skuse (1993, p.39) report that “subjects can learn
behavioural management skills provided teaching is adapted to recognise their
cognitive limitations, audio recording aids rather than written materials are made
available, and intensive in vivo coaching is employed”.

**Relationship-Building Skills**

Recently McGaw, Ball and Clark (2002) used a group intervention to teach parents
with LD relationship-building skills in an attempt to tackle their problem of social
isolation. Although they found that self-concept significantly improved this did not
transform into benefits for their children. Participant’s scores on their perception of
child problem behaviour and quality of parent-child relationship remained the same.

**Parameters of Successful Training Programmes**

The studies reviewed above and information from the literature suggest that there are
several recommendations for training programmes to ensure that success is maintained
and can be generalised (Budd & Greenspan, 1985; Feldman, 1994). Firstly it is clear
that in order for knowledge to translate into performance in the home, interventions
must be achievable and utilise explicit behavioural techniques, such as modelling,
feedback and praise (Feldman, 1994), visual aids, repetition, role-playing and an
emphasis on continuous checking of parental performance and be tailored to the
individual (Budd & Greenspan, 1985; Llewellyn, McConnell, Russo, Mayes &
Honey, 2002). It must take place in the home or as close to a home-like environment
as possible (Bakken et al., 1993; Feldman, 1994) and be intensive and long-term, up to
several years (Budd & Greenspan, 1985). Llewellyn et al. (2002) suggest that it is
important to create a distraction-free home environment, which is conducive to
learning. Control over the home environment and readiness to learn are also key
issues that will impact on intervention success (Llewellyn et al., 2002). Researchers
have highlighted the need to sort out imminent problems first before the training
session per se can start (Budd & Greenspan, 1985; Llewellyn et al., 2002). Personal
issues may well need tackling prior to starting the training programme (McGaw, 1997).
Simultaneous training programmes should be undertaken with care (McGaw et al.,
2002). Budd and Greenspan (1985) and Booth and Booth (1994) highlight the
importance of a good quality working relationship that is vital to creating
'competence-promoting' support. Risk factors such as abusive or unsupportive partners, maternal mental health, previous child removed or multiple home moves may also impact on intervention success (Tymchuk & Andron, 1992, cited in Feldman et al., 1993). There is some debate as to whether group interventions are successful. Peterson et al. (1983) found a small group format had benefits and McGaw et al. (2002) found a group format encouraged relationships to form. However, it is generally acknowledged that individualised programmes are required (Bakken et al., 1993), and are favourable, as they can adapt to individual personalities, capabilities, needs, experiences and learning style (Llewellyn et al., 2002). Tangible reinforcement (Feldman et al., 1992; Peterson et al., 1983) and over-learning (Feldman et al., 1993) may aid with maintenance.

Methodological Issues
Feldman (1994) and Dowdney and Skuse (1993) provide excellent critiques of methodological issues relating to outcome studies. In brief, there are significant problems with the research and include the following reasons: non representative populations with participants often already known by services for concerns regarding parenting ability; lack of clear definitions of parenting and LD (many of the studies use a cut-off IQ of below 85); problems with adequately matched control groups for confounding factors such as low socio-economic status and maturational effects of children; complicating factors such as issues of control, maternal mental health, diversity, gender, participation in other therapies, social network, supportiveness of services; child temperament and developmental level; poor outcome measures; small sample size; asymptotic baselines obscuring training impact; low inter-observer reliability; lack of blind and naive researchers; and short observation sessions.

DIVERSITY ISSUES

There is a notable lack of research of black and minority ethnic parents with a LD. The only major piece of research, investigating whether low IQ mothers rear low IQ children, that had a sample purely comprised of black families, was the Milwaukee Project (Garber, 1988). The issue of single-parents has been neglected (Dowdney & Skuse, 1993) as has the role of fathers (Llewellyn, 1990). Not until very recently have
paternal influences been considered (Booth & Booth, 2002). It is often difficult to ascertain race, culture and ethnicity of the individuals involved in studies. However, there is an assumption, due to the demography of Western populations, that unless specified, participants are White, and the term 'parents' refers to mothers (Tymchuk, 1990, cited in Booth & Booth, 2002).

There are significant practical issues when considering assessment and teaching of parenting skills with black and ethnic minorities. Firstly the standards against which parenting practises are judged, it can be argued, are, in the majority of cases, against the norms of the dominant subculture (Young, et al., 1997). Young et al. (1997) suggest that in the UK the norms of the middle class culture prevail. Secondly, a recent survey suggested that there is three times the prevalence of PLD, below the age of 34, in Asian compared to non-Asian communities (Azmi, Emerson, Caine & Hatton, 1996, cited in Nadirshaw, 1997). As this represents the next generation of adults, there will be an implication for parenting services, including culturally appropriate assessment and delivery of parenting interventions, with such issues as language barriers needing to be considered. Thirdly, it is well established that there is a higher number of black and other ethnic minorities living in social, economic and educational deprivation, factors which are associated with mild and moderate LD (Nadirshaw, 1997). There will therefore be implications for the prevalence of parents and the degree of disadvantage experienced by these communities. Further research and service planning is required so that these issues can be understood and addressed.

CONCLUSION

Sheerin (1998) found no convincing evidence when he reviewed the literature for the four 'myths' identified by Espe-Scherwindt & Crable (1993, cited in Sheerin, 1998) of parenting by PLD: that they will produce children that have LD; have more children than the norm; provide inadequate parenting; and cannot learn adequate parenting skills. From the review of the literature provided it does appear that these parents are certainly not a homogenous group (Booth & Booth, 1994) and that parenting skills can be assessed and taught with successful outcomes, but with some important qualifications.
Assessment needs to multi-dimensional and dynamic. It is clear that IQ alone is not sufficient for the basis of determining adequacy of parenting (McGaw, 1998). Assessment needs to be more involved and all three methods described by Dowdney & Skuse (1993) need to be employed. That is, the assessment should be global, assessing a large number of domains and skills, but should utilise some opportunity to observe parents in specific situations and monitor risk of maltreatment to children. A useful model for assessment has been described by McGaw and Sturmey (1994), which although very comprehensive, can be informed by recent research and models. However, it is notable that further research is still required to provide a more complete examination of important influences (Dowdney & Skuse, 1993).

Intervention outcome studies have indicated that a number of relevant and important skills can be taught to parents with LD, which can help them keep their children in their custody (Feldman, et al., 1993). However, there are significant flaws with the research and indicate that results should generally be interpreted with caution. Factors such as maintenance, generalisation, individualisation, attitudes of professionals and social support, are vital to the success of training programmes.

As Espe-Sherwindt and Crable (1993, cited in Sheerin, 1998) remark, as with the general population there are parents that are adequate and those that are not. Despite the higher prevalence of maltreatment of treatment of children by PLD (Schilling et al., 1982) it is important that it is not purely the label of LD that is assessed and judged, but the many factors described within this discussion, which highlight the complexity of a comprehensive assessment and a successful intervention, are given appropriate acknowledgement. The reality of service provision involves financial and personnel constraints, and lack of a register for PLD, will impact on future planning (McGaw, 1998). The “double jeopardy” (Booth & Booth, 1995, p.32) of being a parent with LD, might mean that it is likely to prove difficult to provide the suggested best practice guidance of inter-agency collaboration and co-ordination with a full range of services and specialist multi-disciplinary teams (McGaw, 1997).
Booth and Booth (1993) have noted that competence is socially constructed and as such it is important that the attitudes of professionals and the extended social network are taken into consideration. Review of case studies have suggested that where professional support is competence-inhibiting, and it is assumed that parents will eventually neglect their children, this can be a causative factor in parenting breakdown (Booth & Booth, 1993).

The “second generation of research” in this area (Murphy & Feldman, 2002, p. 283) is moving beyond simple formulations of factors which impinge on assessment and teaching of parenting skills. Work has started to emerge on the need to be more diverse in the interventions offered to parents and to take account of factors influencing ability other than just cognitive limitations, for example, focussing more on teaching information that equip parents to perform skills rather than teaching the skills per se (McGaw et al., 2002). It therefore maybe worthwhile teaching parents what they themselves think are important, such as making friendships and accessing community facilities (Llewellyn et al., 1998), and which, equally, have been shown to be of important predictive value for ability to parent adequately (Tymchuk, 1992).

Success ultimately relies upon adequate service provision and a partnership between PLD and professionals so that individuals have what is their right to a normal life and role as a parent.
REFERENCES


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Child and Family Essay

Children who have been abused are more likely to become abusers themselves in adulthood. Discuss with reference to assessing and intervening with such children.

December 2003

Year 2
INTRODUCTION
Cases of child abuse, such as that of Victoria Climbie, are often reported in the mass media and highlight child abuse as an issue of national concern. Prevalence figures for children who have experienced abuse are fraught with methodological limitations (Cawson, Wattam, Brooker & Kelly, 2000). However, a recently published retrospective survey by the National Society for the Prevention of Cruelty to Children reported that 13 per cent of young adults were abused as children (Cawson et al., 2000).

Given the potentially huge number of children that have been abused it is pertinent to consider the question of how many go on to abuse others and to understand aetiological factors which lead to such abuse (Haywood, Kravitz, Wasyliw, Goldberg & Cavanaugh, 1996). Estimates of intergenerational maltreatment are also plagued by methodological issues and are therefore, not unsurprising, extremely variable (Falshaw, Browne & Hollin, 1996). Rates reported range from 100 per cent (Steele & Pollock, 1968, cited in Buchanan, 1996) to one per cent (Widom, 1989).

This essay aims to explore the ‘myth’ of the inevitability of the victim-abuser cycle by reviewing research evidence on the cycle of maltreatment in young people (Kaufman & Zigler, 1987). The discussion will focus primarily on physical abuse, neglect, sexual abuse and to a lesser extent emotional abuse. It is out of the scope of the essay to discuss the “violence begets violence” hypothesis (e.g. Widom, 1998, p.226), even though delinquent, offending and violent behaviour may also be considered as ‘abuse’. The main theoretical models for understanding the nature of the cycle will be explored. Next, issues around assessment will be reviewed, including examining risk and protective factors and specific assessment measures. Interventions will then be considered from both preventative and reactive perspectives. Finally there will be a discussion of diversity issues and conclusions drawn.

DEFINITIONS
Many researchers have highlighted the issues regarding the problems surrounding definitions of child maltreatment (e.g. Newcomb & Locke, 2001). For the purpose of this essay definitions used by the Department of Health (DOH; 1991) in “Working
together under the Children Act 1989" for 'emotional abuse', 'neglect', 'physical abuse' and 'sexual abuse' will be utilised. In addition the terminology 'maltreatment' and 'child abuse' will by used synonymously to refer to the four different types of abuse operationalised by the DOH (1991).

There are different terminologies used to describe the cycle of abuse. Intergenerational child maltreatment (Falshaw et al., 1996) refers to intrafamilial abuse, whereas other less specific terms, such as victim-victimiser (Glasser et al., 2001), victim-abuser (Bentovim, 2002) and abuse-abuser (Burgess, Hartman & McCormack, 1987) tend to refer to both intrafamilial and extrafamilial abuse.

**ARE CHILDREN WHO HAVE BEEN ABUSED MORE LIKELY TO BECOME ABUSERS THEMSELVES IN ADULTHOOD?**

Over 15 years ago Kaufman and Zigler (1987, p.191) were advocating that "researchers cease asking, “Do abused children become abusive parents?” and ask, instead, “Under what conditions is the transmission of abuse most likely to occur?”. It is now well established that approximately one third of children who have been maltreated will go on to perpetrate abuse to others (Buchanan, 1996). For many victims their own cycle of perpetration will start when they are still adolescents (Salter et al., 2003). Salter et al. (2003) found that the mean age for boys who had been sexually abused to start abusing others was 14. Researchers have emphasised that not everyone that has been abused will enter into this cycle and it is not inevitable (Egeland, Jacobvitz & Sroufe, 1988). Steel and Pollock’s (1968, cited in Buchanan, 1996) early research suggesting transmission rates of 100 per cent has been criticised for its problems with ambiguous and very broad definitions, skewed sample and lack of a control group (Kaufman & Zigler, 1987). A more recent prospective sexual abuse study found a lower than generally accepted rate of transmission of 12 per cent (Salter et al., 2003.). However, Salter and his colleagues used only officially reported incidents to the authorities. Briggs and Hawkins (1996) found that sex offenders perceived their history sexual abuse as ‘normal’ and hypothesised that these beliefs may account for the low number of male disclosures.
There are a number of models which have been used to explain this cycle of abuse. The psychiatric model is based upon the principles of psychoanalytic therapy which suggests that once the individual has gained insight into the causes of their abusive behaviour remediation of such behaviour is possible (Belsky, 1978).

Social learning theory (Bandura, 1977) has gained empirical support in its suggestion that children who observe violent and abusive behaviour go on to model such behaviours in adulthood (Buchanan, 1996). Muller, Hunter and Stollak (1995) found that a model of intergenerational transmission of corporal punishment based on social learning principles was more consistent with their findings than a model based on child temperament factors, such as predisposition toward aggressive behaviours.

Attachment theory (Bowlby, 1984) postulates that when the early bond between caregiver and child is disrupted a maladaptive pattern of attachment develops. Parenting style and poor attachment impacts upon the creation of the child’s ‘inner working model’ and sense-of-self (Egeland & Susman-Stillman, 1996). Experiences which have been abusive or neglectful will produce expectations of relationships with others to be rejecting and abusive. In this way children adopt the role of the victim and aggressor, which they can use to assert some control once in a position of power (Crittenden, 1985, cited in Buchanan, 1996). Disorganised attachment relationships have been associated with higher rates of infant maltreatment (Carlson, Cicchetti, Barnett & Braunwald, 1989). Although similar to social learning philosophy the theories predict different treatment interventions with social learning theory advancing a (cognitive-) behavioural approach and attachment theory linking to psychodynamic or family therapy aimed at repairing poor attachments (Buchanan, 1996).

Physical and mental health problems, cognitive differences and child temperament factors, have been hypothesised to explain the cycle from a biological viewpoint (Buchanan, 1996).

Both Buchanan (1996) and Belsky (1978) highlight sociological models as important for looking outside the family to conditions in society which cause maltreatment, for example, issues of socio-economic status, poverty and social isolation. The risk of
child abuse has been found to be higher among parents living in poverty, who have
lowed paid jobs or who are unemployed (Gelles, 1997). It is argued that these
individuals experience higher stress levels, caused by the adverse conditions, in which
to undertake the demanding role of parenting (Belsky, 1978). Other factors, such as
cultural norms of parenting behaviour and racism are theorised to have a negative
impact (Ahmed, Cheetham & Small, cited in DOH, 2000). Feminists would contend
the importance of society’s perceptions of traditional gender roles.

Ultimately, research finds support for numerous aspects of many of these models.
Therefore, Buchanan (1996) argues for multi-focus theories to help explain the
phenomenon of the cycle of maltreatment. She advocates a systems approach such as
that of Bonfenbrenner (1977) or Belsky (1980) who propose that factors from
different social systems, such as individual (ontogenetic level), family (microsystem
level), community (exosystem level) and cultural (macrosystem level) factors overlap
and interact. The DOH (2000) cites an updated version of a developmental and
ecological model by Jones and Ramchandani (1999). An understanding of the factors
which comprise such multidimensional models will be described below, because they
form the basis of assessment and intervention with young people who have been
abused.

ASSESSMENT

Cycles of Maltreatment

Buchanan (1996, p.8) suggests that “four major cycles directly or indirectly lead to
intergenerational child maltreatment” and that these cycles map onto the
multidimensional and ecological models. She argues that factors in the socio-political
cycle factors, such international and national policies, race and gender discrimination
impact on family functioning. The second cycle pertains to the role of cultural factors
in the maltreatment cycle, including, for example, the socially constructed concepts of
good or bad parenting, especially for minority groups who live in dominant
subcultures, and the “economic utility” of vulnerable children (Buchanan, 1996, p.74).

The third hypothesised cycle refers to psychological mechanisms, where there have
been a number of aetiological risk factors and protective factors identified (Buchanan,
The final cycle deals with biological factors, such as biological vulnerability, or factors in the environment that can cause biological changes to parent or child and influence the abuse cycle.

In order to assess the potential risk of the cycle of maltreatment it is necessary to integrate risk and protective factors into this ecological framework of cycles (Buchanan, 1996).

**Risk Factors**

Buchanan (1996, p. 205) states that “effective identification of risk and protective factors is central to the assessment process”. Cicchetti and Rizley (1981) used the idea of a multi-focus model where influences to the cycle can occur and interact with any social system to differentiate between types of risk factors involved in perpetuating a cycle of maltreatment.

Still the most widely accepted principle hypothesis in the transmission is experience of abuse in childhood (Widom, 1989). It appears that frequency and severity of abuse is unrelated to the likelihood of transmission (Bentovim, 2002). However, Glasser et al. (1999) found that being a victim of paedophilia, as compared to incest, indicated a higher likelihood of being a perpetrator. Briggs & Hawkins (1996) found that nonoffending individuals experienced greater frequency of sexual abuse than individuals in prison for sexual offences. However, prisoners had experienced significantly more physical and verbal abuse and emotional neglect, came from larger families, had more homes before the age of 17 and whose parents worked more in unskilled occupations (Briggs & Hawkins, 1996). Such differences in demographic and family factors, including low socio-economic status support other research findings (e.g. Quinton, Rutter & Liddle, 1984, cited in Buchanan, 1996). It is therefore apparent that the mechanisms of interplay between risk and protective factors are likely to mediate the transmission of abusive patterns of behaviour and involve more than just experience of abuse (Kaufman & Zigler, 1987).

Experience of intrafamilial violence, witnessing intrafamilial violence, rejection by the family and discontinuity of care were found to be most predictive of sexual abuse.
perpetration by boys who had been sexually abused (Skuse et al., 1998). The importance of these risk factors was confirmed in a prospective study (Salter et al., 2003). In addition, Bentovim (2002) suggests that factors such as rejection by peers, experiencing a generalised sense of grievance, poor identification with father figures, absence of a nonabusive male attachment figure, having a mother who was sexually or physically abused in childhood, maternal depression, poor sibling relationships and low levels of guilt concerning abusive action may also warrant assessment. Glasser et al. (1999) found that being sexually abused by a female relative was a strong predictor of being a perpetrator.

Skuse et al. (1998) hypothesised that living in a ‘climate of violence’ subjected the child to longer periods of stress and anxiety during which time key developmental tasks and personality identity processes were adversely affected. In addition those who experienced disruption to their home lives also had less chance to experience protective factors such as access to supportive figures (Bentovim, 2002). Heyman & Smith Slep (2002) found that childhood physical abuse together with witnessing parental family violence had a cumulative effect on risk of perpetration, with a propensity for a same-gender modelling effect.

The consequences of being abused are likely to feed back into the cycle and become risk factors. Browne and Finkelhor (1985) identified four ‘traumagenic dynamics’ (traumatic sexualisation, betrayal, powerlessness, stigmatisation) the outcomes of which could feedback into the cycle. Stigmatisation is hypothesised to increase the risk for alcohol or drug abuse. In turn alcohol and drug abuse have been found to increase risk of abuse perpetration (Sheridan, 1995).

Newcomb and Locke (2001) suggest that the type of abuse experienced impacts negatively on parenting ability and lead to abuse and neglect in the next generation. Mothers who had been neglected had poorer parenting practices overall with regard to warmth, aggression, rejection and neglect, experience of sexual abuse led to aggressive parenting. Fathers who had been sexually abused tended to exhibit a parenting style characterised as rejecting. Simons, Whitbeck, Conger and Chyi-In (1991) suggest that the method of transmission may be due to the legitimising beliefs
about harsh parenting practices. Newcomb and Locke (2001) hypothesised a role for social learning and attachment theory and advocated specific assessment and screening for at-risk parents for aggressive parenting practices in mothers and rejecting practices in fathers who have a history of sexual abuse.

**Protective Factors**

Protective factors have been studied by investigating those individuals who manage to avoid repeating the cycle of abuse (e.g. Kaufman & Zigler, 1987). In a retrospective study Egeland et al. (1988) found that mothers who broke the abuse cycle reported lower levels of psychological distress (anxiety and depression), were more likely to have had therapy, or had an available non-abusive emotional support during childhood and a supportive partner in adulthood. They proposed that the formation of secure attachment relationships as the mechanism of this protective effect (Egeland et al., 1988).

Grist Litty, Kowalski and Minor’s (1996) findings support Egeland et al. (1988) in suggesting that positive relationships and attachments help attenuate the cycle. They found that there was no difference in potential to abuse between individuals who had been physically abused and those who had not when social support was perceived as high. However, when social support was perceived as low there was a higher potential for individuals with a history of abuse to repeat the cycle. These individuals also reported more conflict in their relationships with others (Grist Litty et al., 1996).

Egeland and Susman-Stillman (1996) found that mothers who broke the cycle had been able to integrate the experiences into their sense-of-self, and were more future-orientated, though still able to recognise their history as part of them. However, those mothers who were in the abuse continuity group had high level of dissociative symptoms and were also users of alcohol and drugs. It was hypothesised that dissociation caused memories of the abuse to be unavailable and separate from their sense-of-self which led them to ignore or inappropriately idealise their childhood experiences. The researchers suggested that the process of dissociation impacts on the individual’s inner working model which effects transmission of maltreatment (Egeland & Susman-Stillman, 1996). Egeland and Susman-Stillman (1996) therefore
propose that being abused by a family member, i.e. an attachment figure, is more likely to cause dissociation.

Other protective factors such as positive school experiences Rutter (1989), high IQ (Egeland & Jacobvitz, 1984, cited in Buchanan, 1996), being a woman (Glasser et al., 1999) and special talents (Cicchetti & Rizley, 1981) have been reported in the literature. In the Salter et al. (2003) study none of the hypothesised protective factors, such as a good relationship with adult, sibling or peer, years spent in foster care and no parental abuse before age 12, interacted with the risk factors to reduce the risk of becoming a sexual abuser. However, their sample did contain more severe and complex cases than would be found in the community. It remains unclear exactly how risk and resilience factors interact to increase or decrease risk of future perpetration.

Bentovim (2002) suggests undertaking an assessment of the risk of abusive behaviour occurring in victims once a disclosure has been made. He asserts that is essential to undertake a review of the pattern or risk versus protective factors, the extent of abuse and the family context, and in particular whether the young person has lived within a climate of violence. In order to assess risk it is also necessary to review what the effects of the abuse have been. Bentovim (2002) states there should be concern noted if emotional responses are externalised, if attachments are disorganised and a fragmented sense-of-self appears to be present. These factors could potentially indicate that the victim is moving into an abuser role. Others have suggested a more formalised examination of risk factors with the use of specific measures and expressed concern about the lack of reliable instruments to measure abuse (e.g. Newcomb & Locke, 2001). Wattam (1999) argues there is a dilemma surrounding the use of predictive checklists and instruments as it implies an understanding of all causal factors and their interconnections.

Risk Assessment Measures

Child Abuse Potential Inventory (CAP; Milner 1986, cited in Milner 1994)
The CAP is a 160 item self-report measure of child maltreatment risk in adult caregivers which classifies respondents as ‘at risk’ or ‘not at risk’ for abuse (Milner, 1994). It has been found to have generally good levels of reliability and validity,
although does have the potential to produce false positives (Milner, 1994). It is also less effective at identifying risk of neglect and/or sexual abuse compared to risk of physical abuse (McNary & Black, 2003). A recent study revealed that the CAP was unable to accurately map changes which occurred as a result of family support interventions onto future episodes of actual abuse (Chaffin & Valle, 2003). However, Chaffin and Valle (2003) advocated its use as a screening instrument.

Although the DOH et al. (2000) Assessment Framework is not a measure specifically looking to ascertain the risk of the cycle of abuse, it has many features which are assessed when a child in need is suffering or at risk of suffering significant harm. The framework covers three domains: the child’s developmental needs, parenting capacity and family and environmental factors. The Assessment Framework also includes questionnaires relating to Rutter’s strength and difficulties questionnaire which assess family and parenting stress and may reveal potential risk or protective factors (Buchanan, 1996). Having this data, together with an understanding of the risk and resilience factors, a clinician is likely to be in a position to assess what the risk is to the ‘child in need’ becoming a future perpetrator.

**INTERVENTIONS**
Information gained from assessment is central to understanding the most appropriate way to intervene to try and prevent the cycle of abuse (e.g. Egeland & Susman-Stillman, 1996). Kaufman and Zigler (1992, cited in Buchanan, 1996) have characterised a number of interventions in terms of their level in an ecological framework and suggest that the most effective input is versatile, spanning all levels and systems within the cycles of maltreatment. Gough (1993) suggests three levels of prevention approaches: primary (interventions for the general population), secondary (strategies for identified ‘at-risk’ groups) and tertiary (reactive intervention to actual incidents of child maltreatment in order to prevent abuse recurring). These three levels encompass the intrafamilial (psychological and biological factors) and extrafamilial (socio-political and cultural) cycles and four levels of systems in the ecological framework.
Chaffin and Vale (2003) emphasise the importance of meaningful outcomes, i.e. reduction in abusive practices and transmission. Wattam (1999, p.319) notes an inherent problem for preventative outcome measures that “it is much easier to identify something that has happened than something that has been stopped from happening.”

**Primary preventative level strategies**

International, national, local government and communities all have a responsibility for modifying and creating policies, laws, procedures and support services and education programmes aimed at breaking the cycles of maltreatment (Buchanan, 1996). Unfortunately, it is out of the scope of the essay to discuss all efforts to break the cycle of abuse. Therefore, community level prevention methods will be discussed as they are most likely to be of immediate clinical relevance.

Educational programmes aimed at both potential victims and abusers have met with some success in improvement in the levels of knowledge gained (Rispens, Aleman & Goudena, 1997). In a meta-analysis of school programmes aimed at providing children with knowledge of self-protection skills and sexual concepts positive effects were found, including an increase in number of disclosures reported in a number of studies. However, it was unclear whether knowledge gained translated in real life situations or reduced actual episodes of abuse (Rispens et al., 1997). A more recent meta-analysis of sexual abuse prevention programmes suggested that programmes which incorporated practical training over a number of sessions to encourage learning, were the most effective (Davis & Gidyez, 2000).

Research examining the impact of general parent education including ante-natal and post-natal programmes has been found to suffer from methodological limitations (Gough, 1993). Anecdotal evidence suggests these types of interventions may be beneficial, though lack of specificity on which components work best is problematic for service providers (Gough, 1993). The Open University (1992, cited in Buchanan, 1996) reported improvement in understanding, skills, self-esteem and attitudes relating to parenting of pre-school children following the use of health education materials such as booklets, audio and video tapes.
Secondary level strategies

Again, problems with study designs preclude findings of effectiveness (Gough, 1993). Many of the interventions targeted at at-risk groups emphasise the use of social support and education, and in a few studies the impact of individual psychotherapy has been investigated (Gough, 1993).

In a meta-analysis home visitation programmes targeted at at-risk populations were found to have less favourable outcomes compared to those targeted at the general population (Guterman, 1999). However, Guterman (1999) suggests that problems with the reliability and validity of screening procedures may introduce bias into the targeted populations, so that services are not appropriately tailored to the needs of the families or include extremes of families where change is difficult to effect.

A study by Barth (1991) found that although at-risk mothers reported satisfaction with a time-limited ante natal parent training programme no significant differences were found on factors such as birth weight, baby-care (routine medical care, number of immunisations), child illness and non-investigated, non-substantiated and substantiated reports of child abuse, when compared to a control group. The authors suggested that in some at-risk groups individuals may need more input than brief time-limited interventions (Barth, 1991).

Bentovim (2002) describes an intervention working with adolescents following disclosure of sexual abuse to tackle prevention of re-victimization and potential offending behaviour. However, the success of such an intervention has not been tested empirically. Bentovim (2002) argues that it is crucial to ensure the child is living in a supportive context, i.e. enhancing protective factors; where they live is likely to depend on whether caregivers acknowledge and believe the child about the abuse. Therapeutic work, both individual and group can then take place. The focus of the work is in three main areas: repairing attachments, by creating a rapport with the therapist or other group members; ensuring adequate coping skills are present to explore abusive experiences, post-traumatic symptoms and externalising responses in order to prevent dissociation and; work to create a positive sense-of-self so that
correct attributions for the events are made. The third area may involve using cognitive elements of challenging or narrative re-storying techniques. Importantly sexual identity and arousal issues need to be tackled. ‘Personal safety skills’, including support seeking, to deal with potentially dangerous situations where perpetrating behaviour could occur need to be developed. Bentovim (2002) suggests parallel therapeutic family work.

**Tertiary level strategies**

There have been a number of studies which have explored treatment, and prevention programmes for individuals who have already experienced abuse or who have progressed within the cycle and become perpetrators (e.g. Gouge, 1993).

**Behavioural Therapy (BT)**

Parent training programmes that have been used to attempt to reduce physically abusive behaviours have met with good success rates (Gough, 1993). Corcoran (2000) in a critical review of treatments for abuse and neglect commented that although BT led to reductions in maltreatment, this did not mean child development was enhanced. Gough (1993) also notes that motivation of clients is likely to impact on treatment outcome. Newcomb and Locke (2001) assert that parent training must take into account the parent’s own experiences of maltreatment or symptoms of post-traumatic stress disorder.

BT techniques, such as aversion therapy, have also been used with sexual abuse offenders. Generally, however, they tend to be abusive in themselves, and offenders do not generally get to explore their own victimisation and its impact upon their behaviour (Muster, 1992). Although there are reported successes (e.g. Maletzky, 1980), Gough (1993) highlights lack of control groups and lack of attention to causal factors as problems.

**Cognitive Behavioural Therapy (CBT)**

One of the criticisms of BT is lack of emphasis on attitudinal and cognitive factors which can influence behaviour (Corcoran, 2000). CBT interventions for perpetrators have generally met with success (e.g. Kolko, 1996). Whiteman, Fanshel, and Grundy (1987, cited in Corcoran, 2000) found that CBT methods (including cognitive
Restructuring, relaxation training and problem-solving) produced most improvements in child management skills and reduced anger arousal compared to either technique alone. Relaxation training was least effective in this sample of physically abuse perpetrators.

CBT has been used with both perpetrators of sexual abuse and adult and child victims. Findings from the small number of studies for both groups have produced positive changes (Gough, 1993). Deblinger, Stauffer & Steer (2001) found that CBT was more effective for children aged two to eight and their non-abusing mothers compared to supportive therapy. Individual psychotherapy has the potential to be beneficial just by creating a strong therapeutic relationship and repairing attachments (Bentovim, 2002).

**Family therapy (FT)**

There have been very few studies on the impact of FT on abuse Corcoran (2000). Kolko (1996) reports a comparison between CBT and FT for both abused children and their abusive parents. CBT was slightly more effective than FT in increasing the time to next abusive episode and reducing aggression and use of physical chastisement (Corcoran, 2000). A multi-family FT intervention was found to be more effective in enhancing parent-child interactions and child assertiveness than a single-family FT (Meezan & O’Keefe, 1998, cited in Corcoran, 2000).

Multisystemic therapy (MST), which is based on ecological theory and involves the interactions between the interconnected systems of the individual, parents, peers, school, community and work has been found to be effective with physically and sexually abused and neglected children who have been perpetrators (e.g. Corcoran, 2000; Borduin & Schaeffer, 2001). MST uses techniques from FT, CBT and BT (Corcoran, 2000). Studies have reported improvements with reduction in re-offending, attachments in the family environment and with peers and improvements in school performance (Borduin & Schaeffer, 2001; Corcoran, 2000).

Social network interventions, individual psychotherapy and atheoretical interventions have also been implemented and studied with victims and abusers. Gough (1993) and Corcoran (2000) provide reviews of their effectiveness.
DIVERSITY ISSUES

Diversity issues play a major role in the understanding of the cycles of maltreatment. Such issues of minority subgroups in dominant cultures with differing opinions on what constitutes appropriate parenting practice (Gray & Cosgrove, 1985) is especially important to consider during the process of assessment. In addition variables such as racism and cultural stereotyping should also be attended to during assessment (DOH, 2000). In the UK there is no data on the numbers of children from minority groups in care or their representation in services, such information is required if services are to be accessible as possible (DOH, 2000). Accessible services are also important for children with learning disabilities who are at increased risk for abuse and may also experience marginalisation and exclusion (DOH, 2000). The DOH (2000) reports lack of recording of religion in case files. Such information is likely to have an impact upon engagement and working practices. The lack of culturally diverse samples and lack of research outside the UK and USA is problematic as it means the information collected is not representative. This has implications for practice (Buchanan, 1996).

CONCLUSION

It is clear from the research that a cycle of abuse does exist (Buchanan, 1996). Examination of aetiological risk and protective factors pertinent in the cycle of abuse is essential to evidence-based assessment and interventions. Bentovim (2002, p.663) emphasises that abuse in childhood “may be an important contributory, but not a necessary, factor in the development of perpetrating behavior”. Hopefully, such findings will help dissolve the public myth of the inevitability the abuse cycle and so for victims such a notion is not a ‘self-fulfilling prophesy’ (Kaufman & Zigler, 1987). The fact that two thirds of individuals who have been abused do not continue in this cycle indicates that very little is irreversible (Buchanan, 1996).

It is apparent that we have an understanding of the aetiological factors involved in the cycle. However, the lack of reliable and valid measures for conducting risk assessments makes it difficult for professionals and psychologists in the field to put this knowledge into practice without fear of such issues as false positives or negatives.
Therefore there is scope for future research to try and remedy these problems. In particular, more longitudinal and methodologically sound research is required to fully investigate the mediating and moderating effects of risk and resilience factors. In addition, there have been relatively few quasi-experimental studies with randomisation procedures comparing differential treatment efficacy directly in relation to the cycle of abuse (Corcoran, 2000). Men and the role of fathers and substitute fathers is also a relatively neglected area in the literature (Buchanan, 1996).

There have been a limited number of studies published on interventions aimed at tackling the abuse cycle. Interventions, particularly at a tertiary level, have reported some limited successes, though methodological limitations and some conflicting findings make it difficult to draw conclusions. It could be argued that the specific nature of CBT/BT interventions, given the complexity of the aetiologies of the cycle, limits their usefulness. Conversely, the success of MST indicates that where interventions are based upon broad ecological models of the cycles of maltreatment effective outcomes can be achieved (Borduin & Schaeffer, 2001).

In conclusion, with the increase in sophistication of research it is possible for clinicians to start thinking about effectively assessing and intervening in the cycle of abuse. Psychologists are in a unique position to assess the child’s current psychosocial context by building up a strong therapeutic relationship. Recommendations from Bentovim (2002) for assessing and preventing offending behaviour are useful and now need empirical validation together with further validation of MST with non-offending child samples in order to establish its effectiveness in breaking the cycle of abuse.
REFERENCES


Older Adults Essay

What is the Role of the Clinical Psychologist in Services for People with Dementia and their Families?

How can we Evaluate our Contribution as Psychologists?

August 2003

Year 2
INTRODUCTION

“What’s the point, when there’s no cure?”
— Anon

When the spouse, and primary caregiver, of a patient with dementia with whom I was carrying out a neuropsychological assessment recently said the above words to me, I was quite taken aback. It made me reflect upon the issues, and ask myself what skills Clinical Psychologists (CPs) have to offer people with dementia and their carers who find themselves in this very frightening and unpredictable situation? And can we make a difference whether it be in the early detection of the dementia, as in the case of my patient, or throughout the course of the disease until the final stages of life?

With the numbers of older people (OP) with dementia estimated at 750,000 (Alzheimer’s Society, 2003) and the rapid population growth of individuals aged 65 years and over (United Nations, 2003) it would seem that the question of what CPs have to offer services for people with dementia and their families is more pertinent than ever. Dementia, literally meaning ‘to lose one’s mind’, results in a progressive and slow global loss of cognitive functions (Midence & Cunliffe, 1996). It has been described as “one of the most feared of all modern ‘diseases’” (Bond, 1999, p. 562) and a state worse than death (Patrick, Starks, Cain, Uhlmann & Pearlman, 1994). There are at least 20 different causes of dementia (McKeith, 1994) the most common is Alzheimer’s disease which accounts for more than 50 per cent of cases (Katzman, 1976). There are a number of clinical manifestations of dementia, including cognitive symptoms and behavioural features which vary to greater and lesser degrees with the neurobiology of the dementia, the individual’s personality, life experiences and the environment (Clare, Baddeley, Moniz-Cook & Woods, 2003a).

This essay will discuss the role of clinical psychology in services for people with dementia and their families. It will explore why CPs should play a role in services and examine what CPs can offer in terms of direct work and ‘therapies’ with individuals with dementia and their families. The essay will also consider other roles for CPs including consultation, training and team-work, research and development and service development. The ideas surrounding how we can adequately evaluate our contribution will be discussed, including some of the inherent problems in this
undertaking. In particular, one possibility, Dementia Care Mapping (DCM; Kitwood & Bredin, 1992), will be explored for evaluating our contribution in service evaluation. The term ‘dementia’ is used to refer to the most common types of the disease, such as Alzheimer’s disease, Vascular disease, dementia with Lewy bodies, and Fronto-temporal dementia. Unfortunately, it is out of the scope of this essay to describe in detail the different types of ‘therapies’ available to people with dementia and their families. In addition, only dementia services for individuals over the age of 65 years will be discussed.

ROLE OF CLINICAL PSYCHOLOGISTS IN SERVICES FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES

The Role of a Clinical Psychologist
Paxton and D’Netto (2001) describe four fundamental and diverse roles for CPs: direct clinical services, ‘disseminating and promoting wider appropriate usage of psychological approaches in health care’ (which encompasses activities such as training, supervision of others and consultation), research and development (which covers service evaluation) and organisational and developmental work. The British Psychological Society (BPS; 1995) published a briefing paper on services for OP and their families which reinforces Paxton and D’Netto’s (2001) framework for the role of a CP in dementia services. However, lay people and other professionals often become confused at the role of a CP due to the overlap that exists in the type of work that CPs and other health-care professionals carry out (Hall & Marzillier, 1992). It was the Manpower Planning Advisory Group (MPAG) report, which was commissioned to review the availability of clinical psychology services in the National Health Services (NHS), that argued that CPs are the only professionals able to work at all three levels of psychological knowledge and expertise, and specifically at the third level (MPAG, 1990, cited in Health Services Employers Agency [HSEA], 2002). MPAG (1990, cited in HSEA, 2002) argues that work at the third level requires a generic knowledge base of multiple theoretical models which enable a flexible, integrative and individualised approach that is especially relevant for complex presenting problems.

Direct Clinical Services
Many authors in the field of dementia care have highlighted just this need for an integrated and person-centred approach for people with dementia and their families (Kitwood, 1997). People with dementia have been recognised as a heterogeneous group due to the impact of the individual’s personality, biography, physical health, neurological impairment and social psychology (Kitwood, 1996). Research aimed at exploring diversity issues, such as race, ethnicity and culture, in dementia service provision illustrates well the notion of heterogeneity in the person with dementia and their carers (Gallagher-Thompson et al., 2003). Direct clinical work offers a number of ‘therapies’ to cater for some of these needs of people with dementia and their carers and includes intervening with challenging behaviour and diagnosis (Department of Health and Social Security and Public Safety [DHSSPS] Clinical Psychology Speciality Advisory Committee, 2003).

‘Therapies’ for People with Dementia

For over 30 years CPs have contributed to the development of theory- and evidence-based interventions for the person with dementia, many of which are multi-component (Woods, 1996). The main aims of the ‘therapies’ are to buffer the primary and secondary effects of the disease (Woods, 1996). Reality Orientation (RO), Reminiscence Therapy (RT), Validation Therapy, Cognitive management strategies, sensory stimulation, cognitive behavioural therapy (CBT), psychoeducational interventions and support groups have all been developed (Woods, 1996). However, with the exception of RO, which has been shown to produce significant improvements in cognitive domains of memory and orientation and behaviour (Spector, Orrell, Davies & Woods, 2000), only non-significant trends for effectiveness have been achieved (Clare, Woods, Moniz-Cook, Orrell & Spector, 2003b; Midence & Cunliffe, 1996; Neal & Briggs, 2003; Spector, Orrell, Davies & Woods, 2002).

Gitlin et al., (2003) have highlighted that only an individualised and multi-component approach will enable an effective service to be provided. For example, Baines, Saxby and Ehlert (1987) found significant and superior outcomes on information, orientation and behaviour measures with patients with dementia who experienced RO first followed by RT, compared to the group who received RT, followed by RO, where no significant results were recorded. Spector, Orrell, Davies and Woods, (2001) have
attempted to combine a number of cognitive, sensory stimulation, validation, RO and RT techniques to create a cognition-based programme drawing on the most effective aspects of these previously researched approaches. They found improvement in a number of areas relating to the functioning and well-being of the person with dementia. Reduction in the psychological distress of relatives was also recorded. The intervention is currently being formally evaluated using a randomised control trial (Spector, et al., 2001). Woods (1996) highlights that the goal of working with an individual with dementia is ‘Individual Programme Planning’ which takes such issues as careful assessment and an integrated approach into account. It is this type of innovative work that reinforces the appropriateness of CPs being involved in dementia services. It highlights their capability for work at the third level of psychological knowledge identified by MPAG (1990, cited in HSEA, 2002).

‘Therapies’ for Caregivers

CBT and support groups have also been developed for the family caregivers and found to be effective (Diehl, Mayer, Forstl & Kurz, 2003; Zarit & Edwards, 1999). In addition, educational strategies and individual and family counselling or therapy are of proven effectiveness for this group (Zarit & Edwards, 1999). Such approaches are important as it is well known that caring for someone with a dementia often leads to the experience of stress and mental health problems, including depression (Ory, Yee, Tennstedt & Schulz, 2000). Furthermore, it has been found that provision of CBT for the carer also has positive benefits for the patient, significantly reducing behavioural disturbance (Marriott, Donaldson, Tarrier & Burns, 2000). However, caregiver characteristics (Zarit & Edwards, 1999), the type of dementia diagnosed (Diehl et al., 2003) and type of presenting problem (Toseland, Rossiter, Peak & Smith, 1990) all impact on what service is likely to be most effective and CPs should be aware of the evidence-base when assessing which type of a service is likely to be most beneficial for carers.

CPs also have a role in tackling the factors which have been identified as barriers to accessing direct clinical services available to caregivers and the person with dementia. Barriers include ‘enabling factors’, such as transportation, location and implied costs of accessing services, which may highlight issues of social deprivation and economic
difficulties (Toseland, McCallion, Gerber & Banks, 2002). Thus CPs must think creatively and develop direct clinical services which acknowledge such diversity.

Although there are effective interventions for family caregivers, there remains only modest support for ‘therapies’ aimed at people with dementia. Therefore most authors have added a caveat that research in this area is in its infancy and due to methodological limitations has little power to detect significant findings (Clare et al., 2003b). CPs have been active in highlighting adaptations and integrating mainstream techniques in order to enhance their effectiveness (Spector et al., 2001). In addition they have attempted to re-conceptualise the ‘disease-cure’ medical model by stressing the notion individual difference (Bird, 1999), which may mask variability and provide evidence for indicators for which interventions work best for different individuals with dementia (Scott & Clare, 2003). While recognition of the individuality of people is essential, the person with dementia and their families are inescapably linked in a system. Systemic ideas appear useful in these domains, such as the importance of context, but research has yet to acknowledge the value of this model fully (Dilworth-Anderson, 2001). Systemic Therapy, for example, has already been found to substantially delay placement in a nursing home for individuals with Alzheimer’s disease by an average of 329 days (Mittelman, Ferris, Shulman, Steinberg & Levin, 1996) and CPs have a role in developing further these types of interventions which recognise both the person with dementia and their families.

Challenging Behaviour

Bird (1999) emphasises that CPs have the skills to play a critical role in the domain of challenging behaviour in dementia, which also requires an ability to intervene with the system. For example, applying well researched areas of cognitive therapy to help alleviate carer distress and reframe behaviours seen as problematic may be productive (Bird, 1999). Application of behaviour theory to behavioural management and environmental manipulation to reduce challenging behaviour is also a frequently reported role attributed to CPs (Bird 1999). Bird (1999) stresses that although the behavioural approach is common-place, it should be applied with caution as there is a lack of an evidence-base in this specialty. CPs have a role to add to this research.
Neuropsychological Assessment

The American Psychological Association (APA; 1998) highlight the role of CPs in diagnosis of dementia using specialised neuropsychological tests. The DHSSPS Clinical Psychology Speciality Advisory Committee (2003) asserts that neuropsychological assessment is a key method in differential diagnosis of dementia. Following diagnosis CPs have an important role to sensitively feedback the results in non-technical language (APA, 1998). In addition, the CP who has undertaken the assessment is in a position to provide education and support to the person with dementia and their family, including referring to other psychologists for specific interventions or undertaking these themselves, especially where CPs are localised within a specialised team (APA, 1998; Audit Commission, 2000).

Disseminating and promoting wider appropriate use of psychology in health care

The National Service Framework for Older People (NSFOP; Department of Health [DOH], 2001) and Forget Me Not report (Audit Commission, 2000) has highlighted the role of CPs as part of a multidisciplinary team in community mental health teams for older people and memory clinics. The Audit Commission (2000, p.22) suggests that “specialist mental health services for older people [which should include CPs] should make special efforts to contact GPs – especially those who make few referrals – and offer support and training”. Therefore, CPs and other specialist team members should provide training to GPs who are a crucial point of contact in the early detection and in the management of dementia (Audit Commission, 2000). For example, the Audit Commission (2000) highlighted that GPs frequently do not use specialist screening assessments. The APA (1998) reiterates the role of CPs in educating health care professionals who may be administering screening tools.

The Audit Commission, (2000) found that GPs who felt more supported and who had access to specialist services were more likely to see the value in early diagnosis of dementia. Memory clinics aim to diagnose and intervene at an earlier stage with people with dementia and they have the potential to improve quality of life for carers of people with mild to moderate dementia (Logiudice et al., 1999). CPs have an identified role in these services (DOH, 2001).
As dementia becomes progressively more severe families are likely to make the difficult decision to admit their relative to a nursing home. This is often incorrectly associated with alleviation of burden and psychological distress for families (Zarit & Whitlatch, 1993). Woods, Ross, Keady and Wenger (2001, cited in Clare et al., 2003a) suggest that CPs can develop and provide training materials to family members and nursing homes to allow these two systems to work together. Clare et al., (2003a) suggest that quality of care to the patient is enhanced where families and nursing homes can work well together.

Many CPs are already providing consultation to their colleagues. I attended a conference organised by South Essex Partnership NHS Trust, Clinical and Counselling Psychology Service in July 2004, where CPs were disseminating their ideas and examples of systemic practice with older adults, particularly in dementia services. As a result of consultation from a systemic psychotherapist a support group for carers and the person with dementia had been set up on the principles of a systemic approach. Supervision was a key aspect of this, a role which psychologists should be delivering (BPS, 1995).

Clare et al., (2003a) highlight the importance of CPs providing supervision to trainee CPs. They assert that continuation of core placements within the specialty is crucial to growth of dementia services.

Research and Development
Clare et al., (2003a) stress that psychologists have a vital contribution to make in research and development, including audit and clinical governance and these issues will be discussed further in the evaluation section. Schulz (2001) highlights that theoretical and conceptual models are important in developing intervention strategies. Carradice, Beail and Shankland (2003) emphasise that CPs must undertake more theory-driven research. As CPs work theoretically they are uniquely placed to carry out this type of work. However, Lee, Critchley-Robbins, Smyth, McDonagh and Dooley (2002), noted that the NSFOP (DOH, 2001) has not acknowledged the role of clinical psychology in research and development. Bird (1999, p.147) asserts that
Academic Dossier: Older Adults Essay

despite our contribution there is much more scope for psychologists to provide an evidence-base for “the practical problems raised by the disorder” and particularly in the area of challenging behaviour. Specifically Bird (1999) calls for case-specific examples of research to be published which take into account long- and short-term outcomes and issues of the heterogeneity and diversity of individuals. Clearly CPs still have more to offer in this role and they needs to raise their profile.

Organisational Work and Service Development
Lee et al., (2002) argue that one way in which the profile of clinical psychology can be raised is to ensure that psychologists obtain positions in key implementation structures and on workforce planning teams. The Forget Me Not report (Audit Commission, 2000, p.50) highlights that “discussions of future service developments, especially for people in the early stages of dementia, may need to involve local authority representatives, physicians, neurologists and clinical psychologists as much as psychiatrists”. The NSFOP (DOH, 2001) has highlighted the importance of recognising the psychological needs of OP and emphasises the role of CPs as essential in achieving this aim. This includes development of cultural competence and recognition of diversity issues so psychological services can be made available and acceptable to minority and disadvantaged populations (APA, 2002). Lee et al., (2002) have stressed the importance of exploring the current ‘real’ situation in clinical psychology and use of our skills to problem-solve our own difficulties, such as lack of economic resources and shortage of CPs working in OP services. Clare and her colleagues (2003a) highlight the importance of affecting change at the educational level to promote the specialty and the opportunity of employment in these services. The BPS (1995, p. 11) stress that psychologists who offer placements to trainee CPs and assistant psychologists “need to give priority to providing a high quality training experience” in order to attract newly-qualified staff into the specialty.

Lastly, CPs have an important role in ensuring ethical and professional practice. For example, ensuring a person-centred approach and being aware issues of elder abuse and informed consent. CPs should disseminate these ideas within their services and practice (APA, 1998). It is vital that CPs continue to work towards reducing age discrimination (DOH, 2001) by modifying and challenging assumptions and myths.
held by ourselves and other CPs, other health-care professionals, services and the clients themselves (Laidlaw, Thompson, Dick-Siskin & Gallagher-Thompson, 2003)

**HOW CAN WE EVALUATE OUR CONTRIBUTION AS PSYCHOLOGISTS**

As was highlighted in the previous section use of evidence-based practice is key to CPs (Hall & Marzillier, 1992). It is essential that we apply this approach to the investigation of our own contribution and efficacy. This can be done by ensuring that individual interventions provided are effective and, in a broader context, and one which the NHS has been championing, in the evaluation of services and clinical governance (DOH, 1998). It has been argued that CPs have great potential to take on and develop their role in clinical governance, which includes clinical audit and research (Baker & Firth-Cozens, 1998). However, with the complexity of the specialty, there are a number of inherent difficulties related to the evaluation of our contribution which require consideration.

**Issues in Evaluation**

Firstly, the person with dementia, until recently, has largely been ignored in the research, perhaps due to the perceived issues surrounding the progressive nature and cognitive limitations of people with dementia (Cotrell & Schulz, 1993). Some researchers have used these issues to argue against using specific outcome measures to examine intervention effectiveness (Hawkins & Eagger, 1999). However, theoretical perspectives, such as that of Kitwood (1997) who argues that the ‘person comes first’, and suggestions that people with dementia can give reliable and valid accounts of their situation, indicate that they should be included in research and the evaluation procedure (Feinberg & Whitlatch, 2001). In fact, Feinberg and Whiltatch (2001) suggest caregivers may misperceive the person with dementia’s preferences, choices and decisions about daily living. Despite this, researchers are still grappling with the issues of how best to include the person with dementia so the heterogeneity and diversity of individuals is reflected in the outcomes of studies. Much research is carried out for groups of caregivers or people with dementia and Scott and Clare (2003) and Bird (1999) emphasise the importance of looking at group and individual
outcomes to help provide information to questions of ‘what works best for whom’ (Harahan, 2001).

Secondly, Schulz (2001), amongst others, has posed the question ‘outcomes for whom’. Schulz (2001) highlights that a positive outcome for one person in the system is not necessarily going to be positive for another part of the system. He suggests that raising such issues and reframing the situation so that the focus of outcome is on the caregiver and person with dementia as a ‘dyad’, rather than as individuals may present a useful way forward (Schulz, 2001).

Thirdly, Schulz et al., (2002) have been vocal in highlighting the tension between statistical significance and clinical significance in the research. Schulz et al., (2002) report that frequently there is a need to produce outcomes in a number of different domains and argue for a core set of outcomes to be used in the research. These relate to the four domains of clinical significance which they identify as symptomatology, quality of life, social significance and social validity. Scott and Clare (2003) call for development of consensus-based measures and guidelines for clinically meaningful outcomes. Schulz (2001) also highlights the paradox of providing interventions, for example, which are psychoeducational or are aimed at improving quality of life, and then measuring outcome as if were to have a consistent impact immediately. He recommends that researchers give thought to ‘proximal’ and ‘distal’ outcome issues to avoid unnecessary expectations of intervention studies (Schulz, 2001).

It is well recognised that, given the progressive nature of dementia, outcomes, whether statistically or clinically significant, must be sensitive and realistic to the aims of the research (Beck, 2001). There is acknowledgment that the aim of most treatments is to “retain or lessen the impact on sufferers” (Midence & Cunliffe, 1996, p.595). Goal attainment scaling (GAS) maybe a technique which challenges the requirement of improvement as a marker of success, enables better understanding of treatment effects and emphasises the importance of individualised targets (Burns, 2002).

Finally, there are issues with research methodology, which plagues all research, not just that in this specialty. Sample sizes are often too small, randomisation and blind
investigators are infrequently employed; Lack of adequate control groups, insufficient intervention or service provision and inappropriate outcome measures, including a lack of consensus in use of outcome measures to draw comparisons between studies and failure to investigate the long-term effects of interventions are frequently reported difficulties (e.g. Beck, 2001; Clare et al., 2003b; Downs, 1997; Schulz et al., 2002). Bird (1999) highlights the lack of honest reporting of intervention failure and the importance of using single case series and observational methods. Aranda (2001) emphasises the lack of research with racial and ethnic minority groups. She discusses five domains of barriers, individual, socio-cultural, economic, scientific and administrative which are currently precluding inclusion (Aranda, 2001).

**How Can CPs Evaluate Their Contribution?**

With all these issues to consider and heed it is sometimes difficult to see how we can reliably evaluate our contribution as CPs. There is a vast array of outcome measures which investigate domains such as quality of life, symptomatology, mood states, communication, interaction, burden, coping skills, longevity and user satisfaction (Schulz et al., 2002). As CPs, we have the skills to evaluate the efficacy of our interventions (Robertson & Hearnshaw, 1998) and should be able to assess which instruments are appropriate in the measurement of our contribution, taking into account some of the issues above.

Obtaining service-user feedback through appropriate questionnaire design is one way to investigate our contribution in service development and interventions (BPS, 1995). This has been emphasised by recommendations in the NHS Plan (DOH, 2000). Carradice et al., (2003) argue that using qualitative methodology to explore process issues can lead to an understanding of which components are most effective for certain individuals and is an area of important future research. Qualitative methodology per se has much to offer in examining the contribution of CPs. For example, focus groups could be used as a method of evaluation.

Using a health services approach to research by illustrating the economic utility of the role of clinical psychology services may provide a useful avenue for evaluation (Beck, 2001). Mittelman et al. (1996) demonstrated that a family therapy intervention allowed the person with dementia to remain at home an average of 329 days longer.
before having to be admitted to a far more costly specialist nursing facility. Beck (2001) cites a study by Thomas, (1996) which reports that an “Edenized” nursing home, which was founded on the basis of creating a ‘healthy human habitat’ with plants, children and animals, reduced medication costs, in comparison to a conventional nursing home, by $75,000 and reduced staff turnover by 26 per cent, mortality by 25 per cent and infection rate by 50 per cent.

Observational methodology may provide an appropriate solution to the problem of how to involve the person with dementia in feedback evaluating the contribution of CPs, particularly where the stage of dementia is severe. Dementia care mapping (DCM; Kitwood & Bredin, 1992), is an observational method that has been useful in examining outcomes for interventions aimed at improving the quality of life of individuals with dementia (Brooker & Duce, 2000) and also in audit (Brooker, Foster, Banner, Payne & Jackson, 1998).

DCM is a tool theoretically based on the concept of ‘personhood’ (Kitwood, 1997). It has been shown to be an effective audit technique over a three year period (Brooker et al., 1998). Brooker et al., (1998) highlight that feedback on excellent care strategies and also on episodes of personal detractions facilitated motivation to implement strategies aimed at achieving standards, which resulted in significant enhancement of well-being scores and reductions in malignant social psychology over the three year cycle.

DCM has been reviewed as a reliable quality of life measure, in those studies which reported inter-rater reliability coefficients, and has good face-validity, thus indicating usefulness in ascertaining clinical significance and efficacy (Beavis, Simpson & Graham, 2002). However, further research is required to establish content and construct validity and to examine the effects of confounding variables, such as psychological and physical problems (Beavis et al., 2002). It has also been criticised because of its large implications in resources, such as official training costs and its labour-intensive nature and the anxiety which DCM can evoke within the nursing team (Beavis et al., 2002).
It is too simplistic to suggest that this method enables an accurate picture of the contribution made by a CP to service development through training, consultation and team-work. However, it does provide a means to evaluate holistic service development, where a CP will have provided input. Perhaps comparisons of audits using DCM with teams with and without CPs maybe an area of fruitful future research.

As highlighted there are many issues to consider when thinking about how we can evaluate our contribution as CPs to dementia services. There is no easy solution and innovative intervention with this complex client group demands innovative evaluation. Carradice et al., (2003) highlight how future research may start to answer these questions by including more research guided by theory and more qualitative research designs to investigate process. Bird (1999) highlights the importance of an individualised approach to evaluation and GAS and DCM offer some promise to achieving this aim.

**DISCUSSION**

A vast number of roles and opportunities exist for CPs to work in dementia services. Our experience and training allows us to work professionally and ethically at the highest level of psychological understanding (MPAG, 1990, cited in HSEA, 2002). The work with people with dementia and their carers has been found to be far from straightforward and requires implementation of a number of different approaches and with a number of systems, emphasising the requirement for innovative practice (Gitlin et al., 2003). CPs have shown that they have the initiative to make a difference in these services (Spector et al., 2001).

Although there is significant diversity in the roles for CPs, the reality of the profession in services for older people is that it is seriously under-resourced, with only approximately one third of the minimum recommended numbers of CPs in this specialty (Boddington, 2002). It is therefore important that we acknowledge our limitations and prioritise our contributions. The BPS (1995, p.8) suggest that where psychology services for older people are limited in personnel “the best use of
psychology services is in consultative and advisory capacities in planning and developing services”. Therefore implementation of innovative services is required, and CPs need to capitalise on the recent technological advances, such as the internet and email (Fortinsky, 2001). We must also recognise the value of our colleagues and the experience and knowledge which they possess. For example, the drama, music and movement therapies all have particular promise (Benbow, 1997).

Evaluation of the contribution of CPs is a challenging topic and the length of the section on issues in evaluation is perhaps related to the real complexity surrounding this domain. Perhaps, it is just a reflection of the complexity and diversity of OP with dementia and their carers. Importantly, the person with dementia is part of a wider system and systemic interventions have already shown some promise. It is likely that systemic ideas including feedback and the recognition of idiosyncrasy will be useful concepts when thinking about evaluation. Qualitative research methods, service-user satisfaction and individualised approaches to service evaluation offer a way of exploring such concepts and may provide future directions for research.

As services within the NHS develop CPs will be working more and more at the primary-care gateway, providing consultation and training to primary-care workers (DHSSPS Clinical Psychology Speciality Advisory Committee, 2003). Future research will need to focus not only the outcome but the feasibility of implementing positive gains into clinical practice. Beck (2001) suggests that combining clinical and health services research will be a useful approach for the future. This may also be a way of evaluating our contribution and ensuring there continues to be a role for CPs in the future.

In conclusion, the reality of dementia is that it is a complex, degenerative process. This represents a real challenge to CPs and requires full use of their skills to apply to the variety of roles and their evaluation (Bond, 1999). There is no easy answer, but it is clear that ‘there is a point’ to intervening, even where there is no cure. To achieve this CPs now need to engender more than a “quiet revolution” (Clare et al., 2003a, p. 250) to train, recruit and retain more CPs to fulfil the breadth of roles described and enhance the profile of clinical psychology in dementia services. In order to
accomplish these aims creative approaches to intervention and systematic evaluation of our contributions need to be generated. This will illustrate the necessity of CPs as essential multidisciplinary professionals in the care of people with dementia and their families.
REFERENCES


Aranda, M. P. (2001). Racial and ethnic factors in dementia care-giving research in the US. Aging and Mental Health, 5 (Supplement 1), S116-S123


Schulz, R. (2001). Some critical issues in caregiver intervention research. *Aging & Mental Health, 5* (Supplement 1), S112-S115


This section comprises of summaries of clinical placement experience gained in the four core placements and a year-long specialist placement. Also contained in this section is a summary of the five case reports written for each core placement and one specialist placement. The five clinical case reports and a full record of clinical activity are submitted, in full in Volume Two of this portfolio.
Summary of Clinical Experience

Adult Mental Health
**Clinical Dossier: Summary of Clinical Experience (Adult Mental Health)**

**Adult Mental Health Placement** – Guildford Community Mental Health Team

**Client Demographics**
- Individual work with 12 clients (8 male, 4 female) ranging in age from 21 to 59.
- Group work with clients whose ages ranged from 27 to 49

**Presenting Problems**
- Social phobia and agoraphobia
- Post-traumatic stress
- Psychosis
- Panic disorder
- Anger
- Depression
- Self-Harm

**Settings**
- CMHT, primary care (GP Practice)

**Assessment Procedures**
- Assessment interviews; questionnaires (BAI, BDI, HADS, CES-D);
- Psychometric assessment (WAIS-III, WMS-III, NART)

**Interventions**
- Cognitive behavioural therapy; group therapy

**Other Experience**
- Carried out audit of GP referrals (Service Related Research Project)
- PowerPoint presentation given to monthly journal club
- Took part in a clinical governance review
- Met with and observed work of other professionals (CMHT Manager, assertive outreach team, CPN, inpatient staff, psychiatrist, social worker)
- Attended day workshop on supervision
Summary of Clinical Experience

People with Learning Disabilities
**Clinical Dossier:** Summary of Clinical Experience (People with Learning Disabilities)

**People with Learning Disabilities Placement** – Redhill Community Team for People with Learning Disabilities & April Cottage, Assessment & Treatment Unit

**Client Demographics**
- Individual work with 10 clients (6 male, 4 female) ranging in age from 14 to 73

**Presenting Problems**
- Parenting
- Bipolar disorder and anxiety
- Dementia
- Autistic spectrum disorders

**Behavioural problems**
- Family and transitional issues
- Bereavement, depression and self-harm
- Psychosis

**Settings**
- Community settings, schools, inpatient unit, residential setting

**Assessment Procedures**
- Assessment interviews; naturalistic observations; questionnaires (RSES, Birleson Depression Scale); psychometric assessment (WAIS-III, NEALE-R, BPVS, LIPS, BAS, dementia assessment)

**Interventions**
- Cognitive behavioural therapy; guided mourning, Autism Specific (TEAACH), behaviour therapy

**Other Experience**
- Worked with: teachers, psychiatrist, support workers, families, care managers, community nurses, named nurses, respite care services, home managers
- Met and/or observed: speech and language therapists, physiotherapist, Community Forensic Team, community day centre, dietician, art therapist, sexuality assessment
- Attended and contributed roughly fortnightly inpatient ward rounds
- Contributed to CPA meetings and pre-discharge meetings
- Undertook a teaching session on the HALO to inpatient staff
Summary of Clinical Experience

Child and Family
Clinical Dossier: Summary of Clinical Experience (Child and Family)

Child and Family Placement – Chertsey Child and Adolescent Mental Health Team

Client Demographics
• Individual work with 11 clients (6 male, 5 female) ranging in age from 5 to 14

Presenting Problems
Enuresis
Cognitive difficulties & ADHD
Encopresis
Phobia
Anger
Sleeping difficulties
Restrictive eating
Behavioural problems
School refusal

Settings
• Community settings, schools

Assessment Procedures
• Assessment interviews and diaries; ABC charts; questionnaires (ARSE, SPPC); psychometric assessment (WISC-III, theory of mind, strange stories)

Interventions
• Cognitive behavioural therapy; behaviour therapy; narrative therapy

Other Experience
• Fortnightly supervision groups with psychotherapist, monthly consultation with psychiatrist, and CBT supervision group.
• Met and/or observed: CPN, social worker, psychiatrist, psychotherapist
• Attended half day seminars on eating disorders, drug services and joint working with adult services
• Undertook a presentation on tools for anger management interventions
Summary of Clinical Experience

Older Adults
**Older Adults Placement** – Worthing Clinical Psychology Service for Older People

**Client Demographics**
- Individual work with 11 clients (7 male, 4 female) ranging in age from 68 to 89

**Presenting Problems**

<table>
<thead>
<tr>
<th>Presenting Issue</th>
<th>Care-giving issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>Anxidity and depression</td>
</tr>
<tr>
<td>Obsessive compulsive disorder</td>
<td>Generalised anxiety disorder</td>
</tr>
<tr>
<td>Panic disorder</td>
<td>Brain Injury</td>
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<tr>
<td>Challenging behaviour</td>
<td></td>
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</tbody>
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**Settings**
- Community settings, residential and nursing home settings

**Assessment Procedures**
- Assessment interviews and diaries; Functional analysis; questionnaires (OCI, RAS, OCS, BDI, BAI); psychometric assessment (WAIS-III, WTAR, MEAMS, RBMT, BADS, RCPM, NART, Doors and People, Verbal fluency, BNT)

**Interventions**
- Cognitive behavioural therapy; life review; behavioural therapy; consultation

**Other Experience**
- Involved in development of an early intervention service and memory groups for individuals newly diagnosed with dementia
- Met and/or visited: Care workers, CPN, OT, residential home managers, Alzheimer’s society, inpatient units, day centres, Carer’s liaison service
- Attended a conference on a systemic approach with older adults and gave a PowerPoint presentation to the psychology department on the conference
- Attended a day workshop on the Single Assessment Process and lecture on stress in older people
Summary of Clinical Experience

Specialist – Paediatric (1 year)
Clinical Dossier: Adult Mental Health Case Report Summary

Specialist (Paediatric) Placement (1 Year) – Great Ormond Street Hospital

Client Demographics
- Individual work with 18 clients (10 male, 8 female) ranging in age from 8 to 15, observation of outpatient clinics, ranging from 0-15 years.

Presenting Problems
| Chronic pain           | Enuresis          |
| Procedure phobia       | Needle phobia     |
| Cognitive deterioration| Depression        |
| Noise phobia           | Autistic spectrum disorder |
| Social skills problems | Chronic illness (Cystic Fibrosis), |
| Metabolic disorders    | adjustment adherence to treatment |

Behavioural and learning problems

Settings
- Hospital outpatient and inpatient, school

Assessment Procedures
- Assessment interviews and diaries; naturalistic observation, questionnaires (McGill Pain Questionnaire, CDI, Beck Youth Inventories); psychometric assessment (WISC-IV, WISC-III, WORD, WOND, NEALE-R, TEA-Ch, CMS, Verbal Fluency, Trail Making, Purdue Pegboard, Sue Spence Social Skills Assessment, Happe Social Stories)

Interventions
- Cognitive behavioural therapy; behaviour therapy; narrative therapy; systemic therapy; liaison with medical and educational professionals

Other Experience
- Presentation to National Cystic Fibrosis Psychosocial Conference in London
- Attended weekly respiratory ward rounds, MDT clinic review meetings and psychosocial meetings; weekly Paediatric Psychology seminars; fortnightly psychology team meetings; monthly ‘trainee group’; cardiac and respiratory speciality meetings; outpatient MDT cystic fibrosis clinics and annual reviews; a Shwachman Diamond Syndrome lecture

Observed/Met: play specialist, clinical nurse specialist, neurodevelopmental clinic
Adult Mental Health Case Report Summary

Cognitive Behavioural Group Intervention for Individuals with Panic Attacks

April 2003

Year 1

Some identifying details and all names have been changed to preserve anonymity.
Reason for Referral
General Practitioners were asked for referrals for a "managing anxiety and panic attacks" time-limited cognitive-behavioural therapy (CBT) group to take place within a primary care psychology service.

Presenting Problem
Of the four individuals who attended the group, Peter Evans, a 49 year old, white British man’s panic attacks started following adverse reaction to antidepressants. Peter was unemployed and caring for elderly parents. Ben Jackson, a 24 year old white British man had a long history of anxiety. His panic attacks deteriorated about two years ago following a stressful train journey and he experienced attacks in crowded areas. Melanie Wright, a 27 year old white British female had an 18-month history of weekly panic attacks, particularly when she was worried about her daughter’s ill health. The fourth group member, Patricia Wood, a 36 year old white British lady had a difficult psychosocial situation with five children and a husband who was depressed. Patricia reported frequent panic attacks, insomnia and depression.

Assessment
Ten clients attended a single 50-minute assessment. Six individuals were not deemed suitable for inclusion in the group. Four individuals were assessed to be suitable and all were motivated to take part in group therapy. All were experiencing regular panic attacks. The Hospital Anxiety and Depression Scale (HADS) and Clinical Outcomes in Routine Evaluation–Outcome Measure (CORE-OM) therapy evaluation tool was utilised to help provide measures of the client’s distress and to measure the outcome of therapy.

Formulation
Individual formulations were developed for each of the four clients, based upon each individual’s background history and experience of their difficulty, their predisposing factors, precipitating factors, maintaining factors and protective factors. A group cognitive behavioural formulation of based on the model for Panic Disorder by Clark (1986) was composed. This included how each individual experienced internal
triggers that they perceived as a threat that lead to anxiety. Individuals experienced catastrophic misinterpretations of the physiological symptoms of anxiety. Associated thoughts, feelings and avoidant and safety behaviours maintained their panic attacks.

**Intervention**

Based on a review of the evidence, and Department of Health (DOH, 2001) recommendations, a cognitive behavioural approach was identified as the most appropriate intervention for the group.

The main components of the intervention were psychoeducation, symptom management, cognitive restructuring, exposure and relapse prevention. Group process issues were reflected upon.

Treatment comprised of six sessions each of one and half hours to the group of four. The group was run jointly with a clinical psychologist. Members were given handouts to read for homework, as well as session-specific tasks.

**Structure, Content and Group Processes**

The initial stages of treatment aimed to achieve a sense of cohesion between the therapists, group members, and the group as a whole. Group members were given a chance to suggest goals. Collaborative group work aided to the building of the group’s culture by developing group norms with the members taking responsibility for its functioning.

The psychoeducation component provided rationale for treatment, socialisation to CBT and a discussion about anxiety. Clients were introduced to the vicious circle of panic disorder, including catastrophic misinterpretation and focus on bodily sensations. Progressive relaxation, breathing techniques and distraction were modelled to the group as part of the symptom management component. The group completed thought diaries and the cognitive restructuring component was used to challenge negative automatic thoughts and recognise thinking errors. Graded practise of the anxiety provoking situations based on a hierarchical approach were introduced to help reduce avoidance and disconfirm misinterpretations. Group members were
Clinical Dossier: Adult Mental Health Case Report Summary

introduced to the cognitive problem-solving approaches and relapse prevention strategies were discussed.

Outcome

Individuals were reviewed for approximately ten minutes by the therapists, and questionnaires were re-administered at the end of session five. All individual’s made progress with small reductions in anxiety and depression as measured by the HADS. Similarly all members’ scores on the CORE-OM decreased and, with the exception of one member, fell within the range for the general, rather than a clinical, population, suggesting meaningful change.

All group members acquired a good understanding and engaged well with CBT techniques. Clark’s (1986) model was found to conceptualise well the difficulties the individuals were experiencing, and all members made successful progress. One client who was afraid that her daughter would die of a seizure implemented some of the behavioural strategies and for the first time in three years had let her daughter sleep in her own bedroom. All individuals reported a reduction in the intensity of their panic symptoms. Members identified that they had found the group setting useful for meeting people with similar problems and discussing their problems within a context of true understanding.
People with Learning Disabilities
Case Report Summary

Extended Assessment of a 14 year old boy with Down Syndrome

September 2003

Year 1

Some identifying details and all names have been changed to preserve anonymity.
Reason for Referral
Simon Fuller, a 14 year old white British boy with Down syndrome, was referred verbally by a Clinical Psychologist (CP) working within the Community Learning Disability Team for a cognitive assessment. The CP had received reports from school querying Simon’s ability and behaviour.

Presenting Problem
Simon was exhibiting inappropriate social behaviour across a number of settings. The church group attended by Simon’s family, school, and respite care service had conveyed reports of swearing, inappropriate touching, being defiant, kissing and tickling and exposing his bottom.

Initial Assessment
A number of sources of information were reviewed for the initial assessment process. Simon’s medical notes were examined, a discussion with the referrer took place and the Speech and Language therapist was consulted. The Leiter International Performance Scale (LIPS) was undertaken.

Outcome of Initial Assessment
The medical notes stated that Simon was diagnosed with Down syndrome (DS) and a heart defect at birth. During his first year Simon was fostered by three different families. Miss Fuller legally adopted him when Simon was 13 months old. Initially Miss Fuller observed Simon to be a quiet and unresponsive child who was un-phased by strangers. When Simon was three and a half his mother adopted another baby boy with DS.


The assessment found that general behavioural difficulties have been a problem for some time. The Community Paediatrician referred Simon to the Clinical Psychologist in 1997 because of “defiant” behaviour at home. In 2000 a school review noted a
referral to the Specialist Support and Development Team for “general but severe
behavioural problems”. This team deals with difficult cases of challenging behaviour.

The Speech and Language Therapist report in 2003 reported that Simon’s verbal
comprehension on the Test for Reception of Grammar fell at an age equivalent of five
years and was markedly below that of his single word vocabulary.

The LIPS was utilised to provide an overview of Simon’s cognitive abilities, IQ and
mental age equivalent. He performed toward the lower end of the significant range of
intellectual impairment, with an IQ of 59. His mental age equivalent was seven years
eight months. Simon’s weakest ability fell at a chronological age of six years; His
strongest ability fell at a chronological age of nine years

Initial Formulation
Simon’s inappropriate behaviours were felt to be conceptualised by a number of
different aspects including biological, developmental, cognitive, behavioural
psychological and contextual factors. Simon’s diagnosis of DS and SLD were
suggested to be predisposing factors underlying his delayed cognitive development,
which contribute to his socially problematic behaviour. In addition, his difficult early
history and possible attachment difficulties may also predispose Simon to difficult
behavioural patterns.

Precipitating factors such as the perceptions of others regarding Simon’s abilities were
hypothesised to affect the ways individuals interacted with him. Individuals were
hypothesised to respond to Simon in an age inappropriate manner, possibly soliciting
socially inappropriate behaviours. Inconsistent boundaries around behaviour at home
were also felt to precipitate problematic behaviour. Differential reinforcement of
behaviours and over-estimation of his abilities by others were felt to maintain socially
inappropriate behaviours.

Simon’s socially inappropriate behaviours were felt to be “socially significant”. The
possible risks to others and possible future unwitting involvement with the police
warranted a more involved extended assessment.
Extended Assessment
Informant Based Assessment with Simon’s school took place. A home visit to speak to Simon’s mother was undertaken. Naturalistic observations of Simon in his respite care setting and at school were carried out.

Further Cognitive Assessment using the British Ability Scale was used to assess Simon’s cognitive strengths and weaknesses. The cognitive assessment indicated that developmentally Simon is roughly six to seven years behind his chronological age. Simon performed relatively well on three tasks of reading, verbal fluency (without a non-verbal component) and similarities. Simon showed marked weakness on short-term memory recall tasks. Simon’s social reasoning abilities were found to fall at the pre-reasoning developmental stage. During one subtest Simon was noted to struggle with instructions but reported he understood.

Extended Formulation
Following the extended assessment reformulation was required. Simon was found to exhibit problems with attention, distractibility and over-activity. Difficulties with processing, attention and non-compliance have been suggested to underlie behavioural problems. Difficulties in these domains and also with memory recall were hypothesised to affect the amount of information Simon could take in and process and could lead to Simon presenting as naughty and defiant.

Inconsistencies in Simon’s hearing were speculated to compound language and comprehension difficulties, and also cause frustration and distractibility, leading to problem behaviours. Simon’s presentation as an intelligent boy with an extensive vocabulary and good conversation skills, as illustrated by strength on a task of pure verbal fluency, was believed to mask significant difficulties with verbal comprehension. This was felt to lead to substantial overestimation of his abilities by others.
Clinical Dossier: People with Learning Disabilities Case Report Summary

Cognitive deficits were felt to contribute to hypothesised lack of skills in Simon’s behavioural repertoire. Tickling behaviour, inappropriate for chronological age, but not necessarily for mental age, may have represented an inappropriate means of gaining attention. He was also able to mask his difficulties well. This was suggested to contribute to maintenance of behaviour as Simon was unable to acquire new patterns of behaviour.

Recommendations

Dissemination of the results of the cognitive assessment, in order that professionals and Simon’s mother could adjust their perceptions of Simon as “bright” or “clever” and understand him at his developmental level were recommended. The second main recommendation focused on creating differential reinforcement of alternative behaviours to the socially inappropriate behaviour. Alternative behaviours were suggested to utilise the assessed areas of cognitive strength, in combination with remediation of Simon’s deficient behavioural repertoires. Helping Simon to increase his skills repertoire through ‘positive behavioural support’ was proposed. Simple social skills training on socially appropriate behaviours using pictures was also suggested, as well as an updated hearing test.
Child and Family Case Report Summary

Behavioural Sleep Intervention Using Some Techniques from Narrative Therapy with a Six Year Old Boy with a Bedtime Settling Problem.

April 2004

Year 2

Some identifying details and all names have been changed to preserve anonymity.
Reason for referral
Daniel Atkinson, a six year old white British boy, was referred by the Clinical Fellow in Paediatrics in May 2002 for difficult behaviour. Daniel had been attending the Paediatric Outpatients Department for his constipation and overflow problems.

Presenting Problem
When Daniel’s family arrived they described a difficulty with bedtime settling problems and consequential behavioural tantrums. They reported that Daniel’s soiling difficulty had spontaneously remitted. His parents reported that Daniel would refuse to go to bed when asked. Neither parent returned him to his own bed.

Assessment
The family attended an assessment session, which lasted an hour and a half. A literature review of sleep difficulties aided with the assessment and formulation process. The family were asked to keep a sleep diary. Graphs of times that Daniel went to bed each night were produced. There was an average of one hour 35 minutes sleep onset delay, from time that Daniel was asked to go to sleep to actually falling asleep.

Daniel’s parents describe sleep as problematic from birth. As an infant, his mother reported that when he cried they immediately comforted him and brought him to sleep in their bed. They stated that they had to lie with Daniel in order for him to fall asleep. Daniel’s parents described a lengthy bedtime routine of over two hours during which Daniel was allowed to play computer games. At the time of assessment Daniel was refusing to settle in his own bed. Daniel’s parents previously consulted the Health Visitor for advice. She stated Daniel would “grow out of it”.

Formulation
Predisposing factors to Daniel’s sleeping difficulties were hypothesised to include Daniel’s temperamental characteristics. He was reported to be an active child, and activity has been associated with sleep disturbance. Additionally, Daniel’s mother reported feeling quite anxious as a new parent and worried about Daniel when he cried at night. Doubts about parenting abilities have been correlated with sleep
disturbances. Consequently, she immediately took Daniel into her bed. As such it was felt that Daniel was unlikely to have learnt any self-soothing skills.

A ‘behavioural chain’ was hypothesised to have been created through the process of Daniel signalling and his parents responding. This could have established a learned condition for Daniel to fall asleep, with his parents becoming a discriminative stimulus for sleep.

Repeated incidents of the ‘behavioural chain’ appear to have developed into a ‘behavioural trap’, a precipitating factor. Antecedent variables such as behavioural ploys asking for drinks or another story, or tantrums and the lengthy two hour bedtime routine and stimulating activities are inappropriate proximal cues to sleep onset and strengthen sleep incompatible behaviours.

Daniel had learnt that his behavioural ploys got him his desired consequences of staying up late and sleeping in his parent’s bed. Daniel’s parent’s responses to his ploys and tantrums maintain his use of these successful strategies. The inconsistent nature of parental responses were suggested to have developed into a powerful intermittent reinforcer, maintaining the behaviour. These are likely to have been strengthened by failed attempts to change behaviour and the resultant post-extinction response burst which enhances the child’s responses further.

**Intervention**

Reviews of the literature suggest that behavioural and learning theories are the primary theoretical approach for understanding sleep problems. Initially psychoeducation and the various choices of behavioural interventions were outlined with Daniel’s parents. We discussed goals which were operationalised. Daniel’s parents decided that they wanted to use a ‘minimal check with systematic ignoring’ procedure. This involved ignoring Daniel’s behavioural ploys and tantrums and checking every 15 minutes (from outside the door) that he was ok and in bed. Issues around how the parent’s would support one another were explored. Positive reinforcement strategies were discussed. A star chart, supported with tangible rewards on a fixed reinforcement schedule (every three nights) was agreed upon. Daniel chose
'Finding Nemo’ stickers as a reward. To help with maintenance of gains fading the fixed schedule was discussed. The parent’s decided that, once Daniel was consistently achieving three stars in a row they would like to renegotiate the target to four stars and give Daniel the choice of a new reward. Positive routines were developed with Daniel’s parents to provide a structured bedtime routine.

In order to enhance Daniel’s motivation and engagement in the new sleep programme Narrative Therapy techniques were employed. Externalising conversations were used to help Daniel explore what he thought about the problem. Daniel was encouraged to give the problem a name, and with some help came up with “the wide-awake monster”. Life cycle concepts such as Daniel ‘growing up’ were emphasised. A narrative letter was written to Daniel after the sleep programme had been successfully working for one month. Narrative techniques highlighted Daniel’s strength in ‘trying new things’ and his maturity.

**Outcome**

Overall, the intervention was felt to be successful in meeting the family’s goals by reducing sleep onset delay, settling problems and behavioural bedtime tantrums. Sleep diaries were reviewed and illustrated the average delayed sleep onset was only one and a half minutes following initiation of the programme; Daniel was getting into bed and going to sleep when asked. No evidence of a post-extinction response burst was noted or a spontaneous recovery. This may have been avoided through the combination of techniques used, and Daniel’s motivation in the process. Anecdotally, Daniel’s mother reported that Daniel’s general behaviour was much improved and that he was more compliant. She stated she was less tired. She also noted a positive effect on her relationship with both partner and son.
Older Adults Case Report Summary

Neuropsychological Assessment with an 83 Year Old Man Presenting With Memory Problems: Dementia? ...Or Something Else?

September 2004

Year 2

Some identifying details and all names have been changed to preserve anonymity.
Reason for Referral
Mr Stanley Edwards was an 83 year-old white British man. The consultant psychiatrist at the community mental health team for older people referred him for investigation of short-term memory difficulties. Stanley had not responded to pharmacological treatment for dementia; the psychiatrist noted he appeared “too good” for diagnosis of Alzheimer’s disease (AD).

Presenting Problem
Stanley reported minor difficulties with memory, but was unable to elaborate further. Stanley’s wife, Margaret, reported he had difficulty with short-term memory. Margaret reported Stanley sometimes lost her when out shopping, and she took care of appointments. The psychiatrist referred Stanley to a driving centre and he passed his test in 2003. Margaret did not feel Stanley was depressed. Stanley could not recall when his memory difficulties started. Margaret reported memory changes following prostate surgery in 2001 but no significant change since. However, the psychiatrist noted deterioration in memory difficulties and Stanley’s scores on the mini-mental state examination.

Assessment
Interviews were conducted with Stanley and Margaret and Stanley’s medical notes reviewed. Stanley had benign prostate problems since 1979, and had surgery in 2001. Stanley could not recall having the operation. Although no difficulties were noted on the discharge summary Margaret reported Stanley was very unwell following the operation and disorientated. He was noted to have a folic acid and iron deficiency. He had no other significant medical history of note. Given the differing accounts of the course of the presenting problem, a number of hypotheses were developed to account for Stanley’s difficulties, which included impact of surgery on older people, cortical dementia and vitamin deficiency.

A number of neuropsychological assessments were selected to test hypotheses. The Wechsler Test of Adult Reading was used to provide a pre-morbid level of functioning and the Wechsler Adult Intelligence Scale (WAIS-III) to gain a current level of functioning. The Middlesex Elderly Assessment of Mental State was used as
Clinical Dossier: Older Adult Case Report Summary

a general cognitive screen to explore different areas of functioning and indicate where further investigation should concentrate. Tests of memory were chosen to investigate the referral question further. The Rivermead Behavioural Memory Test was utilised as a valid measure of recall, recognition and prospective memory. The Doors and People test was chosen to investigate laterality, recall and recognition memory. The Behavioural Assessment of Dysexecutive Syndrome test was used to explore executive functioning. The Controlled Oral Word Association Test was chosen to examine frontal functioning and language ability. Category Naming for animals was used to measure semantic naming. The Boston Naming Test was chosen to examine expressive language and confrontational naming ability.

Results and Discussion
Assessment was conducted over three, two-hour sessions. A discrepancy between Stanley’s predicted and actual level of functioning was significantly different in the verbal domain. Superficially, this would seem to provide evidence for deterioration in functioning. However, further examination of results indicates a significant weakness only on Similarities (WAIS-III), which reduced overall verbal ability. Furthermore, Stanley’s low number of years in education and reports from his wife might indicate that this was a life-long discrepancy with his performance abilities being better than his verbal abilities. Care was taken with the interpretation of the discrepancy, and it was concluded that, at present, Stanley did not appear to show global intellectual decline.

Significant long-term memory difficulties, word finding difficulties, dysphasic difficulties and some orientation problems were noted. Probable problems with higher-order executive functioning were also observed. There were no obvious difficulties with visuospatial ability or processing speed.

Given the lack of evidence for general cognitive decline it was difficult to conclude strongly on the dementia hypothesis. Factors which supported a dementia formulation include the observed profound memory deficit, dysphasia and some probable higher-order executive dysfunction. If Stanley’s difficulties were taken to indicate dementia,
his profile would be more suggestive of AD rather than vascular dementia based on severity of memory problems and lack of history for high blood pressure or stroke.

Conversely, lack of evidence of global deterioration and the sudden onset, together with duration and stability of problems was not consistent with dementia diagnosis. Stanley’s profound memory impairment appeared disproportionally severe and there was no family history of AD, or evidence of brain pathology on the computerised tomography (CT) scan.

Support for the second hypothesis, relating to trauma from prostate surgery, arises from observed lack of global deterioration. Additionally, his difficulties suggested localisation. Stanley’s profound memory difficulty could indicate anterograde amnesia. Stanley’s procedural and working memory remained intact, consistent with case studies of amnesia. The pattern of findings was felt to implicate dysfunction of the temporal lobe, specifically the medial temporal lobe, or diencephalic structures.

Stanley’s dysphasia and possible higher-order executive problems could be explained by disruption to connections to other areas of the brain, particularly frontal regions. Stanley was old and had a low number of years of education; risk factors for post-operative cognitive decline (POCD) following anaesthetic exposure.

However, because POCD could be attributed to numerous factors it was difficult to make firm formulations. There was lack of evidence of localised damage on CT scan and no reports of hypoxia on the discharge summary.

Nutritional deficiency (which had been corrected) rarely causes such significant cognitive impairments. However, remaining vitamin deficiency could exacerbate current cognitive difficulties, and as medical investigation of this problem was undertaken a year previously, it was difficult to draw conclusions on this hypothesis.

Overall, it was very difficult to reach a firm conclusion on the cause of Stanley’s difficulties. There was varying evidence for and against the main hypotheses.
Professionally, it was difficult not to be able to give a clear answer to Stanley and his wife regarding his difficulties

**Recommendations**

A number of recommendations were made, including repeat neuropsychological assessment in 12 months, referral for further neurological investigation, such as functional magnetic resonance imaging, details of support services for carers, strategies to compensate memory difficulties, ongoing, regular monitoring of vitamin and nutritional status and tests of kidney and liver functioning, and discontinuation of driving. It was a noted limitation of the work not to consider a hypothesis of chronic exposure to neurotoxins, since Stanley’s career had been within industrial settings and included electronic paint-spraying.
Specialist (Paediatric) Case Report Summary

Cognitive Behavioural Therapy with a 15 Year Old Girl with Chronic Pain. Was an Intrapersonal Conceptualisation ‘Good Enough?’

April 2005

Year 3

Some identifying details and all names have been changed to preserve anonymity.
Reason for Referral
Amy was 15 years-old, from white British origin and was referred by the Pain Management Consultant to the Paediatric Psychology Department, for help with coping strategies for severe coccygeal pain.

Presenting Problem
Amy described that chronic pain had been present for two years with no improvement despite numerous treatments. The onset of pain was sudden. Amy describes being at school and felt pain in her lower back following a mid-morning lesson. Amy describes experiencing pain every day, with intensity varying from mild to unbearable. The pain significantly impacts on Amy’s life. Amy was absent from school for ten months.

Assessment
Amy, her mother and father attended one clinical assessment session with me, which lasted 90 minutes. Amy’s hospital notes were reviewed prior to the assessment session. Amy was given a pain diary. However, she did not complete it as she reported it was “too repetitive”. Amy did complete the Short Version of the McGill Pain Questionnaire (SF-MPQ) and the Children’s Depression Inventory (CDI).

Formulation
Previous experienced of pain when Amy had reflex sympathetic dystrophy following a knee injury in 1997 and a family history of pain with Amy’s grandfather and mother also suffering with pain were hypothesised as predisposing factors. Amy experiences pain at all times. Her pain can be relieved through relaxation and distraction and therefore feelings of anxiety or low mood (both related and unrelated to pain) were hypothesised to be precipitating factors. In addition physiological changes, such as menstruation and constipation, also exacerbate pain highlighting a biopsychosocial model of pain where biological and psychological factors interact.

Amy experiences a number of beliefs, cognitions and emotions regarding her pain and feels unable to control the pain. A passive locus of control is suggested to precipitate increases in pain. Amy also experienced significantly bullying while at primary
school and current worries about arguments with friends and acquaintances lead to negative automatic thoughts which also increase pain.

Amy’s pain has come to be maintained through initial operant learning mechanisms shifting from pain reduction to positive external reinforcement. Amy’s parents also exhibited a degree of solicitous behaviour, which can encourage symptom maintenance. It is likely that by learning to avoid previous pain, anticipatory anxiety has been elicited. This anxiety becomes a conditioned stimulus for sympathetic activation and maintains chronic pain behaviour. Moreover, muscle contraction from underlying anxiety may cause further pain and become an unconditioned stimulus, creating a vicious fear-avoidance cycle. Amy also has a tendency towards cognitive errors both in relation to pain and non-pain situations that could maintain her pain. Amy’s difficulties were summarised in an Integrated Diathesis-Stress Model of chronic pain.

**Intervention**

Recent studies show favourable outcomes for interdisciplinary CBT for adolescents with long-standing chronic pain, and idiopathic back pain. Therapy included education, activity, exploring cognitions and problem-solving skills, and family orientated cognitive sessions.

In line with current evidence-base and in collaboration with Amy and her family a four session, followed with a review, CBT approach was chosen. Psychoeducation involved a discussion of the Gate Control Theory of Pain and reviewed factors which opened and closed Amy’s pain gate. We set goals and Amy chose to manage her pain efficiently and discretely. Amy wanted to remain in class more frequently. I used reflective listening and accurate empathy to ensure that Amy would feel understood, particularly since Amy felt ‘let down’ by numerous professionals. Amy undertook relaxation training. We used imagery techniques to aid distraction and transform visual images of pain into ‘non-pain’ pictures. In the cognitive element of the intervention Amy identified pain-related and non-pain related negative automatic
thoughts. We discussed strategies to help challenging such thoughts. In the
behavioural component Amy, her mother and I discussed positive and negative
behaviours associated with pain. We highlighted the importance using positive
reinforcement to encourage well behaviours. We also discussed the fear-avoidance
model and the importance of maintaining activity levels. We acknowledged that Amy
was already quite active but still found sitting painful. We developed a hierarchy of
sitting for increasing durations in a Jacuzzi. We considered generalisation and
maintenance strategies.

Outcome

The SF-MPQ and CDI were re-administered following our review meeting. There
was a slight decrease in sensory, affective and total ratings of pain, as well as slight
reduction in overall pain rating. Amy’s depression score fell by one point. Amy’s
scores are consistent with research which indicates that small but significant changes
may occur. Anecdotally, Amy’s mother and sister noted Amy was “much calmer,
cries a lot less and is not as angry”. Reformulation in a systemic model was
undertaken following emergence of new information in the family’s interactions and
relationships, and the possibility of an underlying psychological component to Amy’s
chronic pain. The systemic reformulation explored problem maintaining patterns and
feedback loops, beliefs and explanations, exceptions, emotions and attachments and
contextual factors. At the review session we discussed that it would be useful to have
two family sessions to explore the impact on family members and family patterns.
RESEARCH DOSSIER

This section comprises of the research projects undertaken over the three-year course. It contains the Service Related Research Project, Major Research Project and Research Logbook.
Service Related Research Project

An Audit of General Practitioner Referrals and the Standards of a Duty Team in a Community Mental Health Team (CMHT)

June 2003

Year 1

Identifying details have been omitted to preserve anonymity
<table>
<thead>
<tr>
<th>Contents Page</th>
<th>Page Numbers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>130</td>
</tr>
<tr>
<td>Introduction</td>
<td>132</td>
</tr>
<tr>
<td>Method</td>
<td>134</td>
</tr>
<tr>
<td>Results</td>
<td>136</td>
</tr>
<tr>
<td>Discussion</td>
<td>143</td>
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<tr>
<td>References</td>
<td>146</td>
</tr>
<tr>
<td>Appendices</td>
<td>148</td>
</tr>
</tbody>
</table>
Abstract

Aim: To audit the standards for handling time for referrals to a CMHT and investigate GP referral rates and behaviour which may be impacting on the Team’s ability to meet standards, particularly given the emphasis to provide services for individuals with severe mental illness (SMI).

Method: Retrospective evaluation of speed of handling urgent referrals over two weeks. Recording of 81 GP referrals, over two months, including referral rate, presenting problems, appropriateness and referral priority.

Results: The CMHT met the standards in 100% of cases. No significant differences were found between GP referral rates per 10,000, or between the GPs that Duty Officers hypothesised referred more often. Chi-square did reveal significant differences between numbers of inappropriate referrals and area locality. 78% of inappropriate referrals were returned to primary care because they did not meet the CMHT’s criteria of SMI. Affective disorders accounted for over two thirds of returned referrals. However, there was an association between depression with and without risk-to-self and the urgency of referral.

Conclusion: A higher number of inappropriate referrals was received by this CMHT than has been found in other services. Although it did appear that GPs were categorising the urgency of referrals on the basis of severity, and the team are accepting referrals on this basis. More prolonged monitoring of standards using the integrated care pathway would be beneficial following feedback of referral rates to GPs. Further studies to investigate referral quality and strategy would provide more information which may help reduce inappropriate referrals.
Acknowledgement

Thanks go to my field supervisor, research tutor and project supervisor for their help and support throughout this audit. Thanks also to the members of the CMHT and in particular the Duty Team for their patience with my questions.
Introduction

The National Service Framework (NSF) for Mental Health (DOH, 1999) emphasises recent government initiatives to prioritise SMI. The Mental Health Policy Implementation Guide outlines functions of a Community Mental Health Team (CMHT), including key components required for the service to operate efficiently (DOH, 2002). Two components relate specifically to the referral process between primary care and CMHTs. In response to the guidelines a multidisciplinary CMHT set standards for referral handling. The first aim of the study was to review their success in meeting the standards.

The CMHT was concerned that management of referrals was becoming increasingly difficult due to the large volumes of work they received. They noted that much work involved screening and investigating general practitioner (GP) referrals, which frequently had to be returned because they did not meet the criteria for severe mental illness (SMI). A second aim of the study was to provide the Team with information about GP referral rates and behaviour. They felt this would be beneficial, particularly if they were not found to be meeting the standards. They hoped to use the information to provide feedback to referrers in order to maintain an effective service.

GP referral rates to secondary mental health services vary widely even within the same communities (e.g. Creed, Gowrisunkur, Russell & Kincey, 1990). This is currently at odds with the NSF, which promotes equality of access for the severely mentally ill to these services (DOH, 1999).

In particular, there is a dissonance between service provision for patients with neurotic disorders (such as anxiety and depression) and SMI. Affective disorders have been found to account for the majority of referrals to secondary services (Gater & Goldberg, 1991). Individuals with psychosis, tend to make up a large proportion of CMHT case-loads (e.g. Greenwood, Chisholm, Burns & Harvey, 2000), arrive mainly through less appropriate pathways such as hospital accident and emergency departments and the police (Marriott, Malone, Onyett & Tyrer, 1993). Gask, Sibbald and Creed (1997) reported that CMHTs felt their services should be preserved for
clients with SMI. In contrast, GPs often felt it was appropriate to refer less severe cases to the CMHT, while others had become disillusioned with secondary care services and recruited psychologists and counsellors into their own services. Nandy, Chalmers-Watson, Gantley, and Underwood, (2001) reported two distinct referral strategies for managing “minor mental illness” (anxiety and depression). The reactive, “referrals away” approach, was likely to be used when GPs felt frustrated about lack of progress, or felt that they could not give the patient enough time. The proactive “referrals to” style was used when GPs felt more specialist management would be beneficial.

King (2001) reported a CMHT’s process of operationalising prioritisation criteria was complicated by the Team’s own interests and perceptions of SMI, and strict medical diagnoses. This caused a tension with managing the referral pressure and case-mix. Additionally, strict adherence to SMI referral criteria by a CMHT led to GP dissatisfaction with services for those with neurotic disorders, but increased satisfaction with services for individuals with SMI (Harrison, 2000). A consultation-liaison style of relationship, which encourages face-to-face links between mental health and primary care professionals, increases the number of SMI referrals i.e. more appropriate referrals (e.g. Hull, Jones, Tissier, Eldridge & Maclaren, 2002).

Inappropriate referrals are problematic both for service users and service providers and have been associated with drop-out, client dissatisfaction, poor clinical outcome, non-attendance and large numbers of onward referrals (Ross & Hardy, 1999). Jones-Elwyn and Stott (1994) found 34% of referrals were inappropriate. However, of these, 38% were theoretically avoidable, for example by GPs having access to Community Psychiatric Nurses (CPN), as in a consultation-liaison style of relationship. Hull et al., (2002) found 31% of the total number of referrals received by CMHT’s required ‘weeding out’. That is, returning referrals to GPs, referring onto other services and rapid resolution of cases. Higher rates of inappropriate referrals have been associated with poorer quality referral letters (Jenkins, 1993). Given the push towards providing cost-effective and efficient mental health services with an emphasis on prioritising SMI, referral rate and appropriateness of referral is an important area for audit.
The aims and identified research questions of the study were as follows:

**Research Questions**

1. To investigate whether standards were met for the referral handling time depending on the urgency identified by referrer and/or Duty Officer.
2. To investigate whether differences exist between number of referrals made by GP practices, in particular GPs E, F, K and M, which the team hypothesised referred more. They based this assumption on their history with these practices, the relative social deprivation within the communities that they served, and the personal characteristics of particular GPs, suggesting they used a ‘referrals away’ approach to mental health management.
3. To investigate any associations between GP Practice, localities or hypothesised over-referring GPs and the appropriateness of the referral, i.e. whether the referral was accepted or not
4. To investigate any association between referral reason and appropriateness
5. To investigate any association between urgency of referral and referral reason and whether classification of referral affected appropriateness.

**Method**

**Service Description**

The CMHT is a multidisciplinary team with an open referral system. It receives referrals from 16 GP practices, other NHS, professional and voluntary services, individuals, family, friends and carers. The Duty Office acts as the single point of entry for all referrals. It is responsible for screening incoming referrals, completing urgent assessments and liaising with service users to offer advice and support on service-related issues. The service has a ‘consultation-liaison’ style of relationship with most surgeries. 11 of 16 practices have one or more identified CPN link-workers attached. However, in some cases the relationship is not as formalised as the definition offered by Hull et al., (2002).
Sample
This was a retrospective study of GP referrals received by the CMHT between 10th March 2003 and 9th May 2003 (Nine weeks). 83 referrals were screened (53% female, 47% male). Additionally, the audit of Duty Office standards, of referrals from any source, was completed between 28th April 2003 and 9th May 2003 (Nine working days). 20 referrals (60% female, 40% male) were screened during this period. The team did not wish to audit this information for a longer period because they were concerned about creating extra work.

Procedure
CMHT team members from varying professions, including the Researcher, set the standards for the Duty Office at a working party held in October 2003 (Appendix C). Consultation followed and standards were in place by January 2003. It was agreed that standards 1.3 and 1.4 would be audited 3 months following implementation. The team were informed of the audit at a meeting after the consultation period expired. The Researcher met with the appointed Clinical Governance Lead, Team Manager and Duty Officer (CPN) to discuss the format of the audit. An audit tool was created by the Clinical Governance lead and Researcher in order to assess the standards for the two week period (Appendix A). Additionally, the Researcher designed an audit tool to assess GP referrals in the preceding two months before the scheduled audit of standards (Appendix B). Data collection for GP referrals was carried out by the Researcher using actual referrals, logbook of daily contacts and a record of referrals received by fax and post. During the two week audit of standards the mental health professionals on duty were required to complete an Integrated Care Pathway (ICP), designed by the Clinical Governance Lead, from which the Researcher documented the detailed information required by the standards audit tool. Classification of the primary referral reason, where possible, was based upon the categories used by Greenwood et al., (2000) and Gater and Goldberg (1991).

Ethical issues
To ensure client confidentiality, data was anonymised.
Results

Descriptive Statistics
Two of the 83 referrals were excluded from analysis; one referral for an out of area GP, the other, a rare referral from an army unit, for which the population size was unobtainable. Table 1. shows the number of referrals received from GP practices in each locality and referral rate per 10,000 during the two month time period.

Localities were based upon arbitrary divisions created by psychiatrists to designate work-load. Table 2. summarises referral information for each locality. Table 3. shows referral rates for practices which the Duty Officers hypothesised referred more.

Table 1. Referral Rates for GP Practices.

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### Table 2. Referral Rates for Locality

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### Table 3. Referral Rates for GP Practices Hypothesised to be Over-Referring

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<th>GP Practice</th>
<th>Population</th>
<th>No of Referrals</th>
<th>No of referrals per 10,000</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP Practices hypothesised to be over-referring (E, F, K &amp; M)</td>
<td>45841</td>
<td>32</td>
<td>6.98</td>
</tr>
<tr>
<td>GP Practices hypothesised to be referring normally (A, B, C, D, G, H, I, J &amp; L)</td>
<td>77085</td>
<td>49</td>
<td>6.36</td>
</tr>
</tbody>
</table>

49% of referrals were accepted. 46% were not accepted, and, more information was sought for 5% of referrals. 78% of cases were returned to the GP because they did not fit the team’s criteria of SMI. The remaining inappropriate cases included an out of area address, brokerage of referral to psychiatrist or other services and rapid case closure. Nine out of 81 referrals were classified by the GP as ‘emergency’, 18 were classified as ‘fast-track’ and 46 were recorded as ‘routine’. Urgency of case was not classified on eight referrals. A summary of referral reasons is shown in Table 4. Approximately 60% of presenting problems were affective disorders. Only 11% of referrals identified psychosis as the referral reason.
Table 4. Referral Reasons.

<table>
<thead>
<tr>
<th>Referral Reason</th>
<th>Number of Referrals</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>23</td>
<td>28.4</td>
</tr>
<tr>
<td>Depression plus Suicidal Ideation and/or Deliberate Self Harm</td>
<td>19</td>
<td>23.5</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6</td>
<td>7.4</td>
</tr>
<tr>
<td>Anxiety and Depression</td>
<td>11</td>
<td>13.6</td>
</tr>
<tr>
<td>Psychosis</td>
<td>9</td>
<td>11.1</td>
</tr>
<tr>
<td>Personality Disorder</td>
<td>3</td>
<td>3.7</td>
</tr>
<tr>
<td>Sexual Abuse</td>
<td>1</td>
<td>1.2</td>
</tr>
<tr>
<td>Psychosocial Problems</td>
<td>4</td>
<td>4.9</td>
</tr>
<tr>
<td>Eating Disorder</td>
<td>2</td>
<td>2.5</td>
</tr>
<tr>
<td>Alcohol/Drug-related</td>
<td>3</td>
<td>3.7</td>
</tr>
</tbody>
</table>

Research Question 1
During the audit of standards one referral was classified as ‘emergency’. Contact was made with the client within four hours and an assessment appointment arranged for the same day. This met the standard. Four referrals were classified as ‘fast-track’. Following discussion with the GP, one was reclassified as ‘routine’. In the other three cases contact was made on the day of receipt and an assessment was offered within four working days. 12 referrals were ‘routine’. Four were unclassified and were deemed to be ‘routine’ following review by Duty Officers. Overall, the Duty Team met the standards in 100% of cases.

Research Question 2
No significant difference was found between rates of referrals (per 10,000) for the 13 different GPs ($\chi^2_{(12, N=81)} = 13.00$ ns) (Table 1.). However, the expected frequency counts for five GP practices were less than five. This may affect the validity of the results. No significant difference was found between referral rates for different localities ($\chi^2_{(4, N=81)} = 5.17$, ns) (Table 2.) or for GPs which the Team hypothesised referred more ($\chi^2_{(1, N=81)} = 0.17$, ns) (Table 3.).
Research Question 3.

A large number of expected frequencies with cell counts below five indicated that chi-square statistics were not valid to determine whether any association existed between number of appropriate referrals and different GPs. Figure 1 shows practices F, G, K and L made more inappropriate referrals than appropriate referrals.

Table 5. Number of Referrals Taken on From Each Locality

<table>
<thead>
<tr>
<th>Locality</th>
<th>Taken on</th>
<th>Not taken on</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7</td>
<td>2</td>
<td>9</td>
</tr>
<tr>
<td>2</td>
<td>18</td>
<td>7</td>
<td>25</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>8</td>
<td>10</td>
</tr>
<tr>
<td>4</td>
<td>6</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>5</td>
<td>8</td>
<td>11</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
<td>36</td>
<td>77</td>
</tr>
</tbody>
</table>

There was a significant difference when locality was taken into account ($\chi^2 (4, N=77) = 11.70 \ p<0.05$), although, three cells had expected frequencies of less than five. Fishers
exact tests revealed differences between locality one and three \( (\chi^2_{(1, N=19)} = 6.34 \, p<0.05) \), locality two and three \( (\chi^2_{(1, N=35)} = 7.89 \, p<0.05) \) and locality two and five \( (\chi^2_{(1, N=44)} = 3.99 \, p<0.05) \) (Table 5.). There was no significant difference between the appropriateness of referrals from GP practices which the Team hypothesised referred more frequently and those that did not \( (\chi^2_{(1, N=77)} = 1.36 \, ns) \) (Table 6.).

Table 6. Appropriateness of Referrals for GP Practices Hypothesised to be Over-Referring.

<table>
<thead>
<tr>
<th>GP Practices</th>
<th>Taken on</th>
<th>Not taken on</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgeries thought to be referring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>more (E, F, K &amp; M)</td>
<td>14</td>
<td>17</td>
<td>31</td>
</tr>
<tr>
<td>Surgeries thought to be referring</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>less (A, B, C, D, G, H, I, J &amp; L)</td>
<td>27</td>
<td>19</td>
<td>46</td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
<td>36</td>
<td>77</td>
</tr>
</tbody>
</table>

Research Question 4

Figure 3. illustrates the number of referrals deemed appropriate according to referral reason. All but one of the individuals with psychosis were accepted, whereas for affective disorders (depression, depression with suicidal ideation, anxiety, and anxiety and depression) equal numbers were accepted and returned. Chi-square statistics were not valid.
Presenting Problems Taken On by the Team

![Graph showing the number of referrals accepted according to presenting problems.](image)

**Figure 3.** Number of Referrals Accepted According to Presenting Problem

**Research Question 5**

Figure 4. shows number of referrals accepted according to GP’s classification of urgency. Again, chi-square statistics were not valid. Interestingly, of referrals where the GP did not include nature of urgency, only one case was deemed appropriate.

![Graph showing the appropriateness of referrals according to referral urgency.](image)

**Figure 4.** Appropriateness of Referral According to Referral Urgency
Chi-square analyses were not valid to investigate the association between referral reason and classification. However, the association between depression with or without risk-to-self was significant when cells were collapsed to remove referrals where urgency was not recorded ($\chi^2 (1, N=39) = 15.05 \, p<0.01$) (Table 7.), although two cells still contained expected cell counts below five. Results should therefore be interpreted with care. Further assessment of differences with Fishers exact tests indicated that the differences lay between emergency and routine cases ($\chi^2 (1, N=28) = 4.73 \, p<0.05$) and fast-track and routine cases ($\chi^2 (1, N=31) = 14.41 \, p<0.01$). More depression only cases were classified as routine compared to emergency. Depression with risk-to-self cases were more equally distributed between emergency and routine referrals (Table 7.). Most fast-track cases were found to be referrals for depression with risk and more depression only cases were classified as routine (Table 7/Figure 5.).

Figure 5. Number of Referrals for Presenting Problems According to Urgency
Table 7. Number of Referrals for Depression With and Without Suicidal Ideation According to Urgency

<table>
<thead>
<tr>
<th>Presenting Problem</th>
<th>Emergency</th>
<th>Fast Track</th>
<th>Routine</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression</td>
<td>3</td>
<td>1</td>
<td>16</td>
<td>20</td>
</tr>
<tr>
<td>Depression &amp; Suicidal Ideation</td>
<td>5</td>
<td>10</td>
<td>4</td>
<td>19</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>11</td>
<td>20</td>
<td>39</td>
</tr>
</tbody>
</table>

**Discussion**

The team achieved the agreed standards in 100% of cases. However, number of referrals audited was small and therefore generalisability is limited. More extensive recording of referral handling is required. The ICP was a useful way of recording the information required by this type of audit. Anecdotally, it was reported not to increase time taken to screen and prioritise the referral. Continued use of this approach would be recommended so that further and more extensive review of standards can occur.

No significant differences were found between referral rates (per 10,000) of GP practices, locality, or the Team’s hypotheses about surgeries that over-refer. This is at odds with other research indicating great variability (e.g. Creed et al., 1990; Hull et al., 2002). This sample may have been influenced by its relative social economic stability throughout the area (although age and ethnicity were not controlled for) and perhaps the large number of practices with a CPN link-worker.

Almost half the referrals were not accepted. The majority of which did not fall within the criteria of a ‘severe and enduring mental health problem’. This is a higher proportion of cases found to be inappropriate than is reported in other research (e.g. Jones-Elwyn & Stott, 1994; Hull et al., 2002). No significant association was found between GP practices and hypothesised surgeries and appropriateness. However, a significant difference was found between locality and referral acceptability, particularly for localities one and two, who both had a majority of appropriate referrals and locality three (GP F), which made a high number of inappropriate referrals, as well as between locality two and five. This could suggest that
psychiatrists in some areas work differently to other mental health professionals which impacts on GPs perceptions of the CMHT’s prioritisation criteria.

Affective disorders made up the bulk of presenting problems. This is a common finding (e.g. Gater & Goldberg, 1991). It is notable that only 47% of affective disorder cases were accepted compared to 89% of cases with psychosis, suggesting that the CMHT is following government initiatives to prioritise access to individuals with SMI. However, mood disorders still made up approximately two thirds of total accepted cases. The number of GP referrals for psychoses in this sample was lower than is found in previous research (Marriott et al., 1993). Additionally, there was an association between GPs requests for more urgent screening of clients with depression where risk-to-self was reported compared to routine requests for clients with depression where risk-to-self was not identified; however, causal interpretations cannot be made. Given this high proportion of inappropriate referrals, constituting mainly of neurotic disorders, it would be useful to investigate whether GPs were indeed using a ‘referrals away’ strategy.

Of the eight referrals not classified, seven were inappropriate. This finding is concordant with research suggesting that inappropriate referrals are characterised by poorer quality referrals (e.g. Jenkins, 1993). It has been suggested that using standard referral forms may aid referral quality (Jenkins, 1993). However, where standard CMHT referral forms were used, quality of information was variable. It would be interesting to examine whether quality of referrals was related to appropriateness. This could support the use of a decision aid attached to the referral form, to help enforce prioritisation criteria and reduce inappropriate referrals (Reid, Coupar, & Riley, 1998).

Three practices did not make a referral during the period of data collection. This could be because they cover smaller populations, have less than four practice managers and no allocated CPN link-workers. Anecdotally this fits with evidence that consultation-liaison style relationships increase referral rates for patients with SMI (e.g. Hull et al., 2002).
Limitations
A larger number of GP referrals would have improved the study’s power to conduct more valid statistical analyses; due to the sample size many chi-square tests had an unacceptable number of expected frequencies. Additionally, information about client age, ethnicity and social class would have been useful, as well as knowledge of GP practices employing counsellors and psychologists.

Implications for service
Information regarding the high number of referrals not accepted could be feedback to referrers and psychiatrists to attempt to reduce volume of work and enhance efficiency of the Duty Office. However, data must be presented in an appropriate context (De Marco, Dain, Lockwood & Roland, 1993) and care taken to ensure appropriate primary care service provision for less severely mentally ill patients is available. This may help to avoid GP dissatisfaction which has been noted in services where feedback reduced referral rates for those with less severe disorders (Harrison, 2000).

For future audits the period of monitoring could be extended to gain a better picture of compliance with standards. Regular and consistent use of the ICP could speed up the audit process, in addition to bringing some of the acknowledged advantages, such as improved documentation, co-ordination of interventions between various professionals, standards of care and awareness of key issues (e.g. Hassan, Turner-Stokes, Pierce & Clegg, 2002).
References

Creed, F., Gowrisunkur, J., Russell, E., & Kincey, J., General practitioner referral rates to district psychiatry and psychology services. *British Journal of General Practice, 40*, 450-454


King, C. (2001). Severe mental illness: Managing the boundary of a CMHT. *Journal of Mental Health, 10*, 75-86


Ross, H. & Hardy, G. (1999). GP referrals to adult psychological services: A research agenda for promoting needs-led practice through the involvement of mental health clinicians. *British Journal of Medical Psychology, 72*, 75-91
Appendix A

Audit Tool for Standards
Research Dossier: Service Related Research Project
Appendix B

Audit Tool for GP Referrals
<table>
<thead>
<tr>
<th>Initials</th>
<th>Gender</th>
<th>Mode</th>
<th>Date</th>
<th>Date</th>
<th>Referral</th>
<th>Referral</th>
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<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Received</td>
<td>Surgery</td>
<td>Name</td>
<td>Cetastic</td>
<td>Response</td>
<td>Requested</td>
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</table>

Research Dossier: Service Related Research Project
Appendix C

CMHT Standards for the Duty Team
1.1 Two Professionally qualified Mental Health Workers will be available between
the hours of 9-5 Monday to Friday and will be available to offer advice, support
or assessment where appropriate to anybody making contact with the CMHT
including Primary Care, service users, carers or other agencies.

1.2 All referrals to the CMHT will be screened (triaged) by the dedicated Duty
Officers on the day it is received and prioritised as Emergency, Fast-track or
Routine according to client need.

1.3 An Emergency referral to the CMHT will be contacted by the duty officer
within four hours of receipt of referral and an assessment will be offered for
that working day.

1.4 If the referral is prioritised as ‘Fast-track’ the duty officer will attempt to make
telephone contact with client that working day and an assessment will be
offered within four working days.
Appendix D

Confirmation of Feedback Letter
14th October 2003

Dear Helen

Many thanks for your report and verbal feedback on 9th September 2003 from the audit which you undertook. The results provided some useful information for the team and will hopefully help to improve services.

Best Wishes

CPN and Clinical Governance Lead  Chartered Clinical Psychologist (Supervisor)
Research Dossier: Major Research Project

Major Research Project

Body Image and Psychological Adjustment; An Exploratory Study with Individuals with Cystic Fibrosis

by

Helen Davies

Submitted for the degree of Doctor of Psychology (Clinical Psychology)

Department of Psychology
School of Human Sciences
University of Surrey

July 2005

© Helen Claire Davies 2005
ACKNOWLEDGEMENTS

Thanks go to my field supervisors Mandy Bryon, and, in particular, Ruth Allen who stepped in at the last moment to support the project and also read drafts! Thanks also to my academic supervisor James Murray.

Thank you to all the individuals who took part. I am sure that your contributions will add to the knowledge base surrounding cystic fibrosis and body image. Thanks to all the other professionals in the clinics and wards who facilitated the research and without whom the research would not have been possible.

Finally, big thanks to my long suffering partner, Osi, and my parents who have continued to support me through the whole process, particularly when times were tough! And to my fellow trainees, especially Emily and Siobhán who were always ready to assist with a glass of wine and a sympathetic ear!
# CONTENTS

<table>
<thead>
<tr>
<th>Chapter</th>
<th>Page Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>CHAPTER 1. Abstract</td>
<td>159</td>
</tr>
<tr>
<td>CHAPTER 2. Introduction</td>
<td>160</td>
</tr>
<tr>
<td>CHAPTER 3. Method</td>
<td>184</td>
</tr>
<tr>
<td>CHAPTER 4. Results</td>
<td>197</td>
</tr>
<tr>
<td>CHAPTER 5. Discussion</td>
<td>233</td>
</tr>
<tr>
<td>CHAPTER 6. References</td>
<td>249</td>
</tr>
<tr>
<td>CHAPTER 7. Appendices</td>
<td>263</td>
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</table>
CHAPTER 1

ABSTRACT

Aim: To investigate relationships between body image and psychological adjustment in individuals with cystic fibrosis (CF), a life-limiting respiratory illness. Given the relationship between survival rates and nutritional status it is necessary to elucidate psychological processes which may influence nutritional behaviour.

Method: An exploratory, cross-sectional design investigated 55 CF patients, aged 12-58 years. Participants were recruited from paediatric and adult outpatient clinics, inpatient wards and via postal sampling. Demographic data was collected. Participants completed body image questionnaires, the Shape and Weight Based Self-esteem Scale and measures of mood and self-esteem.

Results: The majority of individuals were dissatisfied with body and/or facial parts (76%) and body size (71%). Most desired a larger body size (53%), but a minority wished to be smaller (18%). Individuals, particularly females, were unhappy with CF-related body parts; men wanted larger body sizes. Older CF patients had significantly poorer body image than younger individuals. Those with greater body mass index wanted to be smaller. Poorer lung function was associated with higher depression, more emphasis on shape and weight, and greater body image dissatisfaction. Greater importance of shape and weight, higher distress and lower self-esteem were related to greater body image dissatisfaction. Significant levels of anxiety or depression were not demonstrated.

Conclusion: The minority who did not want to increase body size, despite being underweight, and normal size females who wanted to lose weight, will concern CF professionals. That distress was associated with body image dissatisfaction, particularly for older and less well individuals, has implications for psychological management.
CHAPTER 2

INTRODUCTION

Cystic Fibrosis (CF) is a genetic life-limiting chronic illness without a cure. Individuals with CF experience lung problems which cause changes to body appearance. High energy demands mean individuals are frequently shorter and lighter than their peers. Nutritional management is a key component of the overall medical strategy and there is pressure to adhere to strict treatment regimes. Given the emphasis on weight, treatment regimes, and the impact of CF on the body’s appearance, it has been argued that there are psychological consequences for body image and psychosocial adjustment. It is the aim of this thesis to explore such issues.

This chapter will provide a description of body image disturbance, including definitions, models and theories. CF will be described, providing a context for why body image issues might be relevant. An overview of body image research will be provided before focussing on issues of body image and psychological adjustment for people with CF.

Body Image Disturbance

Theoretical Perspectives

Definition

Schilder (1935, cited in Price, 1990a, pp.585) first described body image as “the picture of our body which we form in our mind, that is to say, the way in which our body appears to ourselves”. Subsequently Slade (1994, pp.502) conceptualised body image as “a loose mental representation of the body’s shape, form and size which is influenced by a variety of historical, cultural and social, individual and biological factors, which operate over varying time spans”. Current consensus defines body image as multidimensional and complex (Banfield & McCabe, 2002). The nature of the dimensions still remains unclear and oversimplified, but includes perceptual, cognitive, affective and behavioural elements (Banfield & McCabe, 2002).
Models

Two models of body image are examined below and are related to individuals with CF as appropriate.

1. *Slade (1994)*

Slade (1994) suggested that body image fluctuates within a limited boundary over time (the body image band) (Figure 1), and is influenced by at least seven factors (Table 1).

![Diagram of Slade's Model](image)

*Figure 1*. Slade’s (1994) Model of the Development and Manifestation of Body Image.
Table 1.

*Slade’s (1994) Model of Body Image*

<table>
<thead>
<tr>
<th>Factor</th>
<th>Description</th>
<th>Relevance to People with CF</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) History of sensory input to body experience</td>
<td>Temporally dynamic contributions from visual, tactile and kinaesthetic sources that contribute to an individual’s understanding of their size, shape and appearance. Individuals may have current or past additions to their body, including enteral feeding devices or intravenous (IV) lines that may alter sensory and visual perceptions of the body.</td>
<td></td>
</tr>
<tr>
<td>b) History of weight change</td>
<td>History of weight change may play a role in how tight the mental representation of the body is. People may experience fluctuations in weight, depending on health status. Representation of the body might become unfamiliar, where the body image band becomes elongated.</td>
<td></td>
</tr>
<tr>
<td>c) Cultural and social norms</td>
<td>Sociocultural ideals for females of ‘thinness’ and ‘attractiveness’, and for males, a ‘muscular’ body, shaped through exposure to western ideas. Individuals with CF are likely to subscribe to sociocultural norms. Individuals may find it difficult to reconcile sociocultural ideals and medical advice, leading to ambiguity about body image.</td>
<td></td>
</tr>
<tr>
<td>d) Individual attitudes to shape and weight</td>
<td>Attitudes towards issues that affect shape and weight, such as exercise and dieting. Exercise and a high calorie diet are part of treatment. High fat diets are contrary to media messages.</td>
<td></td>
</tr>
<tr>
<td>e) Cognitive and affective variables</td>
<td>Thoughts and feelings about body image. For example, expectations of calorie intake are known to impact body size judgement (Thompson <em>et al.</em>, 1993). Individuals may think they look different to their peers because of effects of CF, or worry about the amount they have to eat in front of others.</td>
<td></td>
</tr>
<tr>
<td>f) Individual psycho-pathology</td>
<td>Psychopathology, such as diagnosed eating disorder or other mental health problem. Some individuals with CF experience mental health problems, including eating disorders.</td>
<td>Biological impact of CF affects body appearance, e.g. loss of appetite when unwell could contribute to body image through weight loss. Bloated stomach due to gastrointestinal problems, or clubbed fingers may influence body image.</td>
</tr>
<tr>
<td>g) Biological variables</td>
<td>Impact of biological variables, such as menstruation cycle, which is known to impact on body image dissatisfaction (Altabe &amp; Thompson, 1990).</td>
<td></td>
</tr>
</tbody>
</table>
2. Price (1990b)

Price’s (1990b) model represents three key components: ‘body reality’, ‘body ideal’ and ‘body presentation’ as corners of an equilateral triangle (Figure 2). Price (1990b) argues these components represent the balance required for a satisfactory body image. Disturbance in any component may alter body image.

‘Body ideal’ represents how the body should look and can be influenced by sociocultural ideas of the ideal. ‘Body presentation’ represents how an individual presents their body to the outside environment. ‘Body reality’ is how the body actually is. Price (1990b) proposes that coping strategies and social support mediate the impact of each corner of the triangle.

Figure 2. Price’s (1990b) Model of Body Image.
Relevance to Individuals with CF

In CF, ‘body reality’ may be affected by the disease. Threats to body image in the ‘body ideal’ domain may include medical interventions such as IV infusions (Price, 1990a) or enteral feeding devices. Factors such as a constant cough, rounded shoulders, finger clubbing, fluctuations in weight, due to episodes of ill health, and the focus placed on weight in medical consultations, might affect ‘body presentation’.

Critique

Theoretical models of body image are helpful in structuring how body image issues operate and their consequences for different people under different sets of circumstances, but much body image research has lacked a theoretical approach (Pruzinsky & Cash, 1990). There are a number of problems with the presented models:

1. Slade’s (1994) Model
   - Based upon empirical evidence only from eating disorders literature.
   - So far empirically unevaluated.
   - More applicable to issues of body image disturbance and disfigurement if:
     1) ‘history of weight change’ is exchanged for ‘history of bodily changes’ and
     2) ‘individual psychopathology’ is exchanged for ‘personality variables’ Newell (2000)

2. Price’s (1990b) Model
   - Lacks empirical validation, although has clinical validity in illustrated case examples.
   - Definitions not clear making empirical testing difficult
   - It is possible for two components to alter when appearance changes leading “to a situation where almost any set of behaviours can be explained” Newell (2000, pp.18)
Cystic Fibrosis

Aetiology
CF is the most common, life threatening recessively inherited genetic condition in Caucasians (Stark et al., 1998). It is caused by mutation in a gene on chromosome 7. This gene encodes for a chloride channel, known as the cystic fibrosis transmembrane conductor regulator (Lewis, 2000), and causes abnormal regulation of salt and water across cells. This results in production of sticky thick mucus in exocrine glands in many organ systems. As a consequence micro-organisms fail to be expelled from the body and lead to infection or blocking of vital ducts, such as in the pancreas (CF Trust’s Clinical Standards and Accreditation Group, 2001).

Epidemiology
One in every 2500 infants are born with CF, with 1/25 adults being a carrier for the condition (CF Trust’s Clinical Standards and Accreditation Group, 2001). Estimates suggest there are over 7750 people in the UK with CF (Dodge et al., 1997). Life expectancy has dramatically increased due to improvements in medical treatment. A child born with CF in the 1990s is now expected to live until their 40s (Elborn et al., 1991). Survival rate is greater for males than females (Walters, 2000), possibly due to poorer nutrition in females (Corey & Farwell, 1995).

Clinical Presentation and Features
The most well recognised presentation of CF is acute or persistent respiratory symptoms (Walters, 2000). Patients also present with malnutrition and failure to thrive (Walters, 2000). Recurrent chest infections compound lung damage and deformity of the chest can develop with the sternum becoming more prominent and shoulders becoming rounded. Clubbing of fingers and toes occur, due to release of substances associated with infection that stimulate soft tissue growth (Harris & Super, 1995). Complication from these defects leads to progressive respiratory failure and premature death (Anthony et al., 1999b).

Gastrointestinal problems are common. Approximately 80% of individuals with CF are pancreatic insufficient (Kopelman, 1996). Implications of gastrointestinal
problems include poor weight gain, weight loss and body wasting (Kopelman, 1996). Low ideal body weight is a significant independent predictor of impaired survival in CF patients (Sharma et al., 2001). In females, decline in lung function is associated with weight centiles and poorer survival (Gurwitz et al., 1979). Growth can also be affected. FitzSimmons (1993) reported that in the United States 50% of patients fell below the 10\(^{th}\) percentile for height, weight or both.

**Treatments**

Individuals with CF must undertake a large number of treatments, including daily physiotherapy, pharmacotherapy and nutritional management. Individuals are reviewed regularly at a multidisciplinary clinic. Most individuals take medication for bacterial and fungal infections. These are generally inhaled, with nebulizers, or given intravenously (Harris & Super, 1995).

**Nutritional and Dietary Requirements**

Nutritional management aims to counteract gastrointestinal problems and high energy usage. Treatment involves providing enzyme replacement supplements, increased calorie intake (125-140\% of recommended daily allowance [RDA]) and vitamin supplements (Stark et al., 1998). Gastrostomies and nasal gastric tubes can be used to deliver feeds directly to the stomach (Conway et al., 1999).

**Theories of Body Image Disturbance**

Three major categories of body image disturbance theories exist: perceptual, developmental and sociocultural, and are reviewed by Heinberg (2001). Theories inform models which aid understanding of body image in the general population and are likely to be relevant to CF patients.

Perceptual theories suggest body image disturbance may be due to size misperception and concurrent interaction with actual size. Developmental theories suggest that body changes and stressful events, influence body image disturbance (Levine et al., 1994). Teasing and subtle negative commentary, have also been found to be predictive of
body image disturbance, low self-esteem and eating disturbance (Thompson et al., 1995).

Sociocultural theories include cultural ideals of thinness and attractiveness and ‘lipophobia’ (Vandereycken, 1993) for females, and muscular, neither ‘too thin’, nor ‘too fat’ ideals for males (Morrison et al., 2004). Feminist paradigms have argued overvaluation of physical attractiveness and thinness equates to sexism (Gilbert & Thompson, 1996). Sociocultural influence of the mass media has been illustrated (e.g. Groesz et al., 2002), linking with ideas from social comparison theory (Festinger, 1954) and self-ideal discrepancy theories. Social comparison has been found to be highly predictive of body image dissatisfaction and appearance self-esteem amongst male and female adolescents (Morrison et al., 2004).

Self-ideal discrepancy theory has demonstrated larger discrepancies between perceived and ideal size are related to higher levels of body dissatisfaction and eating disturbance (Altabe & Thompson, 1992). An alternative self-discrepancy theory has proposed that discrepancy between attributes of the actual-self and ideal-self (or ideal of a significant other), leads to emotions associated with loss, such as, dissatisfaction. When attributes are discrepant from what the self or a significant other thinks ought to be present, threat, agitation and anxiety related emotions arise (Higgins, 1987). This self-discrepancy theory was used to explore body dissatisfaction and disordered eating (Forston & Stanton, 1992; Strauman et al., 1991; Veale et al., 2003).

**Epidemiology of Body Image Disturbance**

Twenty years ago the notion of ‘normative discontent’ was described by Rodin et al. (1985) to portray the level of body image disturbance in the general population. Recent estimates suggest body dissatisfaction is as high as 80% in adolescent females (Kostanski & Gullone, 1998). For males, dissatisfaction prevalence figures tend to be lower (McCabe & Ricciardelli, 2004). The vast majority of females, who report dissatisfaction, indicate they want to lose weight, whereas for males, dissatisfaction may represent a wish to gain or lose weight (McCabe & Ricciardelli, 2004). Body
dissatisfaction prevalence estimates appear to be similar among adolescents and adults, and older women (McLaren & Kuh, 2004).

**Psychological Adjustment and Body Image**

Body dissatisfaction has been associated with depression in adult (Thompson & Psaltis, 1988) and adolescent (Thompson et al., 1995) females. Kostanski and Gullone (1998) found 'general distress' was related to body dissatisfaction in adolescents. Findings in the self-discrepancy literature indicate that 'actual:ideal' self-discrepancies were associated with body shape dissatisfaction (Strauman et al., 1991).

A well validated relationship between body dissatisfaction, eating pathology and global self-esteem exists (Serpell & Troop, 2003). However some researchers suggest within self-esteem, the influence and importance of shape and weight mediates this relationship (Geller et al., 1997). The extent to which individuals base their feelings of self-worth on body shape and weight was associated with body dissatisfaction and eating disorder symptomatology (Geller et al., 2000). This has been replicated by Tchanturia et al. (2002) in a non-Western society. How important shape and weight was to self-esteem differentiated between possible clinical cases of eating disorder pathology, non-eating disordered individuals and psychiatric cases (Geller et al., 1998). It was also consistently negatively correlated with global self-esteem (Geller et al., 1997; 1998; 2000) and positively correlated with depression (Geller et al., 1997; 1998). In summary, it is generally agreed that body dissatisfaction is related to negative psychological emotions, self-esteem and eating disturbance.

**Body Image Issues in Individuals with a Chronic Illness**

Researchers have argued that in chronic illness the body becomes the “focus of attention” (Morse et al., 1994, pp.190). Qualitative work undertaken with individuals with traumatic injuries and life-threatening illnesses revealed themes related to how the body becomes disruptive in its functioning (Morse et al., 1994; Table 2).
Table 2.

*Themes of Body Image in Individuals who have Experienced Traumatic Injury or Life-Threatening Illness.*

<table>
<thead>
<tr>
<th>Theme</th>
<th>Description</th>
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<tbody>
<tr>
<td>Dis-eased body</td>
<td>Symptoms of illness/injury which can be annoying or unbearable and reflect discomfort.</td>
</tr>
<tr>
<td>Disobedient body</td>
<td>Illness or injury may affect the body against individuals’ wishes.</td>
</tr>
<tr>
<td>Deceiving body</td>
<td>The body may act in a deceiving manner where disease was undiagnosed or progressed unnoticed.</td>
</tr>
<tr>
<td>Vulnerable body</td>
<td>Experiences of vulnerability and powerlessness to bodily changes, including impact of medical procedures.</td>
</tr>
<tr>
<td>Violated body</td>
<td>Violation of body boundaries as the body becomes open to scrutiny from medical professionals.</td>
</tr>
<tr>
<td>Enduring body</td>
<td>The disease/injury and treatments are perceived as relentless or intolerable, but must be endured.</td>
</tr>
<tr>
<td>Betraying body</td>
<td>The body reveals unresolved feelings of distress, despite individuals giving the appearance of coping. For example, in somatic complaints or insomnia.</td>
</tr>
<tr>
<td>Resigned body</td>
<td>When individuals relinquish previous perceptions of their body to take account of consequences of illness/injury.</td>
</tr>
</tbody>
</table>

Body image issues have been investigated widely in chronic illness, with some variable results. A large scale study indicated adolescents with a chronic illness had higher levels of body dissatisfaction and engaged in more unhealthy weight restricting practices than control individuals (Neumark-Sztainer *et al.*, 1995). Interestingly, there was no difference in levels of dissatisfaction between chronic illnesses which involved nutritional elements, and those that did not (Neumark-Sztainer *et al.*, 1995).

However, Carroll *et al.* (1999) found no difference in body dissatisfaction for individuals with type II diabetes and the general population. They asserted “it was not diabetes which affected body dissatisfaction, but the associated obesity... however, diabetes did broaden the domains of body dissatisfaction that related to self-esteem and implicated bingeing.” (p.72)
Risk Factors for Development of Body Image Dissatisfaction in CF

1. Early Difficulty with Food
Parental perceived difficulties with feeding have been identified in infants with CF as young as seven months (Powers et al., 2002). Observations of mealtime behaviours illustrated higher aversive interactions in families with a child with CF, compared to controls (Sanders et al., 1997). Parents report it is their role to help their child maintain and increase weight, with some even describing “battling” and “force feed[ing]” to achieve this aim (Savage & Callery, 2005, pp.251).

The long term effect of early perceived problems with feeding and behaviour around mealtimes has barely been investigated. Some early research suggested eating problems in infancy were linked to later childhood problems with food (McCollum & Gibson, 1970). Case examples of food refusal and psychological difficulties in teenagers have retrospectively assessed individual’s histories and noted longstanding issues with feeding difficulties and poor growth (Loan et al., 1995).

2. Later Disturbed Eating Patterns
Eating disorders have been documented in patients with CF (Goldbloom, 1988), although diagnoses of eating disorders are no higher compared with the general population (Raymond et al., 2000). However, disturbed eating patterns are noted in adolescents and adults with CF.

Almost one quarter of a sample of adolescents with CF demonstrated disturbed eating behaviours (Shearer & Bryon, 2004). Worryingly, a small number of those in the underweight category of body mass index (BMI) reported attempts to avoid weight gain and misusing enzymes to control weight (Shearer & Bryon, 2004). Of those individuals in the normal BMI category, 11% were attempting to lose weight or avoiding gaining weight. Using exercise to control weight was reported by 4%.

In adults, although CF subjects dieted less than controls, 4% of males and 13% of females reported restricting food intake substantially (Abbott et al., 2000). Six percent of CF men and 11% of CF women were engaging in binge eating and intended
vomiting (Abbott et al., 2000). Despite significantly lower rates of ‘dieting’ among CF participants, it could be argued that individuals with CF may choose not to eat the required 125-140% RDA of calories. More specific measures would be needed to capture this concept of ‘dieting’.

3. Treatment Regime and Adherence

It has been suggested that emphasis on maintaining treatment regimes for individuals with CF may impact upon body image, eating behaviours and psychological adjustment (Abbott et al., 2000). Individuals perceived more pressure to eat and this was associated with lower lung functioning and weight (Abbott et al., 2000). Adherence to dietary recommendations has been found to be poor (Stark et al., 1995). Only 16% of children adhered to dietary recommendations; adherence was positively associated to low weight (Anthony et al., 1999a). In adults with CF, size perception was linked to compliance with dietary recommendations and nutritional behaviour (Walters, 2001). Adult females tended to overestimate body weight whereas young adult men tended to underestimate body weight (Walters, 2001). This reflects findings in the general population and individuals with anorexia, where females overestimate body size (Slade, 1985).

Conversely, Abbott et al., (2000) reported CF women (and controls) tended to perceive their body weight as less than their actual body weight, whereas men with CF believed that their BMI was greater than in reality. Truby and Paxton (2001) report differing outcomes again, and found boys and girls with CF were more likely to perceive themselves as larger than their actual body size. With the relationship between size misperception and dissatisfaction well established (e.g. Cash & Deagle, 1997) such findings suggest this is likely to be an important issue within CF.

4. Physiological Impact of CF

Physiologically, CF has an effect on height and weight (Fitzsimmons, 1993) and body appearance, as previously discussed. Low ideal body weight is a predictor for impaired survival (Sharma et al., 2001). This could be due to the association between pulmonary function and weight centiles; as lung function falls so does weight (Gurwitz et al., 1979). Researchers have noted the importance of both organic and
psychosocial causes to malnutrition in CF, suggesting the two interact (Anthony et al., 1999b).

Additionally, there may be other important psychological impacts of the physical manifestations of CF. It is widely recognised that puberty is delayed in individuals with CF, both with nutritional problems (Weltman et al., 1990) and without (Johannesson et al., 1997). Teasing and bullying of individuals with CF have been reported (Closs et al., 2001). However, prevalence and consequences of teasing have not been investigated. There are currently no studies examining the potential psychosocial impact of a gastrostomy or Portacath, or the physical consequences of CF.

**Summary of Risk Factors**

Overall, evidence of early difficulties with food and presence of disturbed eating behaviours, such as dieting, bingeing, vomiting and non-adherence in young people and adults suggest some individuals have problems with food. Pressure from others to eat and physiological and psychological consequences of CF, such as poor lung function, delayed puberty and appearance change, are likely to provide a context for issues regarding body image.

**Body Image in Individuals with CF**

The small number of studies investigating body image in CF are presented in Table 3.
<table>
<thead>
<tr>
<th>Study (year)</th>
<th>Sample and Study Design</th>
<th>Measures</th>
<th>Main Findings</th>
<th>Critique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Truby &amp; Paxton (2001)</td>
<td>37 boys, 39 girls with CF; 71 boys, 82 girls, healthy controls 7-12 years</td>
<td>1. Demographics 2. Semi-structured interview to assess body image and weight control behaviours 3. Rosenberg Self-Esteem Scale (Children’s version) 4. Body-Esteem Scale 5. Dutch Eating Behavior-Restraint Scale 6. Children’s Eating Attitude Test</td>
<td>1. BMI CF individuals &lt; BMI controls 2. CF children more satisfied with body image than controls 3. No difference in body dissatisfaction between girls and boys with CF 4. Of girls with CF ≤50th BMI centile, 54% wanted to stay the same or be thinner 5. For girls with CF body dissatisfaction was a significant predictor for BMI 6. For boys with CF body dissatisfaction and body-esteem were significant predictors of BMI</td>
<td>- Lack of BMI-matched controls</td>
</tr>
</tbody>
</table>
| Dickson (2003) | 22 males, 22 females with CF 12-16 years | 1. Demographics 2. Contour Drawing Rating Scale 3. Body Image Questionnaire 4. Role of CF in Bodysatisfaction Questionnaire 5. Children’s Depression Inventory 6. State-Trait Anxiety Inventory 7. Self Perception Profile for Adolescents | 1. Over half were dissatisfied with body size and wished to gain weight 2. Boys desired a larger body size 3. No overall gender differences in satisfaction 4. A significant proportion with normal or underweight BMI wished to be thinner and were dissatisfied with body size 5. Majority did not feel CF had a big impact on body satisfaction 6. 30% identified dissatisfaction with areas of the body affected by CF, such as finger shape. 7. 20% felt they looked different from peers 8. 13% avoided doing certain things because of appearance | - Use of adult BMI categories to classify adolescents  
- No control group |
<table>
<thead>
<tr>
<th>Study (year)</th>
<th>Sample and Study Design</th>
<th>Measures</th>
<th>Main Findings</th>
<th>Critique</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shearer &amp; Bryon (2004)</td>
<td>28 males, 27 females with CF; 11-17 years</td>
<td>1. Demographics</td>
<td>1. 36% felt body shape influenced their self-evaluation. There was no gender difference</td>
<td>• Use of adult BMI categories to classify adolescents</td>
</tr>
<tr>
<td>Adolescents</td>
<td>Quantitative cross-sectional</td>
<td>2. Harter-Hoare Self-Esteem Questionnaire</td>
<td>2. 53% felt body weight influenced their self-evaluation. There was no gender difference</td>
<td>• No control group</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Child's version of the Eating Disorder Examination</td>
<td>3. 15% reported fear of fatness and weight gain despite no participants exceeding desirable BMI.</td>
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<td></td>
<td></td>
<td></td>
<td>4. 12% whose weight fell in the criteria for anorexia were trying to avoid gaining weight</td>
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</tr>
<tr>
<td>Willis et al. (2001)</td>
<td>21 women, 19 men with CF; 16-20 years</td>
<td>1. Royal Children's Hospital (Melbourne) health status index of severity</td>
<td>1. Girls are generally happy with their slender body shape and do not wish to gain weight</td>
<td>• Inability to make formal comparisons between genders</td>
</tr>
<tr>
<td>Adolescents</td>
<td>Qualitative, exploratory, cross-sectional</td>
<td>2. Semi-structured interview</td>
<td>2. Some girls wished to lose weight.</td>
<td></td>
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<td></td>
<td></td>
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<td>3. Boys wanted to gain weight and become more muscular and strong.</td>
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<td></td>
<td></td>
<td></td>
<td>4. Exercise regimes sometimes referred to in terms of living up to expectations of masculinity rather than for health</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td></td>
<td>5. 66% of girls, 21% of boys followed a low calorie diet</td>
<td></td>
</tr>
<tr>
<td>Abbott et al. (2000)</td>
<td>104 males, 117 females with CF; 74 male, 74 female healthy controls; 14-51 years</td>
<td>1. Demographics</td>
<td>1. CF patients had lower BMIs than controls</td>
<td>• Reported sample was 'adults' but included young people from 14 years</td>
</tr>
<tr>
<td>Adults</td>
<td>Quantitative cross-sectional</td>
<td>2. The Body Test</td>
<td>2. Females with CF were happy with their perceived shape and weight compared to control females</td>
<td>• Lack of BMI-matched controls</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Rosenberg's Self-Esteem Scale</td>
<td>3. Males with CF reported being unhappy with their perceived shape and weight and desired to be heavier, despite overestimating their weight. Control males were content with body shape and weight.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>4. Eating Attitudes Test</td>
<td>4. No gender differences between males and females with CF on body satisfaction.</td>
<td></td>
</tr>
</tbody>
</table>
Research Dossier: Major Research Project

Summary
The studies illustrate many individuals with CF are satisfied with their body image. However, a substantial number of children, adolescents and adults are dissatisfied with body image. Although males are generally found to wish for a larger body size than females, actual gender differences in CF patients in body satisfaction have not been found. There is a trend for females to be happier with their slender body. However, females have increased risk of undertaking worrying behaviours to achieve slimness, such as bingeing, vomiting and restricting food intake. Sociocultural ideals are likely to play a significant role (Willis et al., 2001).

Research Limitations
There remain some variable results within the CF literature. Use of such a variety of methodologies and instruments prevents consistent conclusions from being drawn and generalisation. For example, differences in whether individuals with CF overestimate or underestimate their weight could be due to differences in methodology. Abbott et al. (2000) used silhouettes based on BMI to determine size perception, whereas Walters (2001) asked participants to describe how they perceived themselves. There is inconsistency in categorisation of ‘children’ ‘adolescents’ and ‘adults’ with age. Some samples have classified individuals between 14 and 51 years as ‘adults’ (e.g. Abbott et al., 2000). This makes it difficult to conclude on age-related issues. The investigation of the adult CF population is also relatively recent, and there are few studies to review. Dickson (2003) is the only researcher to study disease-specific elements and consequences of body image directly relevant to the CF population.

There are no longitudinal studies which prevent causal inferences to be made; all research is cross-sectional and based on self-report, which can sometimes be susceptible to social desirability (Holtgraves, 2004).

Relatively small sample sizes have been used, potentially creating problems with power. No studies report effect sizes, making it difficult to assess rigour. Small sample sizes are, however, a problem in the study of a specialist group of patients.
Psychological Issues in Individuals with CF

It has been suggested that individuals with a chronic illness are at risk of psychological difficulties up to three times higher than their peers (Pless, 1984). However, a recent review of psychological functioning in people with CF concludes that “...the psychological and psychosocial functioning of this group of patients appears to be relatively normal but there are aspects in which they have significant distress and disability.” (Pfeffer et al., 2003, pp.67). They suggest that older studies of psychological adjustment are increasingly redundant because of developments in treatment and prognosis (Pfeffer et al., 2003).

There have been relatively few recent studies examining psychological wellbeing in individuals with CF, particularly older individuals. Initially, early evidence presented a mixed picture of psychological adjustment which contained both descriptions of poor functioning and normal adjustment. Recent evidence has tended to be more sophisticated, but variable results still remain.

There a number of reasons why individuals with CF may be vulnerable to poor psychological functioning, particularly with regard to fears about the future (Gee et al., 2003). Recent research suggests that as individuals get older they are likely to find it progressively more difficult to adapt to poorer lung function and thus increasing illness severity, and psychological problems will then emerge (Pfeffer et al., 2003). Studies investigating health status and psychological adjustment have found better clinical health predicts lower psychological distress (Anderson et al., 2001). Although some studies have found subjective health perception is a stronger predictor of quality of life and psychological health than actual disease severity (Staab et al., 1998).

Pearson et al. (1991) compared psychiatric symptomatology between adolescents and adults with CF. They found that adults presented with an elevated rate of anxiety, 22%, compared to 7% in adolescents. Significantly higher depression (42%) was also reported by adults compared to younger participants (15%). The researchers concluded that adolescents with CF tended to present with a higher anorexic-type
eating disturbance whereas older individuals with CF had a higher rate of emotional difficulties (Pearson et al., 1991). Other studies have found that psychological difficulties increase with age (Blair et al., 1994).

Thompson and colleagues (1998) found children aged between seven and 12 years with CF experienced more internalising problems, particularly anxiety, compared to individuals with sickle cell disease (SCD). Thirty-five percent of Diagnostic and Statistical Manual for Mental Disorders (3rd Edition; DSM-III, American Psychiatric Association, 1980) diagnoses in CF children were related to anxiety disorders; 7.5% were depression diagnoses.

Sawyer et al. (1995) found adolescents with CF differed from normative data, suggesting poorer outcome on body image and psychopathology for females, but not males. They suggested males with CF may use denial as a coping strategy and recommended intervention for both genders to achieve more normal functioning (Sawyer et al., 1995).

Other studies have emphasised good psychological functioning in individuals with CF. Blair et al. (1994) failed to find any significant differences between individuals with CF and healthy controls for psychological functioning. Szyndler et al. (in press) also found Australian adolescents with CF reported lower levels of individual psychopathology (12.5%) than a normative community sample (15-20%). Dickson (2003) found British adolescents with CF were no more likely than normative community samples of children to experience depression, anxiety or self-esteem problems.

For adults with CF, recent evidence from America suggests they do not experience higher levels of anxiety, depression or other psychopathology in comparison to the general population (Anderson et al., 2001). This supports evidence from Shepherd et al. (1990) that found no difference between adults with CF and controls on psychosocial health and self-esteem. Abbott et al. (2000) also reported comparable levels of self-esteem between controls and CF patients, where females reported lower self-worth than males.
Body Image and Psychological functioning in Individuals with CF

There is little examination of psychological correlates of body image in individuals with CF. These relationships have been shown to be important in the eating disorders literature (Stice & Shaw, 2002) and general population (Thompson, 1990).

Self-Esteem
Lower levels of self-esteem have consistently correlated with poorer body satisfaction in children (Truby & Paxton, 2001), adolescents (Dickson, 2003; Shearer & Bryon, 2004) and adults (Abbott et al., 2000). Shearer and Bryon (2004) also found lower self-esteem was associated with greater pressure to eat, and suggested exerting this sort of pressure would be unhelpful.

Depression and Anxiety
Dickson (2003) has been the only researcher to investigate the relationship between anxiety and body image. She found high body dissatisfaction was associated with increased anxiety and depression.

Quality of Life
Body image, as measured in one domain of a CF specific quality of life measure (Cystic Fibrosis Quality of Life Questionnaire; Gee et al., 2000), was found to be more positive for females, compared to males, and best explained health-related quality of life (Gee et al., 2005).

A Need for Clarification
Evidence assessing body image issues for individuals with CF is limited. Studies have reported inconsistent results, which require clarification. In line with calls for more up-to-date psychosocial research (Pfeffer et al., 2003) there is a need to examine differences across ages in relation to body image and psychosocial adjustment; previous research is over ten years old (e.g. Pearson et al., 1991). There is little recent UK psychological research. New concepts such as shape and weight based self-
esteem may provide new insights. Such work may help improve understanding of the inconsistencies. Well-developed questionnaire measures, demographic variables and a need to review previous findings justifies a quantitative approach. In accordance with the importance of nutrition and lung functioning to survival rates for people with CF, it is vital that further research exploring body image and psychological functioning is undertaken.
Research Questions and Hypotheses

The current research aims to investigate attitudes and perceptions of body satisfaction, psychological adjustment and the relationship between body image and adjustment.

**Question 1:** To investigate attitudes and perception of body image in adolescents and adults with CF

**Hypothesis 1.**
- Individuals will be dissatisfied with their body image (Abbott et al., 2000; Dickson, 2003). Most participants will wish to have a body size larger than their current body size. A minority of individuals will wish to have a body size smaller than their current body size.

**Question 2:** To investigate the relationship between demographic variables, including age, gender, BMI and lung function and body image in individuals with CF

**Hypothesis 2.**

*Age:*
- Greater body image difficulties will be reported by adolescents (Dickson, 2003; Pearson et al., 1991; Shearer & Bryon, 2004)

*Gender:*
- Females will wish to have smaller body sizes than males (Abbott et al., 2000; Dickson, 2003).
- There will be no gender differences in attitudes of body satisfaction (Abbott et al., 2000; Dickson, 2003; Shearer & Bryon, 2004).
BMI:

- The larger the BMI the more frequently individuals will choose an ideal body size smaller than their own (Dickson, 2003; Truby & Paxton, 2001).
- The greater the BMI the lower body dissatisfaction will be reported for males, whereas the greater the BMI the greater body dissatisfaction will be for females (Abbott et al., 2000)

Lung function:

- The higher the lung function the greater the satisfaction in appearance for males (Abbott et al., 2000)

Question 3: To investigate the impact of body shape and weight based self-esteem on body image attitudes and perception in adolescents and adults with CF

Hypothesis 3.

Age:

- No effect of age is expected (Geller et al., 1997, 2000)

Gender:

- Exploratory analyses will be undertaken for SAWBS scores and gender

BMI:

- BMI is not expected to correlate with SAWBS scores on the basis of previous findings (Geller et al., 1997)

Lung function:

- Exploratory analyses will be undertaken for lung function and SAWBS scores.
More importance of shape and weight to self-esteem will be associated with greater body size and body appearance dissatisfaction (Geller et al., 2000; Tchanturia et al., 2002).

**Question 4:** To investigate nature and point prevalence of anxiety, depression and self-esteem in adolescents and adults with CF and the relationship with demographic variables, including age, gender, BMI and lung function

**Hypothesis 4.**

- Individuals will not have high levels of psychological difficulties (Blair et al., 1994; Dickson, 2003; Szyndler et al., in press) or low self-esteem (Abbott et al., 2000).

**Age:**

- Older individuals will be expected to show higher levels of psychological distress (Blair et al., 1994; Pearson et al., 1991; Pfeffer et al., 2003).
- Exploratory analyses will be undertaken with age and self-esteem.

**Gender:**

- On the basis of inconsistent evidence, hypotheses for gender and psychological distress and self-esteem will be exploratory

**BMI:**

- Exploratory analyses will be undertaken for BMI and psychological adjustment and self-esteem

**Lung function:**

- Psychological adjustment will be related to lung function (Anderson et al., 2001).
- Exploratory analyses will be undertaken for lung function and self-esteem.
Question 5: To investigate the relationships between body image and psychological adjustment in adults and adolescents with CF

Hypothesis 5.

- Body appearance dissatisfaction and body size dissatisfaction will be associated with greater psychological distress and lower self-esteem (Abbott *et al*., 2000; Dickson, 2003; Kostanski & Gullone, 1998)

- More importance placed on shape and weight will be associated with greater psychological distress (Geller *et al*., 1998)

- More importance placed on shape and weight will be associated with lower global self-esteem (Geller *et al*., 1997, 2000)

- ‘Perceived:ideal’ discrepancy will relate to depressive symptomatology and dissatisfaction rather than anxious symptomatology (Higgins, 1987)

- Larger ‘perceived:ideal’ discrepancies will be associated with lower self-esteem and greater psychological distress (Altabe & Thompson, 1992).
CHAPTER 3

METHOD

Overview / Study Design

This cross-sectional study was questionnaire-based and exploratory, with specific hypotheses. The study reports demographic information and used questionnaires assessing mood (anxiety, depression, self-esteem), body satisfaction, and shape and weight based self-esteem, to explore relationships between these variables. Reliability and validity data for all measures are provided.

Ethical Approval

The study was approved for two sites in the National Health Service (NHS), and approved by the University of Surrey Ethics Committee (Appendix A). A number of ethical considerations were acknowledged by the researcher and plans formulated to deal with issues (Appendix A). These were highlighted on the information sheets. Considerations included: possible distress generated by participation, disclosure of high levels of distress, and small risk of child protection issues (participants aged 12-16).

Participants

Participants were recruited from a NHS Trust with paediatric and adult CF clinics. There was a potential participant pool of approximately 120 individuals. Of these, approximately 100 individuals were deemed a ‘realistic’ participant pool. This was due to presence of a group of individuals who were persistent non-attendees of the clinic. In total, 89 individuals were approached. Fifty-eight participants were recruited, a response rate of 65%. Due to missing data, the final analysis included data from 55 participants.
Inclusion Criteria

- Adolescents 12-16 years
- Adults (age 16 and above; no upper age limit)
- Males and females
- Diagnosis of CF

Exclusion Criteria

- Individuals not well enough to complete the questionnaires, identified through liaison with the multidisciplinary team
- Individuals admitted to the wards in the end stage of the disease and receiving palliative care.
- Individuals who could not understand spoken English adequately enough to understand the written information sheet and thus give informed consent.

Demographic and Health Status Information

Demographic details for the participants are presented in Tables 4-7. A demographic sheet was completed for all participants (Appendix N). Ethnicity categories were based on categories used by the 2001 National Census (Office for National Statistics, 2001).

Table 4.

*Age, Lung Function and BMI of Participants*

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Adults Mean(SD) Range</th>
<th>N</th>
<th>Adolescents Mean(SD) Range</th>
<th>N</th>
<th>Total Mean(SD) Range</th>
<th>N</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>27.41 (10.27) 16-58</td>
<td>41</td>
<td>13.86 (1.35) 12-16</td>
<td>14</td>
<td>23.96 (10.68) 12-58</td>
<td>55</td>
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<tr>
<td>FEV₁ % Predicted</td>
<td>51.08 (30.11) 14-119</td>
<td>39</td>
<td>84.70 (18.88) 31-111</td>
<td>13</td>
<td>59.48 (31.23) 14-119</td>
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<tr>
<td>BMI</td>
<td>20.91 (2.92) 16.5-29.0</td>
<td>40</td>
<td>18.66 (2.32) 15.6-23.5</td>
<td>14</td>
<td>20.32 (2.93) 15.6-29.0</td>
<td>54</td>
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Table 5.

<table>
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<th>Gender</th>
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<th></th>
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<th></th>
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<td>N</td>
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<tr>
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<td>64</td>
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<td>14</td>
<td>100</td>
<td>55</td>
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</table>

Table 6.

Participants’ BMI Categories (Actual and Predicted)

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>Adults (actual) N (%)</th>
<th>Adults (pred.) N (%)</th>
<th>Adolescents (actual) N (%)</th>
<th>Adolescents (pred.) N (%)</th>
<th>Total (actual) N (%)</th>
<th>Total (pred.) N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Underweight &lt;18.5</td>
<td>8 (20.0)</td>
<td>8 (20.0)</td>
<td>8 (57.1)</td>
<td>1 (7.1)</td>
<td>16 (29.6)</td>
<td>9 (16.7)</td>
</tr>
<tr>
<td>Normal 18.5-24.9</td>
<td>29 (72.5)</td>
<td>28 (70.0)</td>
<td>6 (42.9)</td>
<td>12 (85.7)</td>
<td>35 (64.8)</td>
<td>40 (74.1)</td>
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<tr>
<td>Overweight 25-29.9</td>
<td>3 (7.5)</td>
<td>4 (10.0)</td>
<td>0 (0)</td>
<td>1 (7.1)</td>
<td>3 (5.6)</td>
<td>5 (9.3)</td>
</tr>
<tr>
<td>Obese &gt;30</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Total</td>
<td>40 (100)</td>
<td>40 (100)</td>
<td>14 (100)</td>
<td>14 (100)</td>
<td>54 (100)</td>
<td>54 (100)</td>
</tr>
</tbody>
</table>

Pred. = predicted

Table 7.

Ethnicity of Participants

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<thead>
<tr>
<th>Ethnicity</th>
<th>Adults</th>
<th></th>
<th></th>
<th>Adolescents</th>
<th></th>
<th></th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
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<tr>
<td>White British</td>
<td>37</td>
<td>90.2</td>
<td>13</td>
<td>93</td>
<td>50</td>
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<td>White Other</td>
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<td>2.4</td>
<td>1</td>
<td>7</td>
<td>2</td>
<td>3.6</td>
<td></td>
<td></td>
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<tr>
<td>Mixed White and Black Caribbean</td>
<td>1</td>
<td>2.4</td>
<td>1</td>
<td>1</td>
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<tr>
<td>Asian or Asian British Indian</td>
<td>1</td>
<td>2.4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1.8</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Black or Black British African</td>
<td>1</td>
<td>2.4</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1.8</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>41</td>
<td>100</td>
<td>14</td>
<td>100</td>
<td>55</td>
<td>100</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
BMI was calculated for all participants. The generally agreed formula for calculating BMI is weight (kg) divided by height (cm) squared (World Health Organisation [WHO], n.d.). For adolescents BMIs were calculated. The Expert Consensus Group of the Royal College of Paediatrics and Child Health (Wright et al., 2002) recommends use of BMIs for children and adolescents, as opposed to percentage height for weight values. Using United Kingdom 1990 BMI reference curves for boys and girls up to the age of 23 years (Cole et al., 1995), 25 adolescents’ and adults’ BMIs were extrapolated to the age of 20 for a ‘predicted BMI’. WHO (n.d.) state that BMI categories are valid for adults from the age of 20 years. A possible reduction in accuracy for predicted BMI was accepted in order that statistical analyses using BMI categories across the total sample could be conducted. BMI reference curves may overestimate BMI for individuals with CF (Morison et al., 1997). This is because with increasing age and disease progression, lung function deteriorates and individuals with CF find it difficult to maintain weight, unlike the general population. Results utilising BMI categories should therefore be interpreted cautiously.

Procedure

Power Analysis
A priori power analyses were undertaken using G* Power (Faul & Erdfelder, 1992) to inform the sample size required to provide valid results. A similar study was used to inform the calculation (Dickson, 2003). Dickson (2003) found significant correlations between body dissatisfaction and depression ($r = -.59$), anxiety ($r = -.68$), and self-esteem ($r = .61$). These correlations are all indicative of a large effect size. The power analysis indicated for a two-tailed test, where power was .8 and alpha was .05, the largest sample size that would be required was 17.

Different measures, and adults were included in the current study, therefore, a further power calculation based on Cohen’s (1988) special conventions was conducted. In order to detect a large effect using a correlational design (two-tailed) (Alpha = .05; Effect Size = .3; Power = .8), a sample size of 26 was required.
A number of hypotheses required statistical analysis of group differences. Power analyses using Cohen’s (1988) conventions revealed in order to detect a large effect size using a t-test design (two-tailed) (Alpha = .05; Effect Size = .8; Power = .8) a sample size of 52 was required.

Tabachnick and Fidell (2001) suggest you choose the largest number of cases indicated by the power analysis for the sample size. Therefore 52 participants were sought for the study.

**Recruitment for the Study**

Three main methods of recruitment were used; outpatients attending weekly CF clinics and annual reviews, inpatients, and postal recruitment. Recruitment of adults and adolescents differed slightly due to issues of informed consent. For adolescents, parents gave consent and adolescents assented to participating in the research.

**Outpatients**

Adults and adolescents were asked to participate in the study via an information sheet (Appendices B, D, E) and invitation (Appendices C, G) sent approximately one week before their appointment at the CF clinic. For adolescents the parents or legal guardian also received their own information sheet (Appendix F) and invitation (Appendix H). The information sheet contained written information about the study. For adolescents there were two information sheets, one for potential participants aged 12 (Appendix D), and the other for participants aged 13-16 years (Appendix E).

Potential participants were contacted by phone, one day prior to their appointment at the CF Clinic, to follow up on the information sheet and answer any questions. For the adolescent sample, parents or legal guardians were contacted.

The researcher met the individual participants at their clinic appointment. Informed consent was gained. Individuals signed written consent forms (Appendices I, J). Participants were given one of the consent forms to keep. Parents also received a copy. Participants completed the set of questionnaires whilst waiting for their appointments during the CF clinic. If they preferred they could complete the
questionnaires at home, and a stamped addressed envelope was provided. The researcher met with all participants to administer the human figures drawing task, the Contour Drawing Rating Scale (CDRS; Thompson & Gray, 1995; Appendix V). In line with recommendations from Geller et al. (2000) the Shape and Weight Based Self-Esteem Scale for Adolescents (SAWBS-A; Geller et al., 2000; Appendix S) was also administered verbally to adolescent participants.

**Inpatients**

Participants recruited from the hospital ward were provided with an information sheet (Appendices B, D, E) and invitation letter (Appendices C, G) when they were admitted. Parents or legal guardians of adolescent inpatients also received an invitation (Appendix H) and information sheet (Appendix F). Either the researcher or a member of the multidisciplinary team gave participants the information. Participants were given one to seven days to read the information. The researcher answered any questions prior to gaining written consent (Appendices I, J). Participants were then provided with a set of questionnaires and an envelope to place them in once completed. Questionnaires were administered as with outpatients. For adults a box was provided behind the nursing station for return of sealed envelopes. Adolescents were provided with an envelope for the completed questionnaires. Sealed envelopes were addressed to the researcher care of the CF Consultant’s Secretary.

**Postal**

Information sheets (Appendices B, D, E) and invitation letters (Appendices C, G) were sent out and followed-up one week later by phone. If verbal consent was obtained an appointment was arranged to meet with the participants. Written consent was gained (Appendices I, J) and the questionnaires and CDRS and SAWBS-A were administered.

The period of data collection was approximately five months (February 2005-June 2005). Every participant was asked if they wished to be notified with a short summary of the results, and provide contact details for this summary (Appendix K, L).
Following completion of the questionnaires the participant’s GP was sent a short letter (Appendix M) informing them that their patient had taken part in the study. This letter provided researcher contact details should the GP want further information about the study.

Confidentiality of Information
Once completed, questionnaires were allocated a unique number that was used to identify the participant’s name and consent details. In this way all questionnaires were kept anonymous. The consent form was separated from the questionnaires. Only the researcher had access to the participant number and the corresponding details. This was kept separately from questionnaires in a locked drawer. The data was stored on a computer using only this unique participant number. The computer was password-protected. Once the data had been entered onto the computer, questionnaires were stored in a locked filing cabinet on NHS premises.

Measures

Body Image Satisfaction Measures

Body Image Questionnaire (Hatfield & Sprecher, 1986)
The Body Image Questionnaire (BIQ; Hatfield & Sprecher, 1986) is a 25-item questionnaire which asks about satisfaction with different body parts (Appendix O). It is also known in the literature as ‘Body Parts Satisfaction Scale’ (Berscheid et al., 1973).

The BIQ assesses individuals’ satisfaction with nine parts of the face and 14 parts of the body, including satisfaction with height and weight. Two questions ask about overall satisfaction with facial attractiveness and overall physical appearance. Individuals are asked to rate satisfaction of body parts on a six-point scale from 1 (Extremely Dissatisfied) to 6 (Extremely Satisfied).

Abbott et al. (2000) removed two items and undertook principal-component analyses with varimax rotation to ensure the instrument was valid. A similar structure for both
the control and CF group were found on the BIQ. This structure was a two-factor solution; body physique satisfaction accounting for 51.5% of the variance; head/facial attractiveness satisfaction accounting for 15.4% of the variance. The internal consistency reliability was good for both factor one (.91) and two (.88).

Construct validity was found to be good. Scores on the BIQ correlated with measures of self-esteem (Abbott et al., 2000). The scale has good face validity. Dickson (2003) used the BIQ with a sample of adolescents with CF to measure body satisfaction. Reliability analysis revealed good Cronbach Alpha coefficients for the two factors identified by Abbott et al. (2000) (body physique satisfaction .93; head/facial attractiveness .86) and for a third total score of body satisfaction (.94) (Dickson, 2003).

In the current study the 23-item version of the BIQ was used. Higher scores on the three factors indicate higher satisfaction with body parts. Scores on the Head/Facial Attractiveness factor range from 10 to 60, and 12 to 72 on the body physique scale. Total scores range from 22 to 132. As with previous research one item ‘Overall Body Appearance’ was not included in the three factors.

**Contour Drawing Rating Scale (CDRS; Thompson & Gray, 1995)**

The CDRS is a figure silhouette paper instrument for assessing body image perception (Appendix V). It has a set of nine front-view contour male and female drawings. These are graduated in size for precise increases in waist-to-hip ratio. Reliability is adequate at .78. Test-retest reliability is strong, above 98%. Concurrent validity is good with contour drawing selection being strongly correlated with weight ($r=.71$) and BMI ($r=.59$).

Gardner et al., (1998) highlight a number of limitations with silhouette measures. To account for these they recommend investigators use Thompson and Gray’s (1995) scale, presenting figures separately and randomly. They advise that standard deviations are recorded and results investigated using non-parametric analyses.
Administration of the CDRS
The CDRS was administered to all participants. Each of the nine silhouettes was presented on a six inch card in a random order. Participants were asked to identify their current body size. Cards were presented again in random order and participants asked to choose their ideal body size. Participants were told that there was no right or wrong answer, and that they could choose the same silhouette if they wished.

Discrepancy scores were calculated by taking away current body size from ideal body size. This gave a satisfaction score. Negative numbers indicated a desired body size smaller than current body size. Positive numbers indicated a desired body size larger than current body size. For the purposes of some analyses, absolute values were calculated.

Role of Cystic Fibrosis in Body Satisfaction Questionnaire
This is a 20-item questionnaire, used specifically in a body image study with adolescents with CF to investigate the impact of issues related to CF and body image (Dickson, 2003). It consists of three parts and was developed through the use of expert sampling and literature review, aiming to ensure content validity. The first section addresses how satisfied the individual is with his/her physical appearance, using a six-point Likert scale, from ‘extremely dissatisfied’ to ‘extremely satisfied’. Questions relating to how much the individual feels CF has played a role in satisfaction with height, weight and physical appearance was investigated on a five-point Likert scale from ‘not at all’ to ‘very much’. Further questions ask how satisfied significant others are with the individual’s height, weight and overall physical appearance. On the adolescent version the significant others include mother, father and doctor (Appendix Q). On the adult version the significant others include partner (or if not partner, parents), friends and doctor (Appendix P).

The second section investigates impact of CF specific treatments on body image. Participants are asked to indicate how bothered they are regarding these treatments.
The final section of the questionnaire relates to how issues of body image might impact on the behaviour of a person with CF. There is an additional question on the adult version concerning intimate relationships.

**Shape and Weight Based Self-Esteem Scale – Adult Version (SAWBS; Geller et al., 1997)**

The SAWBS assesses the importance of shape and weight to global self-esteem (Appendix R). A number of self-attributes are listed and the participant must choose which attributes they feel have been important to them in the last four weeks. The list of attributes includes: Intimate or romantic relationships, Body shape and weight, Competence at school/work, Personality, Friendships, Face, Personal development, Competence at activities other than school/work, and Other. Participants rank their chosen attributes in order of how important each is to how they have felt about themselves. A rank of one represents the most important attribute. The third step asks participants to complete a pie chart to indicate how much each attribute means to them. The score is the angle (in degrees) of the shape and weight piece of the circle.

The SAWBS has been validated on an undergraduate female sample (Geller et al., 1997) and in individuals with eating disorders and psychiatric diagnosis (Geller et al., 1998). Test-retest correlation was \( r = .81 \). The SAWBS has good concurrent validity, being correlated with perceptions of shape and weight and eating disorder symptomatology. It also demonstrated discriminant validity. It was not associated with demographic factors, but was negatively correlated with global self-esteem (Geller et al., 1997). The SAWBS differentiated between individuals with eating disorders, and psychiatric and undergraduate controls (Geller et al., 1998).

**Shape and Weight Based Self-Esteem Scale – Adolescent Version (SAWBS-A; Geller et al., 2000)**

The SAWBS-A (Appendix S) is essentially the same instrument as the SAWBS (Geller et al., 1997). However, the instructions are simplified, and the list of attributes is age appropriate. The list of attributes is as follows: Getting along with grown-ups, Body shape and weight, Your “smarts”, Personality, Getting along with your friends,
Face, Religion or spiritual beliefs, How good you are at a hobby, music or sport and Other.

The attribute ‘Your “Smarts”’ was anglicised in order that it would be understood by English (UK) speaking adolescents. The attribute name was changed to ‘Your intelligence’. The process was checked for integrity by an American colleague by translating back into an American statement and achieving the same meaning.

The validity and reliability of the SAWBS-A has been reported by Geller et al. (2000). Test-retest correlations were \( r = 0.77 \); SAWBS-A scores were found to be stable over time. Adequate concurrent and discriminant validity was found; SAWBS-A scores were significantly associated with measures of eating disorder pathology and global self-esteem. SAWBS-A scores were positively correlated with BMI, but not age or socio-economic status. It achieved good predictive validity in identifying high SAWBS-A scores in the eating disorder group.

**Psychological Adjustment Measures**

**Rosenberg Self-Esteem Scale (RSES; Rosenberg, 1989)**
The RSES is a 10-item Guttman scale designed for adolescents, and later validated on adults, to assess global self-esteem (Appendix T). Statements are rated on a four-point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’. Five statements are reverse scored. Scores range from 10 to 40, with higher scores corresponding to lower levels of self-esteem. It is the most commonly used of the self-esteem scales (Demo, 1985) and has been widely used with CF populations (e.g. Abbott et al., 2000). It is face valid and quick to administer. Extensive strong reliability, including test-retest correlations ranging between \( r = 0.82–0.88 \), and internal consistency, and validity, both convergent and discriminant, exist (Blascovich & Tomaka, 1991).

**Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983)**
The HADS is an 18-item scale investigating the presence of anxious and depressive symptomatology (Appendix U). It is a widely used tool in research and clinical
settings, and is particularly suitable for individuals in medical settings and has been used with CF populations (e.g. Limbos et al., 2000). The HADS can be scored to give separate anxiety and depression scores as well as a total ‘negative affect’ score, confirmed by adequate factorial validity (Herrmann, 1997). All items are scored on a four-point scale (0-3). Higher scores indicate more pathology.

A recent review of the validity and reliability of 747 papers that used the HADS indicated the mean Cronbach’s alpha reliability coefficient was .83 (Bjelland et al., 2002). Cut-off scores for sensitivity for caseness was 8 on both anxiety and depression scales (Bjelland et al., 2002). Concurrent validity was found to be ‘good’ to ‘very good’, with the HADS correlating with other measures of psychopathology and health status (Bjelland et al., 2002). There is good construct validity with the HADS discriminating between different populations that are known to have differing prevalence rates of anxiety and depression (Herrmann, 1997). A recent large UK normative study (N=1792) found high levels of endorsement of anxious and depressive items on the HADS and suggested higher cut-off levels of 10/11 be applied in light of the findings (Crawford et al., 2001).

The HADS has been validated for use with adolescents, aged 12 to 17 (White et al., 1999). It was found to have adequate test-retest correlations. Factor analysis revealed two clusters: anxiety and depression items, which generally agreed with the original structure identified by Zigmond and Snaith (1983) in an adult population (White et al., 1999). Validity was found to be good, with scores for adolescents who were depressed and anxious consistently higher than those in the control group. White et al. (1999) suggested that the HADS is ideal for assessment of depression in adolescents with a physical illness because of the lack of somatic symptoms assessed. Cut-off scores recommend that for screening purposes in adolescents a score of 12 for anxiety and 10 for depression be used to indicate clinical difficulties (White et al., 1999).
**Statistical Analyses**

The data was inputted into SPSS version 12 and examined for its normative properties. Measures of skewness and kurtosis and histograms were examined. Kolmogorov-Smirnov tests were conducted. Age was found to be positively skewed and transformed. Lung function was found to be a bimodal distribution, indicative of two populations. FEV₁%predicted was therefore divided into two groups based on the mean and median: mild-moderate (≥60%Predicted) and moderate-severe (≤9%Predicted). A number of the variables could not be transformed, including the SAWBS score (angle) and depression. As indicated in the literature the CDRS must be investigated using non-parametric statistics. Descriptive statistics, non-parametric correlations and group comparisons were utilised.
CHAPTER 4

RESULTS

Demographic Information of Participants

On the advice of the multidisciplinary CF team one individual who was very unwell was not approached and one individual who lived abroad and could not speak English was not asked to participate. No other participants were excluded. No individuals experienced distress following questionnaire completion. Fifty-eight individuals took part in the study. Three sets of data were excluded from the analysis due to significant amounts of missing information. Some demographic data could not be located for four participants. These participants were excluded pairwise from analyses. Demographic data is presented in Tables 4-7.

Independent samples t-tests were used to explore gender differences in age. No statistically significant differences were found (t(53)=-0.11, p=.91, $\eta^2=-.002$). No significant differences were found between genders for BMI (t(52)=-0.06, p=.93, $\eta^2<.001$) or lung function ($\chi^2(1,N=52)=.08$, p=.78, Cramér’s V=.04).
Research Questions

**Question 1:** To investigate attitudes and perception of body image in adolescents and adults with CF.

Attitudes of body image on the Body Image Questionnaire (BIQ)

The body physique satisfaction scale demonstrated good reliability (coefficient alpha=.93) as was the head/facial attractiveness satisfaction (coefficient alpha=.90) and overall satisfaction (coefficient alpha=.95). Attitudes to body image were investigated using the BIQ. Satisfaction with body, facial appearance and total satisfaction were examined. Higher scores on all scales indicate higher satisfaction with parts of the body. The reported mean satisfaction with appearance can be seen in Table 8.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>Range</th>
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</thead>
<tbody>
<tr>
<td>Body physique satisfaction</td>
<td>51.73</td>
<td>11.58</td>
<td>24 – 72</td>
</tr>
<tr>
<td>Head/facial attractiveness satisfaction</td>
<td>48.38</td>
<td>8.03</td>
<td>24 – 60</td>
</tr>
<tr>
<td>Overall body satisfaction</td>
<td>100.11</td>
<td>18.19</td>
<td>48 – 132</td>
</tr>
</tbody>
</table>

Dissatisfaction with specific body and face parts was explored. BIQ scores for each body part or facial characteristic were rated as ‘dissatisfied’ if individuals reported a score between one (extremely dissatisfied) and three (somewhat dissatisfied), and ‘satisfied’ if they reported a rating of between four (somewhat satisfied) and six (extremely satisfied).

Table 9 shows the number of body parts with which participants were dissatisfied. The mean was 3.70 body/facial parts (SD=4.06) and dissatisfaction with body and facial parts ranged from 0-17 parts. Thirteen participants (24%) were not dissatisfied.
by any body or facial parts. Five individuals (9%) reported dissatisfaction with 10 or more body or facial parts.

Table 9.

*Number of Body and Facial Parts with Which Participants Reported Dissatisfaction.*

<table>
<thead>
<tr>
<th>Number of body and face parts</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>13</td>
<td>23.6</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>16.4</td>
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<td>5</td>
<td>9.1</td>
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<td>3</td>
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</tr>
<tr>
<td>8</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>9</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>11</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>12</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>13</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>14</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>15</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>16</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>17</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100</td>
</tr>
</tbody>
</table>

Perception of body image on the Contour Drawing Rating Scale (CDRS)

Descriptive statistics were used to investigate individual’s actual and ideal perception of themselves on the CDRS (Tables 10). Perceived body size, corresponding to the silhouette figure chosen by the participant, ranged from 1 to 8 (Figure 3) and ideal body size ranged from 3 to 9 (figure 4). A Wilcoxon test revealed that individuals had a statistically significant preference for a greater ideal body size, \( z = -3.27, p < .001 \), suggesting participants ideal body size was larger than their perceived body size.
Figure 3. Pie Chart of Frequencies and Percentages of Participants Choosing Each Figure for Perceived Body Size.

Figure 4. Pie Chart of Frequencies and Percentages of Participants Choosing Each Figure for Ideal Body Size.
Table 10.

Descriptive Statistics for Perceived and Ideal Body Size of the Total Sample.

<table>
<thead>
<tr>
<th></th>
<th>Mean(SD)</th>
<th>Median(IQR)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>CDRS perceived body size</td>
<td>4.47(1.70)</td>
<td>5 (3)</td>
<td>1 - 8</td>
</tr>
<tr>
<td>CDRS ideal body size</td>
<td>5.30(1.08)</td>
<td>5 (1)</td>
<td>3 - 9</td>
</tr>
</tbody>
</table>

IQR=Interquartile range.

Levels of body satisfaction were examined (Table 11). In total, 10 individuals (18%) wished to be slimmer, 16 (29%) were satisfied with their current body size and wished to stay the same, whereas as 29 participants (53%) wanted to gain weight and had an ideal body size greater than their perceived current body size. Collapsing ‘wish to be slimmer’ and ‘wish to be larger’ into one variable ‘dissatisfied’ and keeping ‘wish to be the same’ variable as ‘satisfied’, Chi square statistics revealed a significant difference between the number of individuals who were satisfied with their body size and individuals who were dissatisfied ($\chi^2(1,N=55)=9.62, p=.002$, effect size=.17). The proportion of individuals who were dissatisfied with their body size ($P=.71$) was significantly greater than individuals who were satisfied ($P=.29$).

Table 11.

Level of Body Image Satisfaction on the CDRS

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wish to be smaller</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 body sizes</td>
<td>6</td>
<td>10.9</td>
</tr>
<tr>
<td>1 body size</td>
<td>4</td>
<td>7.3</td>
</tr>
<tr>
<td>Satisfied (wish to stay the same)</td>
<td>16</td>
<td>29.1</td>
</tr>
<tr>
<td>Wish to be larger</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 body size</td>
<td>10</td>
<td>18.2</td>
</tr>
<tr>
<td>2 body sizes</td>
<td>8</td>
<td>14.5</td>
</tr>
<tr>
<td>3 body sizes</td>
<td>9</td>
<td>16.4</td>
</tr>
<tr>
<td>4 body sizes</td>
<td>2</td>
<td>3.6</td>
</tr>
<tr>
<td>Total</td>
<td>55</td>
<td>100</td>
</tr>
</tbody>
</table>
Attitudes of body image and CF as rated on Role of CF in Body Satisfaction Questionnaire.

Individuals were also asked how much they thought their CF had affected their weight, height and physical appearance (Table 12).

Table 12.
*Individual's Perceptions Regarding how much CF has Affected Weight, Height and Physical Appearance.*

<table>
<thead>
<tr>
<th></th>
<th>Weight</th>
<th>Height</th>
<th>Physical appearance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
</tr>
<tr>
<td>Not at all</td>
<td>2 (3.6)</td>
<td>16 (29.1)</td>
<td>9 (16.4)</td>
</tr>
<tr>
<td>Very little</td>
<td>10 (18.2)</td>
<td>13 (23.6)</td>
<td>12 (21.8)</td>
</tr>
<tr>
<td>A little</td>
<td>9 (16.4)</td>
<td>14 (25.5)</td>
<td>15 (27.3)</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>22 (40.0)</td>
<td>4 (7.3)</td>
<td>12 (21.8)</td>
</tr>
<tr>
<td>Very much</td>
<td>12 (21.8)</td>
<td>8 (14.5)</td>
<td>7 (12.7)</td>
</tr>
<tr>
<td>Total</td>
<td>55 (100)</td>
<td>55 (100)</td>
<td>55 (100)</td>
</tr>
</tbody>
</table>

Individuals were asked to respond to how satisfied significant others were with the individual's weight, height and physical appearance. Adolescents were asked about the perception of their mother, father and doctor. Adults were asked to say how satisfied their partner (or if they did not have a partner, their parents), friends and doctor were regarding the weight, height and physical appearance. The results are illustrated in Figures 5 and 6.
**Figure 5.** Mother’s, Father’s and Doctor’s Perceptions of Adolescent’s Weight, Height and Physical Appearance

**Figure 6.** Partner’s (or Parent’s), Friend’s and Doctor’s Perceptions of Adult’s Weight, Height and Physical Appearance

**CF Treatments**

Individuals indicated the presence and impact of different treatments and physical difficulties (CF and non-CF related). Frequencies were used to explore how concerned participants were regarding their CF treatments or other difficulties (Table 13).
Table 13.

*Participants concern for different CF treatments or Other Physical Difficulty*

<table>
<thead>
<tr>
<th>Concern</th>
<th>Gastrostomy</th>
<th>Portacath</th>
<th>Sores</th>
<th>Scars</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
<td>N</td>
</tr>
<tr>
<td>Not at all</td>
<td>2</td>
<td>25.0</td>
<td>4</td>
<td>26.7</td>
<td>14</td>
</tr>
<tr>
<td>Very little</td>
<td>6</td>
<td>40.0</td>
<td>1</td>
<td>100</td>
<td>9</td>
</tr>
<tr>
<td>A little</td>
<td>3</td>
<td>37.5</td>
<td>3</td>
<td>20.0</td>
<td>5</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>1</td>
<td>6.7</td>
<td>1</td>
<td>6.7</td>
<td>2</td>
</tr>
<tr>
<td>Very much</td>
<td>3</td>
<td>37.5</td>
<td>1</td>
<td>6.7</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>8</td>
<td>100</td>
<td>15</td>
<td>100</td>
<td>1</td>
</tr>
</tbody>
</table>

Ten individuals reported ‘other’ difficulties:

- 4 individuals reported non CF-related scars
  - 1 “not at all” concerned
  - 1 concerned “very little”
  - 2 concerned “a little”

- 1 individual reported scoliosis of the spine
  - concerned “very much”
  This individual stated this was:
  “*a big factor, more so than any other, for the reason I don’t like the way I look*”

- 1 individual reported osteoporosis
  - concerned “very little”

- 1 individual had a birthmark on his/her face
  - concerned “a little”

- 1 reported a hole from a past gastrostomy
  - “not at all” concerned

- 1 individual reported visual problems
  (corrected with glasses)
  - concerned “quite a lot”

- 1 individual requiring 24-hour oxygen
  - concerned “very much”
**Dissatisfaction with any body part.**

Participants were asked if there was any part of their body that they were not happy with (Table 14).

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CF-related responses</strong> (number reporting body part)</td>
<td><strong>CF-related responses</strong> (number reporting body part)</td>
</tr>
<tr>
<td>Arms (5)</td>
<td>Arms (8)</td>
</tr>
<tr>
<td>Legs (5)</td>
<td>Fingers/Nails (8)</td>
</tr>
<tr>
<td>Stomach (2)</td>
<td>Height (6)</td>
</tr>
<tr>
<td>Hands</td>
<td>Stomach (5)</td>
</tr>
<tr>
<td>Bottom</td>
<td>Back (3)</td>
</tr>
<tr>
<td>Chest (Scoliosis)</td>
<td>Bottom (3)</td>
</tr>
<tr>
<td>Shoulders</td>
<td>Ankles (2)</td>
</tr>
<tr>
<td>Face</td>
<td>Weight (2)</td>
</tr>
<tr>
<td>(tired/gaunt)</td>
<td>Hands (2)</td>
</tr>
<tr>
<td></td>
<td>Height</td>
</tr>
<tr>
<td></td>
<td>Hips</td>
</tr>
<tr>
<td></td>
<td>Torso</td>
</tr>
<tr>
<td></td>
<td>Shoulders</td>
</tr>
<tr>
<td></td>
<td>Fingers/Nails</td>
</tr>
<tr>
<td></td>
<td>Teeth (stained from enzymes)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Non-CF related responses (number reporting body part)</th>
<th>Non-CF related responses (number reporting body part)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ears</td>
<td>Nose (2)</td>
</tr>
<tr>
<td>Bad skin/spots</td>
<td>Face (2)</td>
</tr>
<tr>
<td>Skin (2)</td>
<td>Hair</td>
</tr>
<tr>
<td></td>
<td>Teeth</td>
</tr>
<tr>
<td></td>
<td>Eyes (dark circles and bags)</td>
</tr>
</tbody>
</table>

21 Participants (38.2%) indicated there was no part of their body that they were unhappy with. Of these individuals 10 were adolescents and 11 were adults.
Thirty-four participants (61.8%) reported a part of their body with which they were unhappy. Of these, 4 were adolescents and 30 were adults. Chi Square statistics (Pearson $\chi^2(1,N=55)=8.80, p=.003, \Phi=.40$) revealed a significant difference between age and number of body parts with which individuals were unhappy. The probability of being unhappy with a body part was 2.52 times more likely as an adult as opposed to an adolescent.

A statistically significant difference was found for gender and dissatisfaction with a body part, (Pearson $\chi^2(1,N=55)=10.86, p=.001, \Phi=.44$). The probability of being unhappy with a body part was about 2.06 times more likely for a female than for a male.

**Feeling different from peers**

Twenty-nine participants (52.7%) reported that they felt different to their peers. Reasons for feeling different included, “being shorter”, “looking younger”, “looking thinner”, “looking unwell”, “getting out of breath quickly”, “having different nails”, “having a gastrostomy” and “having small breasts”.

**Avoidance of activities/situations**

Eighteen individuals (32.7%) reported that they avoided doing certain things because of how they looked. Things that individuals avoided included “swimming”, “going to the beach”, “going out”, “wearing short skirts” or “shorts” and other “revealing clothing”, “avoiding certain colours of clothes (such as black)”, “meeting people”, “clubbing”, “scuba diving” and “sunbathing”.

**Engagement in activities/situations**

Seventeen participants (30.9%) reported that they do certain activities because of the way they look. Activities included “eating more”, “going to the gym” and “weight training”, “going on a diet” and “wearing high heels and padded bras”.

**Platonic relationships**

Nine individuals (16.4%) felt that the way they looked affected their relationships with others. The reasons included: having “less confidence” and “feeling shy”, “being
paranoid about people talking about the way you look”, “people staring”, “feeling depressed”, the impact of “looking young” and “not fitting in to what is considered as normal”.

**Intimate relationships**
Adults were asked if the way they looked had an impact upon their intimate relationships. Thirty individuals (73.2%) did not feel there was any impact. Eleven (26.8%) felt there was an impact and reported the following reasons: “looking pale and thin can put people off”, “feeling jealous of others”, “feeling unattractive due to bloated stomach”, “feeling embarrassed about a gastrostomy”, “weighing less than female partners”, “hiding certain body parts” and “not feeling adequate”.

**Results of hypothesis 1**
The hypothesis that individuals with CF are likely to be dissatisfied with body image was supported; 76% reported dissatisfaction with one or more body or face part. Most participants (53%) wished to have a body size larger than their current body size. Only a minority (18%) wished for a body size smaller than their current body size.
**Question 2.** To investigate the relationship between demographic variables, including age, gender, BMI and lung function and body image in individuals with CF

Spearman’s Rho correlations for relationships between demographic variables were examined (Table 15). Age and BMI were positively correlated. When BMIs were converted to ‘Predicted BMI’ the correlation with age was no longer significant. BMI and predicted BMI were strongly positively correlated. Age and lung function were negatively associated.

Table 15.

**Correlations Between Demographic Variables.**

<table>
<thead>
<tr>
<th></th>
<th>BMI N=54</th>
<th>Predicted BMI N=54</th>
<th>Lung function N=52</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>.50**</td>
<td>.08</td>
<td>-.46**</td>
</tr>
<tr>
<td>BMI</td>
<td>.82**</td>
<td>- .05</td>
<td></td>
</tr>
<tr>
<td>Predicted BMI</td>
<td></td>
<td></td>
<td>.24</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01; Sig.=Significance

Due to the non-parametric nature of the CDRS and the inability to transform the overall self-satisfaction variable, partial correlations and regression analyses could not be explored to examine which demographic variables (age or lung function) produced the strongest relationship in instances of common significant relationships between body satisfaction measures (overall self-satisfaction, absolute discrepancy) (Table 17 and 23).

**Age**

Individuals scores on satisfaction with physical appearance were combined with satisfaction with height and weight from the BIQ (measured on the same Likert scale) to provide an ‘overall self-satisfaction’ variable. Descriptive statistics for all body image variables according to age group can be seen in Table 16.
Table 16.
Mean, Standard Deviations (SD) and Ranges for Body Image Variables for Different Age Groups

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Total (N=55)</th>
<th>Adolescents (N=14)</th>
<th>Adults (N=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>Range</td>
<td>Range</td>
</tr>
<tr>
<td>Body Physique Satisfaction</td>
<td>51.73 (11.58)</td>
<td>56.79 (9.68)</td>
<td>50.00 (11.77)</td>
</tr>
<tr>
<td></td>
<td>24-72</td>
<td>39-70</td>
<td>24-72</td>
</tr>
<tr>
<td>Head/Facial Satisfaction</td>
<td>48.38 (8.03)</td>
<td>47.86 (6.31)</td>
<td>48.56 (8.60)</td>
</tr>
<tr>
<td></td>
<td>24-60</td>
<td>38-60</td>
<td>24-60</td>
</tr>
<tr>
<td>Total Body Satisfaction</td>
<td>100.11 (18.19)</td>
<td>104.64 (14.48)</td>
<td>98.56 (19.21)</td>
</tr>
<tr>
<td></td>
<td>48-132</td>
<td>79-128</td>
<td>48-132</td>
</tr>
<tr>
<td>Overall Self-Satisfaction</td>
<td>12.89 (2.84)</td>
<td>13.71 (2.97)</td>
<td>12.61 (2.77)</td>
</tr>
<tr>
<td></td>
<td>7-18</td>
<td>7-17</td>
<td>8-18</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>4.47 (1.70)</td>
<td>4.86 (1.29)</td>
<td>4.34 (1.81)</td>
</tr>
<tr>
<td></td>
<td>1-8</td>
<td>3-8</td>
<td>1-8</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>5.29 (1.08)</td>
<td>5.29 (1.20)</td>
<td>5.29 (1.05)</td>
</tr>
<tr>
<td></td>
<td>3-9</td>
<td>4-9</td>
<td>3-8</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
<td>0.82 (1.65)</td>
<td>0.43 (1.16)</td>
<td>0.95 (1.77)</td>
</tr>
<tr>
<td></td>
<td>-2-4</td>
<td>-2-3</td>
<td>-2-4</td>
</tr>
<tr>
<td>Absolute Body Size Dissatisfaction</td>
<td>1.40 (1.18)</td>
<td>0.71 (0.99)</td>
<td>1.63 (1.16)</td>
</tr>
<tr>
<td></td>
<td>0-4</td>
<td>0-3</td>
<td>0-4</td>
</tr>
</tbody>
</table>

Spearman’s Rho correlations investigated relationships between age (as a continuous variable) and body image measures (Table 17). Age was found to be negatively associated with body physique satisfaction, total body satisfaction and overall satisfaction with self. This indicates that the older individuals with CF are, the more dissatisfied they are with their body physique, total body, and overall self-satisfaction.

Table 17.
Correlations for Age and Body Image Variables

<table>
<thead>
<tr>
<th>Age (N=55)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Physique Satisfaction</td>
</tr>
<tr>
<td>Head/Facial Satisfaction</td>
</tr>
<tr>
<td>Total Body Satisfaction</td>
</tr>
<tr>
<td>Overall Self-Satisfaction</td>
</tr>
<tr>
<td>Perceived Body Size</td>
</tr>
<tr>
<td>Ideal Body Size</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
</tr>
<tr>
<td>Absolute Body Size Dissatisfaction</td>
</tr>
</tbody>
</table>

*p<.05; **p <.01
Age was significantly positively correlated with absolute body dissatisfaction. This indicates the greater the age the greater the discrepancy between perceived and ideal body size. Figure 7 shows the individuals’ frequency of adults and adolescent dissatisfied with body size.

![Satisfaction with Body Size](chart)

Figure 7. Number of Adolescents and Adults Dissatisfied with Body Size.

**Result of hypothesis 2a**

The hypothesis was not supported; adults were found to have significantly greater body appearance and body size dissatisfaction than adolescents.

**Gender**

Exploratory analyses were carried out with body image measures according to gender and age group (Table 18). Statistically significant differences were found using Mann-Whitney $U$ tests between gender and body physique satisfaction, $z=-1.93$, $p=.05$ effect size index=8.35. This indicates females were more dissatisfied with their body physique than males.
Ideal body size differed significantly according to gender, $z=-2.37$, $p=.02$ effect size index=6.63, indicating males wanted a significantly larger ideal body size than females.

Table 18.

Mean, Standard Deviations (SD) and Ranges for Body Image Variables for Different Age Groups and Gender

<table>
<thead>
<tr>
<th></th>
<th>Male (N=29)</th>
<th>Female (N=26)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Total (N=29)</td>
<td>Adolescent (N=9)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Range</td>
<td>Range</td>
<td>Range</td>
</tr>
<tr>
<td>Body Physique</td>
<td>54.55 (10.46)</td>
<td>60.22 (5.74)</td>
</tr>
<tr>
<td>Satisfaction Head/Facial</td>
<td>50.21 (6.63)</td>
<td>49.22 (5.04)</td>
</tr>
<tr>
<td></td>
<td>35-72</td>
<td>35-72</td>
</tr>
<tr>
<td>Total Body</td>
<td>104.76 (15.39)</td>
<td>98-125 (7.03)</td>
</tr>
<tr>
<td>Satisfaction</td>
<td>13.59 (2.58)</td>
<td>14.78 (2.17)</td>
</tr>
<tr>
<td></td>
<td>8-18</td>
<td>8-18</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>4.69 (1.63)</td>
<td>5.00 (1.41)</td>
</tr>
<tr>
<td></td>
<td>2-8</td>
<td>3-8</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>5.59 (0.98)</td>
<td>5.67 (1.32)</td>
</tr>
<tr>
<td></td>
<td>4-9</td>
<td>5-9</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
<td>0.90 (1.35)</td>
<td>0.67 (1.00)</td>
</tr>
<tr>
<td></td>
<td>-2-3</td>
<td>0-3</td>
</tr>
<tr>
<td>Absolute Body Size</td>
<td>1.17 (1.10)</td>
<td>0.67 (1.00)</td>
</tr>
<tr>
<td>Dissatisfaction</td>
<td>0-3</td>
<td>0-3</td>
</tr>
</tbody>
</table>
On the CDRS, a 2-way contingency table analysis revealed no significant difference between males and females on body size satisfaction, Pearson $\chi^2(1, N=55) = 0.87$, $p = .35$, $\Phi = .13$. Males and females shared roughly equal levels of body size dissatisfaction and satisfaction (Table 19).

Mann-Whitney $U$ tests revealed no gender differences for adolescents or adults in body image variables.

Table 19.

<table>
<thead>
<tr>
<th></th>
<th>Total</th>
<th>Male $N$ (%)</th>
<th>Female $N$ (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Adult</td>
<td>Adolescent</td>
<td>Adult</td>
</tr>
<tr>
<td>Wish to be smaller</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 body sizes</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(3.4)</td>
<td>(5.0)</td>
<td>(19.2)</td>
</tr>
<tr>
<td>1 body size</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>(6.9)</td>
<td>(10.0)</td>
<td>(7.7)</td>
</tr>
<tr>
<td>Satisfied (wish to stay the same)</td>
<td>10</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>(34.5)</td>
<td>(55.6)</td>
<td>(25.0)</td>
</tr>
<tr>
<td>Wish to be larger</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 body size</td>
<td>7</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(24.1)</td>
<td>(33.3)</td>
<td>(20.0)</td>
</tr>
<tr>
<td>2 body sizes</td>
<td>4</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(13.8)</td>
<td>(20.0)</td>
<td>(15.4)</td>
</tr>
<tr>
<td>3 body sizes</td>
<td>5</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>(17.2)</td>
<td>(11.1)</td>
<td>(20.0)</td>
</tr>
<tr>
<td>4 body sizes</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(7.7)</td>
<td>(9.5)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>29</td>
<td>9</td>
<td>20</td>
</tr>
<tr>
<td></td>
<td>(100)</td>
<td>(100)</td>
<td>(100)</td>
</tr>
</tbody>
</table>

**Result of hypothesis 2b**

As hypothesised, females desired a smaller ideal body size than males. In support of the second hypothesis there were no gender differences in body appearance satisfaction or body size satisfaction.
Spearman’s Rho correlations were used to investigate body image variables and actual and predicted BMI (Table 20). Predicted BMI constitutes actual adult BMI and predicted adolescents and adults BMI at age 20 (see Method).

Table 20.

**Correlations for BMI and Body Image Variables**

<table>
<thead>
<tr>
<th></th>
<th>Total Actual BMI</th>
<th>Total Pred. BMI</th>
<th>Male Actual BMI</th>
<th>Female Actual BMI</th>
<th>Male Pred. BMI</th>
<th>Female Pred. BMI</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=54</td>
<td></td>
<td></td>
<td>N=28</td>
<td>N=26</td>
<td>N=28</td>
<td>N=26</td>
</tr>
<tr>
<td>Body Physique</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>-.24</td>
<td>-.02</td>
<td>-.42*</td>
<td>.01</td>
<td>-.16</td>
<td>.11</td>
</tr>
<tr>
<td>Head/Facial</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>-.13</td>
<td>-.21</td>
<td>-.10</td>
<td>-.09</td>
<td>-.25</td>
<td>-.16</td>
</tr>
<tr>
<td>Total Body</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>-.23</td>
<td>-.12</td>
<td>-.37</td>
<td>-.05</td>
<td>-.28</td>
<td>-.03</td>
</tr>
<tr>
<td>Overall Self</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Satisfaction</td>
<td>-.08</td>
<td>.15</td>
<td>-.18</td>
<td>.06</td>
<td>.19</td>
<td>.10</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>.45**</td>
<td>.59**</td>
<td>.28</td>
<td>.70**</td>
<td>.51**</td>
<td>.72**</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>.11</td>
<td>.09</td>
<td>.14</td>
<td>.27</td>
<td>.14</td>
<td>.07</td>
</tr>
<tr>
<td>Body Size</td>
<td>-.37**</td>
<td>-.52**</td>
<td>-.28</td>
<td>-.48*</td>
<td>-.51**</td>
<td>-.61**</td>
</tr>
<tr>
<td>Dissatisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Absolute Body Size</td>
<td>.03</td>
<td>-.24</td>
<td>.07</td>
<td>-.02</td>
<td>-.20</td>
<td>-.24</td>
</tr>
<tr>
<td>Dissatisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05; **p<.01; Pred.=Predicted

Statistically significant positive correlations were found between perceived body size and actual and predicted BMI, indicating that the greater the BMI the larger participants perceived their body size, providing validity for the CDRS (Figure 8). This finding was true for both males and females when predicted BMI and body image variables were explored. When actual BMI was explored, only males were found to have higher body physique dissatisfaction with lower BMI, and for females only actual BMI correlated with perceived body size and body size dissatisfaction.

With increasing BMI, individuals want a smaller body size; thus those with a low BMI want a larger body; those with a large BMI want a smaller body size (Figure 9).
Figure 8. Perceived Body Size According to Predicted BMI Category

Figure 9. Body Size Satisfaction According to Actual and Predicted BMI

For body size dissatisfaction Mann-Whitney U tests revealed significant differences between underweight and overweight groups, $z=-2.90$, $p=.004$, effect size index=6.69, and normal and overweight groups, $z=-2.73$, $p=.008$ effect size index=16.65. Participants more frequently chose a body size that was smaller than their own if they
fell in the overweight category. Individuals in the normal and underweight BMI
categories were found to desire a larger body size (Table 21).

Body size satisfaction according to BMI category can be seen in Table 21. All
individuals who were overweight wished to be smaller. Two individuals in the
underweight category wished to stay the same, whereas 7 individuals wished to have a
larger body size. Of the individuals who fell in the normal category, 6 wished to be
smaller, 22 wished to be larger and 12 were satisfied and wished to stay the same.

Table 21.

<table>
<thead>
<tr>
<th>Predicted BMI</th>
<th>Underweight BMI &lt; 18.5</th>
<th>Normal BMI 18.5 - 24.9</th>
<th>Overweight BMI 25 - 29.9</th>
</tr>
</thead>
<tbody>
<tr>
<td>N (%)</td>
<td>N (%)</td>
<td>N (%)</td>
<td></td>
</tr>
<tr>
<td>Wish to be</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>smaller</td>
<td>2 body sizes</td>
<td>0</td>
<td>4 (10.0)</td>
</tr>
<tr>
<td></td>
<td>1 body size</td>
<td>0</td>
<td>2 (5.0)</td>
</tr>
<tr>
<td>Satisfied</td>
<td></td>
<td>2 (22.2)</td>
<td>12 (30.0)</td>
</tr>
<tr>
<td>(wish to stay the same)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wish to be</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>larger</td>
<td>1 body size</td>
<td>2 (22.2)</td>
<td>8 (20.0)</td>
</tr>
<tr>
<td></td>
<td>2 body sizes</td>
<td>1 (11.1)</td>
<td>7 (17.5)</td>
</tr>
<tr>
<td></td>
<td>3 body sizes</td>
<td>3 (33.3)</td>
<td>6 (15.0)</td>
</tr>
<tr>
<td></td>
<td>4 body sizes</td>
<td>1 (11.1)</td>
<td>1 (2.5)</td>
</tr>
<tr>
<td>Total</td>
<td>9 (100)</td>
<td>40 (100)</td>
<td>5 (100)</td>
</tr>
</tbody>
</table>

Of the individuals in the normal category all 6 individuals who wished to be smaller
were females. Twelve males and 10 females wished to be larger. Eight men and 4
women were satisfied with their body size (Table 22).
Table 22.

Body Size Satisfaction According to Predicted BMI Category and Gender.

<table>
<thead>
<tr>
<th>Predicted BMI</th>
<th>Underweight BMI &lt; 18.5 N (%)</th>
<th>Normal BMI 18.5 - 24.9 N (%)</th>
<th>Overweight BMI 25 - 29.9 N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Males</td>
<td>Females</td>
<td>Males</td>
</tr>
<tr>
<td>Wish to be smaller</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 body sizes</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>1 body size</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Satisfied (wish to stay the same)</td>
<td>1 (20.0)</td>
<td>1 (25.0)</td>
<td>8 (40.0)</td>
</tr>
<tr>
<td>1 body size</td>
<td>1</td>
<td>1</td>
<td>6</td>
</tr>
<tr>
<td>2 body sizes</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>3 body sizes</td>
<td>2</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>4 body sizes</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>5</td>
<td>4</td>
<td>20</td>
</tr>
</tbody>
</table>

**Results to hypothesis 2c**

The hypothesis that the larger the BMI the more frequently individuals would choose an ideal size smaller than their own was supported. The hypothesis that the greater the actual BMI (but not predicted BMI) the greater body satisfaction for males was supported for body physique only. The hypothesis that the greater the BMI the lower body parts satisfaction will be for females was not supported; results were non-significant.
Lung Function

Table 23.

Correlations for Lung Function and Body Image Variables

<table>
<thead>
<tr>
<th></th>
<th>Total Lung Function N=52</th>
<th>Male Lung Function N=27</th>
<th>Female Lung Function N=25</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Physique Satisfaction</td>
<td>.24</td>
<td>.29</td>
<td>.18</td>
</tr>
<tr>
<td>Head/Facial Satisfaction</td>
<td>-.13</td>
<td>-.17</td>
<td>-.14</td>
</tr>
<tr>
<td>Total Body Satisfaction</td>
<td>.10</td>
<td>.10</td>
<td>.05</td>
</tr>
<tr>
<td>Overall Self-Satisfaction</td>
<td>.31*</td>
<td>.48*</td>
<td>.21</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>.33*</td>
<td>.23</td>
<td>.43*</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>-.15</td>
<td>-.07</td>
<td>-.25</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
<td>-.45**</td>
<td>-.30</td>
<td>-.57**</td>
</tr>
<tr>
<td>Absolute Body Size Dissatisfaction</td>
<td>-.53**</td>
<td>-.47*</td>
<td>-.62**</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01

Spearman’s Rho correlations for lung function and body image variables were investigated (Table 23). Overall self-satisfaction was positively correlated with lung function, suggesting that the better the lung function, the more satisfied individuals were with weight, height and physical appearance. This was only true for males and not for females.

Perceived body size was also positively correlated with lung function, indicating that the greater perceived body size, the better lung function. This was only true for females and not for males. Body size dissatisfaction as measured by the discrepancy between perceived and ideal body size on the CDRS (both actual and absolute) was significantly negatively correlated with lung function. This indicates the greater the discrepancy, the poorer lung function. Only females were found to have a significant correlation for actual body size dissatisfaction.

Mann Whitney U tests revealed one statistically significant result between absolute body size dissatisfaction and lung function, z=-3.53, $p<.001$ effect size index=-14.42 (Table 24). This indicates that individuals with mild-moderate level of lung dysfunction were more satisfied with body size than individuals with moderate-severe lung dysfunction (Figure 10).
Table 24.
Means, Standard Deviations (SD) and Range for Body Image Variables According to Lung Function.

<table>
<thead>
<tr>
<th>Lung Function (FEV1 % Predicted)</th>
<th>Mild (60%-120%)</th>
<th>Severe (0%-59%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=26, Mean, (SD), Range</td>
<td>N=26, Mean, (SD), Range</td>
<td></td>
</tr>
<tr>
<td>Body Physique Satisfaction</td>
<td>53.65 (11.31) 24-70</td>
<td>49.04 (11.02) 30-70</td>
</tr>
<tr>
<td>Head/Facial Satisfaction</td>
<td>47.58 (7.91) 24-60</td>
<td>48.85 (8.30) 31-60</td>
</tr>
<tr>
<td>Total Body Satisfaction</td>
<td>101.23 (18.04) 48-128</td>
<td>97.89 (17.90) 65-129</td>
</tr>
<tr>
<td>Overall Self-Satisfaction</td>
<td>13.58 (2.37) 9-17</td>
<td>12.08 (2.97) 7-16</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>4.81 (1.41) 2-8</td>
<td>4.12 (1.99) 1-8</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>5.23 (1.24) 3-9</td>
<td>5.38 (0.98) 4-8</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
<td>0.42 (1.24) -2-3</td>
<td>1.27 (1.97) -2-4</td>
</tr>
<tr>
<td>Absolute Body Size</td>
<td>0.88 (0.95) 0-3</td>
<td>2.04 (1.11) 0-4</td>
</tr>
</tbody>
</table>

Figure 10. Body Size Dissatisfaction According to Severity of Lung Function.

Result to hypothesis 2d
The hypothesis that for males the better the lung function the greater the satisfaction in appearance was substantiated. The correlation was non-significant for females.
Question 3. To investigate the impact of body shape and weight based self-esteem on body image attitudes and perception in adolescents and adults with CF

Properties of the SAWBS scores inventory were investigated (Table 25). For the rankings of the shape and weight piece compared to other attributes, 9 of the 55 individuals (16.4%) ranked shape and weight most important to their feelings of self worth, 10 (18.2%) ranked shape and weight second, 3 (5.5%) third, 6 (10.9%) fourth, 3 (5.5%) fifth, 3 (5.5%) sixth, 0 (0.0%) seventh, 1 (1.8%) eighth. Twenty individuals (36.4%) did not assign any ranking to shape and weight.

Table 25.
Mean and Standard Deviation (SD) of Properties of SAWBS in the Total Sample and for Adolescents and Adults.

<table>
<thead>
<tr>
<th></th>
<th>Total (N=55)</th>
<th>Adolescents (N=14)</th>
<th>Adults (N=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean(SD) Range</td>
<td>Mean(SD) Range</td>
<td>Mean(SD) Range</td>
<td>Mean(SD) Range</td>
</tr>
<tr>
<td>Total number of pieces</td>
<td>4.53 (2.03) 1-9</td>
<td>5.07 (2.46) 2-9</td>
<td>4.35 (1.85) 1-8</td>
</tr>
<tr>
<td>(attributes)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rank order of shape</td>
<td>3.58 (1.85) 1-8</td>
<td>3.93 (1.64) 1-7</td>
<td>3.46 (1.92) 1-8</td>
</tr>
<tr>
<td>and weight piece</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SAWBS score (angle)</td>
<td>65.93 (89.24) 0-360</td>
<td>29.93 (40.91) 0-141</td>
<td>78.22 (97.97) 0-360</td>
</tr>
</tbody>
</table>

Relationship between SAWBS and demographic variables.

Spearman’s Rho correlations (two-tailed) were conducted between the SAWBS angle score and demographic variables (Table 26). A significant negative correlation between SAWBS score and lung function (FEV₁ %predicted) indicates an association between increasing importance of shape and weight to overall self-esteem and poorer lung function.
Table 26.

*Correlations between SAWBS score and demographic variables*

<table>
<thead>
<tr>
<th></th>
<th>SAWBS score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (N=55)</td>
<td>.25</td>
</tr>
<tr>
<td>BMI (N=54)</td>
<td>-.06</td>
</tr>
<tr>
<td>Predicted BMI (N=54)</td>
<td>-.26</td>
</tr>
<tr>
<td>Lung Function (N=52)</td>
<td>-.30*</td>
</tr>
</tbody>
</table>

* p<.05; ** p<.01

Mann-Whitney U tests revealed no significant differences between SAWBS scores and adolescents and adults (Table 25), or between males and females.

**Results to hypothesis 3a**

No statistically significant correlations for SAWBS angle and age were found, in support of the current hypothesis. There were no gender differences in importance of shape and weight to self-esteem. As expected neither BMI nor predicted BMI were correlated with SAWBS scores. Higher SAWBS scores and lower lung function were associated.

**Relationship between SAWBS, attitudes towards body image and perceptions of shape and weight.**

Spearman’s Rho correlations (two-tailed) were conducted between the SAWBS angle score and other body image measures (Table 27). A significant negative correlation between SAWBS scores and body physique satisfaction and self-satisfaction were found, indicating that the greater the SAWBS angle (i.e. the more important shape and weight is to overall feelings of self-esteem) the lower the satisfaction with body physique and overall satisfaction with self.

Statistically significant positive correlations were found between SAWBS angle and actual and absolute discrepancy between perceived and ideal body size. This indicates that the greater the SAWBS angle the greater the body size dissatisfaction (i.e. the
discrepancy between perceived and ideal body size). Such results provide concurrent validity for the SAWBS measure in a chronic illness sample.

Table 27.

Correlations between SAWBS Scores and Body Image Attitudes and Perceptions

<table>
<thead>
<tr>
<th></th>
<th>SAWBS score</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N=55)</td>
</tr>
<tr>
<td>Body Physique Satisfaction</td>
<td>-.39**</td>
</tr>
<tr>
<td>Head/Facial Satisfaction</td>
<td>-.01</td>
</tr>
<tr>
<td>Total Body Satisfaction</td>
<td>-.25</td>
</tr>
<tr>
<td>Overall Self-Satisfaction</td>
<td>-.30*</td>
</tr>
<tr>
<td>Perceived Body Size</td>
<td>-.21</td>
</tr>
<tr>
<td>Ideal Body Size</td>
<td>.05</td>
</tr>
<tr>
<td>Body Size Dissatisfaction</td>
<td>.27*</td>
</tr>
<tr>
<td>Absolute Body Size Dissatisfaction</td>
<td>.31*</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01

Table 28.

Mean and Standard Deviation (SD) of Properties of SAWBS According to Body Size Dissatisfaction.

<table>
<thead>
<tr>
<th></th>
<th>Wish to have a smaller body size (N=10)</th>
<th>Wish to stay the same (N=16)</th>
<th>Wish to have a larger body size (N=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of pieces (attributes)</td>
<td>Mean(SD) Range</td>
<td>Mean(SD) Range</td>
<td>Mean(SD) Range</td>
</tr>
<tr>
<td></td>
<td>4.50 (1.78)</td>
<td>4.75 (2.44)</td>
<td>4.41 (1.92)</td>
</tr>
<tr>
<td>Rank order of shape and weight piece</td>
<td>2-8</td>
<td>2-9</td>
<td>1-8</td>
</tr>
<tr>
<td></td>
<td>4.10 (2.33)</td>
<td>4.06 (1.53)</td>
<td>3.14 (1.79)</td>
</tr>
<tr>
<td></td>
<td>1-8</td>
<td>1-6</td>
<td>1-7</td>
</tr>
<tr>
<td>SAWBS score (angle)</td>
<td>50.60 (64.51)</td>
<td>30.13 (46.54)</td>
<td>90.97 (106.74)</td>
</tr>
<tr>
<td></td>
<td>0-200</td>
<td>0-141</td>
<td>0-360</td>
</tr>
</tbody>
</table>

Mann-Whitney U tests indicated that there was a significant difference in SAWBS scores between individuals who were satisfied with their current shape and those who wished to be larger, z=-2.196, p=.03 effect size index=-.78 (Table 28; Figure 11).
Figure 11. Distribution of the SAWBS Score Angle According to Body Size Satisfaction.

Results to hypothesis 3b
In line with the hypothesis, greater importance on shape and weight was associated with greater body size dissatisfaction and body appearance dissatisfaction.
Research Dossier: Major Research Project

**Question 4.** To investigate nature and point prevalence of anxiety, depression and self-esteem in adolescents and adults with CF and the relationship with demographic variables, including age, gender, BMI and lung function.

Psychological adjustment was investigated by examining individuals’ scores on the Hospital Anxiety and Depression Scale. Higher scores indicate greater pathology. Cronbach’s alpha reliability coefficients for anxiety, depression and negative affect were .75, .81, .85, respectively. Global self-esteem was measured using the Rosenberg Self-Esteem Scale. Larger scores indicate lower levels of self-esteem. Descriptive statistics are provided in Table 29.

Table 29.

*Age Differences in Psychological Adjustment.*

<table>
<thead>
<tr>
<th></th>
<th>Total (N=55) Mean(SD) Range</th>
<th>Adolescents (N=14) Mean(SD) Range</th>
<th>Adults (N=41) Mean(SD) Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>6.84 (3.64)</td>
<td>6.00 (3.96)</td>
<td>7.12 (3.53)</td>
</tr>
<tr>
<td>Depression</td>
<td>3.25 (3.30)</td>
<td>2.00 (1.84)</td>
<td>3.68 (3.58)</td>
</tr>
<tr>
<td>Negative affect</td>
<td>10.09 (6.16)</td>
<td>8.00 (5.32)</td>
<td>10.80 (6.32)</td>
</tr>
<tr>
<td>Global self-esteem</td>
<td>18.51 (6.70)</td>
<td>16.57 (5.12)</td>
<td>19.17 (7.07)</td>
</tr>
</tbody>
</table>

As expected, Spearman’s Rho correlations revealed a significant positive correlation between anxiety and depression, indicating the greater the anxiety score the greater the score for depression (Table 30). Statistically significant positive correlations were also found between anxiety and self-esteem and depression and self-esteem. This suggests that individuals who are anxious or depressed will experience lower levels of self-esteem.
Spearman’s Rho correlations were examined for association between psychological adjustment and demographic variables (Table 30). Significant positive correlations were found between age and self-esteem, anxiety, depression, and negative affect. This indicates the older the individual, the greater psychological distress.

Significant positive correlations were also found between actual BMI and self-esteem, anxiety and negative affect. Although when examined against predicted BMI these became non significant. One statistically significant negative correlation was found for lung function and depression, indicating that the poorer the lung function the greater the levels of depression.

Table 30.

**Correlation Matrix for Demographic and Psychological Adjustment Variables**

<table>
<thead>
<tr>
<th></th>
<th>BMI</th>
<th>Pred. BMI</th>
<th>Lung function</th>
<th>Self-esteem</th>
<th>Anxiety</th>
<th>Depression</th>
<th>Negative affect</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>.50**</td>
<td>.08</td>
<td>-.46**</td>
<td>.30*</td>
<td>.35**</td>
<td>.43**</td>
<td>.39**</td>
</tr>
<tr>
<td>(N=55)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>BMI</strong></td>
<td>.82**</td>
<td>-0.05</td>
<td>.28*</td>
<td>.36**</td>
<td>.26</td>
<td>.34*</td>
<td></td>
</tr>
<tr>
<td>(N=54)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Pred. BMI</strong></td>
<td>-.24</td>
<td>.09</td>
<td>.21</td>
<td>.13</td>
<td>.20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N=54)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Lung function</strong></td>
<td>-.17</td>
<td>-.16</td>
<td>-.34*</td>
<td>-.23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N=52)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Self-esteem</strong></td>
<td>.62**</td>
<td>.56**</td>
<td>.64**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N=55)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td>.66**</td>
<td></td>
<td>.94**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N=55)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td>.87**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(N=55)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*p<.05; **p<.01; Pred.=Predicted
Table 31.

**Age and Gender Differences in Psychological Adjustment.**

<table>
<thead>
<tr>
<th></th>
<th>Total (N=55)</th>
<th>Adolescents (N=14)</th>
<th>Adults (N=41)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
<td>Mean(SD)</td>
</tr>
<tr>
<td></td>
<td>Male (N=29)</td>
<td>Female (N=26)</td>
<td>Male (N=9)</td>
</tr>
<tr>
<td></td>
<td>Range</td>
<td>Range</td>
<td>Female (N=5)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>6.38 (3.54)</td>
<td>5.11 (3.44)</td>
<td>6.95 (3.52)</td>
</tr>
<tr>
<td></td>
<td>7.35 (3.75)</td>
<td>7.60 (4.72)</td>
<td>7.29 (3.62)</td>
</tr>
<tr>
<td></td>
<td>0-14 2-14</td>
<td>0-11 3-14</td>
<td>1-14 2-14</td>
</tr>
<tr>
<td>Depression</td>
<td>2.76 (2.75)</td>
<td>1.89 (1.96)</td>
<td>3.68 (2.30)</td>
</tr>
<tr>
<td></td>
<td>3.81 (3.79)</td>
<td>2.20 (1.79)</td>
<td>4.19 (4.17)</td>
</tr>
<tr>
<td></td>
<td>0-9 0-18</td>
<td>0-5 0-4</td>
<td>0-9 0-18</td>
</tr>
<tr>
<td>Negative affect</td>
<td>9.14 (5.82)</td>
<td>7.00 (4.95)</td>
<td>9.80 (6.03)</td>
</tr>
<tr>
<td></td>
<td>11.15 (6.46)</td>
<td>9.80 (6.06)</td>
<td>10.10 (6.65)</td>
</tr>
<tr>
<td></td>
<td>0-23 2-28</td>
<td>0-15 3-18</td>
<td>2-23 2-28</td>
</tr>
<tr>
<td>Global self-esteem</td>
<td>16.90 (5.82)</td>
<td>14.00 (2.65)</td>
<td>18.20 (6.42)</td>
</tr>
<tr>
<td></td>
<td>20.31 (7.22)</td>
<td>21.20 (5.45)</td>
<td>20.10 (7.67)</td>
</tr>
<tr>
<td></td>
<td>10-32 10-36</td>
<td>10-17 14-28</td>
<td>10-32 10-36</td>
</tr>
</tbody>
</table>

**Anxiety**

For adults the cut-off score for caseness is suggested to be 8 (Bjelland et al., 2002). Fifteen (36.6%) adults had scores of 8 or above. For adolescents the cut-off score for caseness is suggested to be 12 (White et al., 1999). One individual (7%) had a score of 14.

If the higher cut-off criterion of 10 or 11 is utilised, given findings from a larger normative sample (Crawford et al., 2001), 12.7% (7 individuals) reach levels of caseness for anxiety. Using a binomial test, this was not found to be significantly different to the 12.6% reported level of anxiety in the large normative study (p=1, two-tailed, effect size=.001) (Crawford et al., 2001).

Mann-Whitney U tests found no significant difference between adults and adolescents or between males and females on levels of anxiety (Table 31).
Depression

For adults the cut-off score for caseness for depression is suggested to be 8 (Bjelland et al., 2002). Five (12.2%) adults had scores of 8 or above. For adolescents the cut-off score for caseness for depression is suggested to be 10 (White et al., 1999). No individuals had clinical levels of depression; the highest adolescent score was 5.

When a cut-off score of 11 is applied for adults as suggested by Crawford et al.’s (2001) large normative study only 1 individual in the total sample (1.8%) was found to have a clinically significant level of depression. Using a binomial test this was not found to be significantly different to the 3.6% level of depression reported in the large normative sample ($p=.81$, two-tailed, effect size=.02) (Crawford et al., 2001).

Mann-Whitney $U$ tests found no significant difference between age and gender for levels of depression (Table 31).

Mann-Whitney $U$ tests indicated a significant difference between individuals with mild-moderate and moderate-severe lung function on levels of depression, $z=-2.13, \ p = .03$ effect size index=-8.84, suggesting that individuals with mild-moderate lung function have lower levels of depression than participants with moderate-severe lung function.

Negative Affect

No significant results were found using Mann-Whitney $U$ tests between adults and adolescents or males and females on levels of negative affect.

Self-Esteem

Mann-Whitney $U$ tests indicate that there was no significant difference between adults and adolescents on levels of self-esteem.
Gender differences were explored in self-esteem using Mann-Whitney $U$ tests (Table 31). Only the Mann-Whitney $U$ test for gender and adolescents was significant, indicating that female adolescents had statistically significantly lower levels of self-esteem than male adolescents, $z=-2.49, p=.01$ effect size index= -7.00 (Figure 12).

![Box plot showing self-esteem scores for male and female adolescents.](image)

**Figure 12.** The Distributions of Self-Esteem Scores for Male and Female Adolescents.

**Results of hypothesis 4a**
The hypothesis was supported. Individuals with CF were found to have comparable levels of anxiety and depression to the general population.

**Results of hypothesis 4b**
The hypothesis was supported; increasing age was associated with greater psychological distress and lower self-esteem.

**Results of hypothesis 4c**
No gender differences were found for anxiety or depression. Gender differences in self-esteem were found only for adolescents. Males had significantly higher levels of self-esteem than females.
**Results of hypothesis 4d**
Greater actual BMI was associated with more anxiety, negative affect and lower self-esteem. However, when using the more relevant measure of predicted BMI, the relationships were no longer significant.

**Results of hypothesis 4e**
A medium correlation was found between disease severity (i.e. lung function) and depression, partially supporting the hypothesis that lung function would be associated with psychological distress. No association was found between lung function and self-esteem.
Question 5. To investigate the relationships between body image and psychological adjustment in adults and adolescents with CF

Table 32.
Correlation Matrix for Body Image and Psychological Adjustment Variables.

<table>
<thead>
<tr>
<th></th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
<th>5.</th>
<th>6.</th>
<th>7.</th>
<th>8.</th>
</tr>
</thead>
<tbody>
<tr>
<td>All - N=55</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. Body Physique Satisfaction</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Head/Facial Satisfaction</td>
<td>.65**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Total Body Satisfaction</td>
<td>.95**</td>
<td>.85**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Overall Self-Satisfaction</td>
<td>.80**</td>
<td>.44**</td>
<td>.73**</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Perceived Body Size</td>
<td>.40**</td>
<td>.09</td>
<td>.30*</td>
<td>.48**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Ideal Body Size</td>
<td>.14</td>
<td>.15</td>
<td>.17</td>
<td>.10</td>
<td>.29*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Body Size Dissatisfaction</td>
<td>-.33*</td>
<td>.00</td>
<td>-.21</td>
<td>-.41**</td>
<td>-.79**</td>
<td>.30*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Absolute Body Size Dissatisfaction</td>
<td>-.49**</td>
<td>-.09</td>
<td>-.38**</td>
<td>-.58**</td>
<td>-.44**</td>
<td>.17</td>
<td>.61**</td>
<td></td>
</tr>
<tr>
<td>9. Anxiety</td>
<td>-.46**</td>
<td>-.37**</td>
<td>-.46**</td>
<td>-.40**</td>
<td>-.13</td>
<td>.30*</td>
<td>.33*</td>
<td>.29*</td>
</tr>
<tr>
<td>10. Depression</td>
<td>-.66**</td>
<td>-.46**</td>
<td>-.65**</td>
<td>-.59**</td>
<td>-.32*</td>
<td>-.01</td>
<td>.34*</td>
<td>.45**</td>
</tr>
<tr>
<td>11. Negative affect</td>
<td>-.59**</td>
<td>-.46**</td>
<td>-.59**</td>
<td>-.52**</td>
<td>-.22</td>
<td>.17</td>
<td>.35**</td>
<td>.37**</td>
</tr>
<tr>
<td>12. Self-esteem</td>
<td>-.65**</td>
<td>-.60**</td>
<td>-.67**</td>
<td>-.54**</td>
<td>-.18</td>
<td>.09</td>
<td>.26</td>
<td>.32*</td>
</tr>
</tbody>
</table>

*p<.05; **p<.01

Attitudinal measures
Spearman’s Rho correlations were used to investigate the relationships between anxiety, depression and negative affect and self-esteem and body image variables (Table 32).
Statistically significant negative correlations were found between anxiety, depression, negative affect and self-esteem and body physique satisfaction, head/facial satisfaction and total body satisfaction. Results indicate that higher levels of psychological distress and lower self-esteem were significantly related to lower satisfaction as measured on the BIQ.

Overall self-satisfaction was also significantly negatively correlated with anxiety, depression, negative affect and self-esteem suggesting the higher the level of psychological distress and lower self-esteem the lower overall self-satisfaction.

**Results to hypothesis 5a**
In support of the hypothesis, body appearance dissatisfaction and body size dissatisfaction were associated with greater psychological distress and lower self-esteem.

**Relationship between SAWBS and psychological adjustment.**

Spearman’s Rho correlations were conducted between the SAWBS angle score and other psychological adjustment measures. No statistically significant results were found between anxiety, depression and negative affect and SAWBS score.

In support of the proposed hypotheses a trend for a positive correlation between SAWBS scores and global self-esteem was found, $r(55)=.20, p=.07$, one-tailed, indicating that the greater the SAWBS angle (i.e. the more important shape and weight is to overall feelings of self-esteem) the lower global self-esteem.

Median splits for anxiety and depression, creating high and low levels of anxiety and depression, were not found to be significantly different to SAWBS scores as investigated using Mann-Whitney $U$ tests.
Results to hypothesis 5b
The hypothesis that more importance on shape and weight in self-worth would be
associated with greater psychological distress was not found to be supported.

Results to hypothesis 5c
The hypothesis was partially supported. There was a trend, though not statistically
significant, for importance of shape and weight to self-worth to be associated with
lower global self-esteem.

Perceptual measures (self-discrepancy)
Spearman Rho’s correlations between psychological adjustment and self-esteem and
body size dissatisfaction (i.e. the discrepancy between perceived and ideal body size)
measured using the CDRS were explored (Table 32).

Significant positive correlations between anxiety and ideal body size, indicated
association between greater ideal body size and higher anxiety. Significant negative
correlations were found between depression and perceived body size, suggesting a
relationship between lower perceived body size, and greater depressive
symptomatology.

Anxiety, depression and negative affect were positively correlated with body size
dissatisfaction (actual and absolute). The results suggest that higher levels of body
size dissatisfaction are associated with higher levels of psychological distress.

Self-esteem was significantly positively correlated with absolute body size
dissatisfaction, indicating that lower levels of self-esteem are associated with body
size dissatisfaction.

Although all results for self-discrepancy scores were significant, depression had the
strongest correlation with body size satisfaction, over anxiety, negative affect and self-
esteeem, partially supporting the self-discrepancy hypothesis.
**Results to hypothesis 5d**

The hypothesis that 'Perceived:ideal' discrepancy will relate to depressive symptomatology and dissatisfaction rather than anxious symptomatology was partially supported. All psychological distress variables were found to be associated with body size dissatisfaction ('Perceived:ideal' discrepancy), including anxiety, but depression had the strongest relationship with body size dissatisfaction and overall self-satisfaction.

**Results to hypothesis 5e**

Larger 'perceived:ideal' discrepancies (body size dissatisfaction) were found to be positively associated with self-esteem (i.e. lower self-esteem) and higher psychological distress, in line with the hypothesis.
CHAPTER 5

DISCUSSION

The aim of the research was to investigate issues of body image and psychological adjustment for people with CF. Findings from the study will be outlined with interpretations and discussion of relevant literature. Limitations of the study will be discussed, clinical implications and future research considered. Conclusions will be drawn.

Body Image

Perceptual Aspects of Body Image

For the majority of individuals with CF (71%) body size dissatisfaction existed. Under one third (29%) indicated they were satisfied with their body size and wished to remain the same size. Of the dissatisfied individuals (53%) had an ‘ideal’ body size larger than their perceived size. Only 18% of dissatisfied individuals wished to have a smaller ‘ideal’ body size. This supports previous research indicating body size dissatisfaction is prevalent within the CF population (e.g. Dickson, 2003; Shearer & Bryon, 2004), but contrasts with others who found only males with CF were dissatisfied (Abbott et al., 2000). These current results differ from the general population where the majority of dissatisfied females wished to be slimmer, and men wished either to be slimmer or larger (McCabe & Ricciardelli, 2004).

Males in the study wanted a larger ‘ideal’ body size than females, although there were no differences between males and females on body size dissatisfaction. However, of the 10 individuals (18%) who wished to be slimmer, seven (70%) were female and three (30%) were male, suggesting that more females than males wished to lose weight.

Overall, although the majority of individuals with CF wish to be larger there is roughly one fifth who wish to be slimmer. The number of individuals wishing to lose weight is lower than a previous study of adolescents; although adult categories for
BMI were used for adolescents, giving spuriously high results for individuals who wished to lose weight based on their BMI category (Dickson, 2003).

These findings may reflect that individuals are already smaller than their peers. It also suggests they are aware of the medical advice that maintaining a healthy BMI is related to health status and survival. It appears that the majority of individuals wish to fulfil this objective. Regular multidisciplinary clinic visits are likely to reinforce the importance of nutritional status, with the emphasis of the medical model in CF on maintaining health. However, this is only indirect evidence. Even though individuals may wish to be larger, and are aware of the medical advice, this may not translate into ‘action’, especially given poor adherence rates. Other priorities may be at play. For example, in the case of smoking; many people continue to smoke, despite having an understanding of the health risks, so called ‘consonant smokers’ (Kunze, 2000).

As the majority of individuals had underweight or normal body sizes (only five individuals, based on predicted BMI, were deemed overweight), it is likely that sociocultural aspects also interact with health status. There is no reason to assume that individuals with CF would not subscribe to the same ideals as the general population. Therefore, it is possible that females’ already slim figures allow them flexibility to contemplate increasing weight on health grounds. For males, the sociocultural pressure to not be too thin, or too fat, also allows leeway to desire a larger size. This allows males to meet both perceived health benefits and sociocultural standards for masculinity.

However, for the women and men who fall in the normal category of weight, there may exist an ambiguous relationship between wanting to be healthy and wishing to, as one participant described, “fit in to what is considered normal”. For these individuals the wish to be “normal” may mean they want to fit sociocultural ideals of Western society. Such sociocultural and health issues would be relevant to the model described by Slade (1994) in the development of body image for individuals with CF.

The normal weight individuals who wish to be slimmer will be of concern to medical professionals, given the link between pulmonary function, BMI and survival (Sharma
et al., 2001). Body dissatisfaction is also a well-established aetiological risk factor for eating disturbance and eating disorders (Stice & Shaw, 2002), and there is evidence that some adolescents with CF present with disturbed eating behaviours and attitudes (Bryon & Shearer, 2004). Thus individuals with CF who want to be thinner, despite having a normal BMI, could be at risk for eating disturbance and psychological distress. It is unknown how normal CF management, which stresses adherence to nutritional standards, may impact on these patients.

Adults were almost twice as likely as adolescents to be dissatisfied with their body size. Eighty percent of adults indicated dissatisfaction, while 43% of adolescents were dissatisfied; most wished to gain weight. This high level of dissatisfaction among adolescents is consistent with previous research (e.g. Dickson, 2003; Shearer & Bryon, 2004). However, the extremely large dissatisfaction figure for adults with CF contradicts previous research suggesting that adults with CF appear to be well adapted on measures of body satisfaction (Abbott et al., 2000). This age difference could reflect developmental differences and/or interaction with disease progression, given the relationship between both age and lung function with body image variables. Developmental differences could reflect adolescents’ achievement of sociocultural standards for slimness, and, if anything, wish to be larger. Older individuals are likely to be more ill, have greater CF-related body appearance changes, and find it difficult to maintain weight. Older individuals may also understand how the body is letting them down. This would support themes described in Morse et al.’s (1994) qualitative study of adults with injury or chronic illness. As previously described, the focus on good nutritional status for survival is likely to influence older individuals who may already feel like ‘survivors’, given that they have surpassed expectations for living as treatments have advanced.

The impact of BMI on body size dissatisfaction was investigated. The greater the individual’s BMI the more likely they were to choose an ideal body size smaller than their own. This supports previous research with children with CF (Truby & Paxton, 2001) and a sociocultural explanation. All individuals who were overweight wished to be slimmer. Of the individuals whose BMI fell in the normal category all six who
Research Dossier: Major Research Project

wished to lose weight were females; more males than females wished to stay the same or be larger.

Disease severity played an important role in body size satisfaction. Individuals with moderate-severe lung problems had a larger discrepancy between ‘perceived’ and ‘ideal’ body size than those with moderate-mild lung problems. This provides further support for importance of perceptions between health and body size, indicating an adaptive wish to increase body size when lung function is low. It may also suggest that progression of CF with age, given the relationship between lung function and age, is apparent, and may mediate body image in CF. It would be interesting to explore the ‘meaning’ of body size to adult patients.

Attitudinal Aspects of Body Image

Roughly three quarters of individuals were dissatisfied with one or more body parts. This mirrors pervasive levels of body dissatisfaction in the general population (Thompson, 1990). Despite no difference in ‘body size’ satisfaction between males and females, females appeared more dissatisfied with specific parts of the body than males with CF. This is contrary to previous research, which found no difference between males and females with CF (Abbott et al., 2000). However, it does complement findings in the general population which suggest more women than men are dissatisfied with their body (McCabe & Ricciardelli, 2004). Again, this may relate to sociocultural ideals, that females be slim and attractive.

Older individuals were also more dissatisfied with their body physique and overall satisfaction, than younger people with CF. It is possible the developmental, health and sociocultural issues previously discussed account for these findings. BMI did not influence satisfaction with body or facial parts, or overall satisfaction with self. The fact that better lung function was associated with greater satisfaction with height, weight and physical appearance but not with satisfaction with body or face parts is not unsurprising. If individuals are concerned about the link between body size and survival, then satisfaction with specific body parts is unlikely to have much influence on this relationship.
Impact of CF on Body Image

The majority of individuals (61.8%) felt CF impacted upon their weight, but less so upon their height. Individuals were divided on whether CF affected physical appearance. This is contrary to a previous study which found that adolescents did not feel CF had a large impact upon them (Dickson, 2003). However, the difference may reflect developmental issues of an older sample. Recent improvements in knowledge and treatments mean there is less risk of failure to thrive and poor body weight and height. Older individuals, from earlier patient cohorts, would have been more susceptible to such risks.

Thirty-two individuals reported dissatisfaction with body parts which were likely to be influenced by the presence of CF, such as hands, small breasts, and, despite their small stature, bloated stomachs. Eight individuals reported non CF-related body part dissatisfaction, such as bad skin and dissatisfaction with nose. More women than men reported dissatisfaction with CF-related body parts which could suggest that for women the impact of CF has more of an affect on their body image. However, women, in the general population, are generally found to be more dissatisfied than men (McCabe & Ricciardelli, 2004). Thus, this finding could reflect gender differences interacting with presence and impact of CF on body image. Such issues are likely to be important contributors to body image models proposed by Slade (1994) and Price (1990b). It also suggests that CF itself is an important contributing factor to body image development and manifestation, as Price’s (1990b) model would advance. This contrasts with previous research with individuals with diabetes, where researchers proposed that body image problems were not a result of diabetes, per se, but due to associated obesity (Carroll et al., 1999). It would be interesting to compare these results to a female control sample to investigate whether differences truly reflect an impact of CF.

In support of the impact of CF on body dissatisfaction roughly half the participants (52.7%) felt they looked different to their peers, for reasons including being shorter, looking younger, thinner and unwell. Almost a third (32.7%) reported that they avoided doing certain activities because of their appearance, such as swimming and wearing certain clothes. Seventeen participants (30.9%) reported that they did do
certain activities because of the way they looked, such as eating more and going to the gym.

For a minority of the sample, body image was felt to impact on their platonic and intimate relationships. The responses were characterised by reports of low self-confidence and concern about the perception of others regarding the way they looked. Thus body image issues may have wide-ranging implications for how people feel. This would be potentially relevant to Slade's (1994) model, particularly in relation to cognitive and affective variables.

The impact of treatments or consequences of treatments revealed a large variety of responses, indicating some people were not concerned at all, while others were greatly troubled. Unfortunately, such varied views could not be explored due to low sample size and power, but are likely to impact differently on individuals’ body image. It is possible this will have an important impact on adherence to specific treatments. It would be interesting to explore how treatment decisions are made and what factors impact when individuals and team members consider new treatment options, particularly those which impact on body boundaries. This could be undertaken using qualitative methodology.

**Shape and Weight Based Self-Esteem**

Greater importance of shape and weight to overall feelings of self-esteem was found to be associated with poorer lung function. This may be due to individuals’ understanding of the relationship between nutritional status and optimum health. As expected, and in line with Geller *et al.* (1997), no correlation was found with BMI for either age group. This highlights that it is the extent to which feelings of self-worth are based upon shape and weight, and not *actual* shape and weight, which is important.

As hypothesised, individuals who based more of their self-esteem on shape and weight were found to have lower satisfaction with body image, supporting previous findings (Geller *et al.*, 2000; Tchanturia *et al.*, 2002). Individuals who desired a larger
body size based more of their self-worth on shape and weight compared to those who were satisfied with their shape. This suggests individuals understand the importance of BMI and body size to health; for individuals who wish to gain weight, the way they look becomes an important part of their self-esteem, possibly reflecting this key issue to their survival and sense of self.

**Psychological Adjustment**

Individuals reported higher levels of anxiety than depression. There were no gender differences in anxiety, depression or negative affect, supporting previous findings (Dickson 2003; Limbos et al., 2000). This is contrary to the general population where levels of anxiety and depression are higher among females (Piccinelli & Wilkinson, 2000; Pigott, 1999).

Increasing age correlated with psychological distress, supporting some previous findings (Pearson et al., 1991; Pfeffer et al., 2003); others have found conflicting results (Anderson et al., 2001). As previously discussed, the reality of being older may equate to being a ‘survivor’ for some individuals, who may have seen friends and acquaintances die. For these individuals, where they have surpassed expectation for their survival and seen others die, anxiety may be high. For example, they may feel they are living on ‘borrowed time’, knowing death is inevitable but not knowing when, particularly as lung function starts to deteriorate. However, as Pfeffer et al. (2003, pp.63) highlight when considering age “…it is difficult to distinguish between the effect of ageing itself and the effects of the changing prognosis, treatments and attitudes of different patient cohorts, as outlook has improved”.

The finding that age and lung function are significantly correlated and both are related to depression could perhaps relate to another factor that captures disease progression with age. It could be suggested that older individuals are more aware of the impact of CF, in comparison to younger individuals, whose parents may play more of a protective role. Additionally, it is likely older individuals have been ‘in the system’ longer with likely increasing clinic and hospital visits.
Of the sample, 15 individuals (36.6%) reported levels of anxiety which were at or above clinically significant levels suggested by Zigmond and Snaith (1983) and Bjelland et al. (2002), compared to five individuals (12.2%) with clinically significant levels of depression. Such a finding lends support to the content specificity hypothesis asserted by Harris and Brown (1989), which suggests that threatening events, such as a life-limiting chronic illness, would be associated with anxiety, rather than depression, which is associated with loss events.

This level of anxiety is higher than has been found in recent studies of psychological adjustment in adults (Anderson et al., 2001) and adolescents (Dickson, 2003) with CF. However, care must be taken as a direct comparison is not possible due to utilisation of different measures. Older studies, however, have found elevated levels of anxiety in children, with 35% reaching a diagnosis of anxiety (Thompson et al., 1998). Recently, the general population were found to endorse a large number of anxiety items on the HADS; 33% met the criteria for caseness, a similar figure to the current study (Crawford et al., 2001). When the suggested higher cut-off score was utilised, 12.7% (seven individuals) reached levels of caseness, which is not significantly different to the 12.6% anxiety level in the normative study (Crawford et al., 2001). This is consistent with figures from large epidemiological studies in the general population (Meltzer et al., 1995). Therefore, although anxiety appears higher than recent studies of individuals with CF, when compared to a large normative non-clinical sample, levels of anxiety are not higher.

Levels of depression (12.2%) were similar to a normative non-clinical sample (11.4%) when a score of eight and above was applied (Crawford et al., 2001). When a cut-off score of 11 was applied for adults only one individual was found to have a clinically significant level of depression, which was no different from the general population (Crawford et al., 2001). No adolescents reported clinically significant levels of depression, suggesting individuals with CF do not show elevated symptoms of depression. Levels of depression, consistent with the general population, concur with previous studies with adolescents (Dickson, 2003) and adults with CF (Anderson et al., 2001). Depression was found to be associated with poorer lung functioning. This supports contentions by researchers that with decline in health comes mood
deterioration (Pfeffer et al., 2003). This is consistent with a content specificity hypothesis, that is, a significantly severe threat event, or loss event (i.e. significant loss of lung function, indicating approaching death), relates to depressive symptomatology (Finlay-Jones & Brown, 1981).

Self-esteem was found to be lower in adolescent females than adolescent males with CF. The gender difference and level of self-esteem is consistent with some previous findings for adolescents with CF (Sawyer et al., 1995). Others did not find gender differences for adolescents in self-esteem (Dickson, 2003; Shearer & Bryon, 2004). In adults there were no gender differences in self-esteem. This is contrary to findings of Abbott et al., (2000), who reported females (both controls and individuals with CF) had lower self-esteem than males (with and without CF). Therefore, the current finding endorses some previous research suggesting a gender difference with adolescents in the CF population, but not with adults. However, the sample size for adolescents was small and the finding will need to be verified.

Body Image and Psychological Adjustment

Individuals with greater body dissatisfaction were found to experience higher levels of psychological distress (anxiety, depression, negative affect) and low self-esteem. This mirrors research in the general population (Kostanski & Gullone, 1998) and previous research in CF (Abbott et al., 2000; Dickson, 2003). It also supports the proposition that psychological distress, as opposed to only depression per se, is related to body image dissatisfaction (Kostanski & Gullone, 1998).

‘Perceived’ and ‘ideal’ body size were related to depression and anxiety, respectively. Lower depression was associated with greater ‘perceived’ body size suggesting that people who feel they have an adequate body size are less depressed than those who feel too small. As previously indicated for individuals with CF the relationship between nutritional health status and survival is crucial and is likely to have an emotional impact. Such attitudinal and cognitive processes are likely to be important influences in Slade’s (1994) model of body image. That individuals are increasingly more anxious the greater their ‘ideal’ body size would complement this proposal,
suggesting it is important for individuals to reach a satisfactory healthy body size. Anxiety develops when they perceive that they have not attained their ideal.

Body size dissatisfaction was significantly related to all measures of psychological distress and self-esteem, thus supporting the hypothesis that the greater the ‘perceived:ideal’ discrepancy the greater the level of distress and lower the self-esteem (Altabe & Thompson, 1992). The hypothesis that ‘perceived:ideal’ discrepancy is related to depressive symptomatology rather than anxiety was partially supported, since all measures of psychological distress were related to body size dissatisfaction but the relationship with depression was the strongest. This was the same for attitudinal body dissatisfaction variables. The finding supports others (e.g. Szymanski & Cash, 1995) who suggested dissatisfaction and distress, as opposed to depression, as originally suggested by Higgins (1987), is the outcome of ‘perceived:ideal’ discrepancies. However, the stronger association for depression, over anxiety, indicates depression remains a key component of such distress.

The importance of shape and weight to self-esteem was not correlated with anxiety, depression or negative affect. However, previous studies have found a complicated relationship between SAWBS angle of the shape and weight piece, and psychological distress (Geller et al., 1998). Depression and SAWBS angle were not found to correlate in a non-clinical sample compared to an eating disorders sample and the authors had to perform a median split on depression scores to understand the relationship more fully (Geller et al., 1998). Median splits on anxiety and depression were not related to SAWBS angle in the current sample. However, as the current study investigated a sample of individuals with a chronic illness, where levels of depression were not significantly higher than the general population, it is unlikely that the relationship between SAWBS scores and depression would be found. It is possible that with a larger sample size other studies may find a relationship with SAWBS angle when levels of depression are high.

Although not significant, there was a trend for greater importance of shape and weight to self-worth to be associated with lower levels of global self-esteem, supporting previous findings (Geller et al., 1997; Geller et al., 1998; Geller et al., 2000).
Overall, although basing more of one’s self-esteem on shape and weight was not related to psychological adjustment, it was related to body dissatisfaction and was particularly important to those who wished to gain weight. Individuals who were dissatisfied with their body size and appearance did experience higher levels of psychological adjustment difficulties.

**Methodological limitations**

The current study was exploratory and a significant limitation was the lack of a control group. The findings were correlational in nature and therefore prevent inferences on causal relationships being made. Thus the study’s results cannot be generalised. Sample size, like many other studies with individuals with CF, was small, particularly for the adolescent group. Repetition of the study, longitudinally across multi-centre sites with a control group, would be beneficial. However, a strength of the study was being able to investigate body image and psychological functioning in older adults with CF, up to the age of 58 years.

All questionnaires were self-report and completed by a self-selected sample. Again, generalisations must be made with extreme caution. Ethical restrictions prevented demographic data collection from individuals who declined to participate.

There have been a number of criticisms of the using paper and pencil silhouette measures for body size dissatisfaction, including inflated test re-test reliability figures and the ‘coarse’ nature of the measure, in which participants are asked to select a single figure from a continuous variable, leading to loss of information (Gardner et al., 1998; Doll et al., 2004). However, due to time and budget restrictions and lack of a coherent solution to these limitations, it was deemed appropriate to use Thompson and Gray’s (1995) CDRS, with the adjustments recommended by Gardener et al. (1998). Regrettably, alternative methods such as adjustable mirrors, light beams or TV-video procedures were not feasible.
It would have been helpful to have further demographic information on perceived illness severity. Given the importance of associations between menarche and body image, and as puberty in CF is frequently delayed, such information for adolescents would have been useful. Age of diagnosis may also be relevant, as a small number of older adults, with milder CF do not receive a diagnosis until adulthood. Body image may differ depending on whether individuals have had to encompass CF into their sense of self from childhood, or have had to do this later. Additionally, teasing history, which is related to body image, would be informative. Social support is likely to be important, especially for psychological functioning.

Finally, care needs to taken when interpreting predicted BMI differences between adolescents and adults. Individuals with CF may not proceed along general population growth curves, due to increasing disease severity (Morison et al., 1997). However, this method was deemed an improvement on classifying adolescents on the basis of adult categories which could lead to spurious results.

**Clinical Implications**

The majority of individuals who did report dissatisfaction with their body wished to have a larger body size. For medical professionals working within CF services this is likely to be an encouraging finding, illustrating success in their attempts to provide education on the importance of maintaining a satisfactory body weight. It would suggest these individuals would be motivated in adhering to dietary recommendations. Size perception has been linked to adherence to dietary recommendations and nutritional behaviour (Walters, 2001), although more studies are needed to corroborate this finding. The important issue for medical professionals will be how they can capitalise on these individual’s perceptions and beliefs and transform such beliefs into positive health behaviours. Perhaps, research from other fields of health psychology may yield helpful lines of future enquiry.

A large number of individuals, particularly females, identified dissatisfaction with parts of the body which could be altered due to impact of CF. Such a high level of dissatisfaction with CF-related body parts may be one reason why individuals do not
adhere to nutritional treatment regimes. This adds credence to the multidimensional and complex nature of body image, highlighting the distinction between perceptual (body size satisfaction) and attitudinal (satisfaction with body parts) dimensions of body image. Therefore, despite wanting to be larger, individuals for example, who have bloated abdomens, may feel ambiguous about increasing weight and size. This requires further exploration.

However, with dissatisfaction comes experience of psychological distress. This is likely to require both a dietician and clinical psychologist to work collaboratively with individuals in order to maximise nutritional status whilst avoiding negative feelings associated with body dissatisfaction. For individuals whose BMI fell in the normal range, and wished to be larger, perhaps corrective psychoeducation around principles of BMI and BMI categories may be helpful. This may allow these individuals to allay fears of not being large enough and the negative health connotations associated with low BMI. Where individuals place a significant amount of self-esteem on body shape and weight, it could be useful to encourage them to broaden their self-worth to include other elements, such as interpersonal relationships, school, work or hobbies. This may have the advantage of increasing global self-esteem and reducing body dissatisfaction.

The study did identify a minority of individuals (15%) of normal weight who wished to have a smaller body size or who were underweight and did not wish to increase weight. All but one of these people were adult females. It will therefore be important to identify such individuals, given the well-established relationship between negative body image and disordered eating (Stice & Shaw, 2002). A simple screening device to identify such individuals would be helpful. Currently such a device does not exist, although the SAWBS can identify individuals with disordered eating patterns and predict individuals who have eating disorders (Geller et al., 1997). However, this would need further validation within a CF population.

Clinical psychologists may be able to utilise clinic visits to provide psychological management around body image issues and intervention with individuals who report a wish to lose weight or who are not adhering to dietary advice. Perhaps body image should be a subject that is routinely enquired about and incorporated into standardised
annual review procedures. Body image interventions, used with individuals with eating disorders, and in the general population, have shown positive outcomes (e.g. Grant & Cash, 1995). However, such therapies have not been validated for individuals with CF and this would need to be pursued. One successful intervention involved a focus on self-esteem which had positive implications for body image satisfaction and eating attitudes (Newns et al., 2003). Improving self-esteem for at-risk individuals may have a number of wider positive consequences.

Psychologically, it does not appear that individuals with CF have elevated levels of anxiety or depression in comparison to the general population. Individuals tend to experience more anxiety than depression. However, this is likely to represent higher prevalence of anxiety over depression, and the significant threat of early death. For the majority of individuals it is perhaps a normative reaction to their current circumstances. Thus, while medical professionals must not lose sight of the experience of individuals with CF, care must be taken not label individuals unnecessarily with clinical symptoms of anxiety or depression.

**Future Research**

The findings from this study point to a number of areas requiring further research. For example, it will be important to investigate how to best manage nutritional treatment demands for individuals who wish to have a smaller body size, despite being either underweight or normal weight. A qualitative piece of research would initially be helpful to explore individual attitudes and cognitions, which could provide systematic lines of enquiry for further quantitative study. How to capitalise on the views of the majority, wishing to be larger, in terms of increased adherence to medical treatment regimes, is also a worthy area for further investigation. Additionally, given the low rates of adherence to dietary management, further examination, perhaps using models of health psychology, to explore why this might be, will be vital, particularly if people with CF are aware of the health consequences (like consonant smokers).

Given the finding that the majority of individuals were dissatisfied with a number of body parts that could be altered by the presence of CF, it will be important that the
relative influence of CF and non-CF factors which may impact on body image are more comprehensively investigated. Furthermore, what causes some treatments to trouble some individuals and not others, and their subsequent impact on body image as highlighted by Price’s (1990b) model of body image is a valid question for further research. This may aid detection of factors influencing adherence. The finding that a minority of individuals felt the way they looked impacted negatively upon their relationships is of concern and needs further exploration.

It would be useful for theory-based research such as social comparison and self-discrepancy theory to be tested against one another in order to clarify mechanisms which may play a role in body image problems. Wider sociocultural influences on body image and eating attitudes require investigation with people with CF in order to understand how body image develops, and is manifested, and how such influences impact different groups of patients, such as older, later diagnosed and more severely ill individuals. This would enable therapeutic interventions to be better informed and targeted.

The proposition for the concept of ‘survival’, particularly for patients from older cohorts, together with self-concept of older individuals needs to be examined. Qualitative methodology would be useful to explore whether some of the suggested explanations regarding the inferred relationship regarding body image, health and ‘survival’, is an important construct for people with CF. Finally, purely investigating age differences in future studies should be done with care, given a possible mediating impact of ‘disease progression’, and requires further exploration.

Conclusion

Individuals with CF do report attitudinal and perceptual body dissatisfaction. However, contrary to the general population, the majority desire a larger body size. In spite of this, there are a minority, with normal range BMI, who wish to be slimmer. This group of individuals will be of concern to professionals working with CF patients. Older individuals appear less satisfied and illness severity appears to be important, with lower lung functioning being associated with greater body image
dissatisfaction, higher importance of shape and weight to self-esteem and higher levels of depression. Views and beliefs of older cohorts of patients are complex and seem different to younger cohorts, deserving further exploration. Psychologically, individuals with CF did not have higher levels of anxiety or depression than the general population. However, greater body dissatisfaction was associated with greater distress and psychological intervention is implicated.

The challenge is to identify the minority of individuals who wish for a slimmer body size, despite being of a normal weight, or who do not wish to be larger despite being underweight. Additionally, it is important that the motivation to adhere to treatment regimes is developed in those who want a larger body size. The current structure of CF multidisciplinary team working is likely to be a good model for ensuring that individual differences regarding body image can be explored.
CHAPTER 6

REFERENCES


APPENDIX A

Ethical Approval Letters

Ethical Considerations
14th February 2005

Miss Helen Davies
Trainee Clinical Psychologist
University of Surrey
Department of Psychology
University of Surrey,
Guildford, Surrey
GU2 7XH

Dear Miss Davies,

Full title of study: An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

REC reference number: 04/Q0604/68

Thank you for your letter of 18 January 2005, responding to the Committee’s request for further information on the above research.

The further information was considered at the meeting of the Sub-Committee of the REC held on 14 February 2005. A list of the members who were present at the meeting is attached.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

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<tr>
<td>Application</td>
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<td>25/10/2004</td>
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The study should not commence at any NHS site until the local Principal Investigator has obtained final management approval from the R&D Department for the relevant NHS care organisation.

**Membership of the Committee**

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

**Notification of other bodies**

The Committee Administrator will notify the research that the study has a favourable ethical opinion.
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

04/Q065/468 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project,

Yours sincerely,

Chair

E-mail:
22 March 2005

Ms Helen Davies
Department of Psychology
School of Human Sciences

Dear Ms Davies,

An exploratory study of body image, body dissatisfaction and psychological adjustment in adults with Cystic Fibrosis (EC/2005/28/Psych) - FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: 22 March 2005

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:

- Document Type: Application
  Dated: 28/02/05
  Received: 16/03/05

- Document Type: Approval Letter from the
  Dated: 14/02/05
  Received: 16/03/05

- Document Type: Research Proposal
  Received: 16/03/05

- Document Type: Body Satisfaction Scale
  Received: 16/03/05

- Document Type: Role of Cystic Fibrosis in Body Satisfaction Questionnaires
  Received: 16/03/05

- Document Type: Contour Drawing Rating Scale
  Received: 16/03/05

- Document Type: Rosenberg Self-Esteem Scale
  Received: 16/03/05

- Document Type: SAWBS Inventory (Adult & Adolescent)
  Received: 16/03/05

LREC 267
This opinion is given on the understanding that you will comply with the University’s Ethical Guidelines for Teaching and Research, and with the condition set out below.

- That the Protocol Cover Sheet, signed by all investigators is forwarded to the University Ethics Committee to be placed on the file.
- The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected, with reasons.
- I would be grateful if you would confirm, in writing, your acceptance of the conditions above, enclosing the requested document as soon as available.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely,

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc:
Dear Miss Davies,

RE: An exploratory study of body image, body dissatisfaction and psychological adjustment in individuals with cystic fibrosis

Thank you for sending confirmation of your approval from the ethics committee. I am now happy to inform you that the Trust will indemnify against any negligence that might occur during the course of this project. Should any untoward events occur it is essential that you contact the R&D office immediately. If patients or staff are involved in an incident, you should also contact the Clinical Risk Manager on

Please note that all NHS and social care research is now subject to the DoH Framework for Research Governance. If you are unfamiliar with the standards contained in this document, or the policies that reinforce them, you can obtain details from the Joint R&D office or from the DoH Internet site. The address


As part of research governance, all investigators accessing individually identifiable personal information are required to comply with current information governance requirements. The Health Records Department will not release patient notes for research purposes unless

- a) If you are an internal member of staff (i.e. have a full or honorary contract) you produce this letter at the time you request batches of notes,

- b) If you are a researcher with no form of contract with the Trust you must produce a PIAC number, in line with Section 60 of the Health and Social Care Act. For further information on this section of the legislation you should contact the NHS Information Authority or your local Caldicott lead.

Please inform us if your project is amended and you need to re-submit it to the LREC / MREC or if your project terminates. This is necessary to ensure that your indemnity cover is valid and also helps the office to maintain up to date records. For studies where the Trust is acting as sponsor you must send a copy of any monitoring/audit reports to the Research Governance and GCP Manager

I hope the project goes well.

Yours sincerely,
ETHICAL CONSIDERATIONS

A number of ethical considerations were acknowledged by the researcher. These were highlighted on the information sheets provided to all participants.

1. **Possible distress generated by participation**

   While the questionnaires were not anticipated to cause upset in themselves, the researcher felt that they could identify existing psychological problems that could have been distressing. Participants were advised prior to completing the questionnaires that if they became distressed following completion of the questionnaires they could discuss these feelings with the researcher or with the psychologists attached to the CF teams. If participants indicated that they wished to discuss issues raised whilst undertaking the study, the researcher agreed to meet with them in confidence at the time, or at a pre-arranged appointment.

2. **Disclosure of high levels of distress on the questionnaires**

   Guidelines for the process to adopt if this became an issue were formed. Had any individual indicated on the questionnaires worrying information, the researcher planned to discuss it with the participant in person. Together the researcher and participant would explore options open to them, such as discussing the issues further with the team psychologists, or seeking a referral to mental health services through their GP.

3. **Possible child protection issues, (participants aged 12-16 years)**

   During completion of questionnaires, or subsequent discussions surrounding distress, child protection issues may have been raised or been suspected. The researcher and her supervisors agreed to follow the NHS Trust procedures if this situation arose.
APPENDIX B

Adult Information Sheet
PATIENT INFORMATION SHEET (November 2004, Version 2.)

- Study title

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

- Invitation paragraph

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

- What is the purpose of the study?

People with cystic fibrosis (CF) have an extensive treatment regime in order to try and counteract the effects of the disease. One part of this regime is to take enzyme supplements and eat a high calorie diet. We know that all individuals think about their body and how it looks. We also know that how we think about our body has an important impact on our self-esteem and feelings of wellbeing. As CF impacts upon the way the body grows and develops and due to the pressures of the treatment regime, we are interested in finding out whether this has any impact on the psychological experience of people with CF.

We are interested in finding out how people with CF view their body and how they feel in themselves. At the moment there is very little research in this area. We hope that if we have more information and a greater understanding about the psychological impact of these factors we can help to inform services that people with CF use.

- Why have I been chosen?

You have been chosen to participate because you have been diagnosed with CF. In total we hope to get 60 adolescents and adults to participate.

- Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.
Research Dossier: Major Research Project

• What will happen to me if I take part and what do I have to do?

You will be asked to complete a questionnaire pack on the day of your clinic appointment or home visit. If you are on the hospital ward you can complete the questionnaires whenever it is convenient before your discharge. You will also complete a task where you will be asked to look at some line drawings of human bodies. This task only takes about five minutes. The researcher will make an appointment with you. This will be either on the day of your clinic appointment, home visit or whilst you are in hospital. Altogether the questionnaires and body drawings task should take no longer than 35 minutes. You will only have to complete the questionnaires and body drawings task once.

• What are the possible disadvantages and risks of taking part?

There are no known risks to taking part in this study. However, because some of the questionnaires ask about anxiety, depression and self-esteem, it might be that thinking about these things is distressing for you. If you become upset by answering the questionnaires, you will be able to talk about these issues with the researcher or another clinical psychologist in confidence.

If when we analyse your answers on the questionnaires we are concerned that you are at risk of hurting yourself or are very low or depressed we might contact you (in the first instance) to raise this concern. Together with the researcher or another psychologist you can then discuss these issues in confidence.

• What are the possible benefits of taking part?

Although there are no direct clinical benefits to taking part in this study it is hoped that your contribution and the results of this study will help us to better understand this area. In the long-term it is hoped that this information can help us give patients a better service and understand their needs better.

• What if new information becomes available?

It is unlikely that new information will become available but if this happens the researcher will tell you about it, by contacting you and discussing with you whether you want to continue in the study. If you decide to withdraw there will be no impact on the standard of care you receive. If you decide to continue in the study you will be asked to sign an updated consent form.

• What if something goes wrong?

It is extremely unlikely that any of the questionnaires being used will cause you harm. However, if you wish to complain, for whatever reason, about the study, or the way you have been treated, the normal NHS complaints mechanisms may be available to you.

• Will my taking part in this study be kept confidential?

If you consent to take part in the research a small amount of information from your medical records will be recorded. The information that will be recorded will be your age, gender, ethnicity, height, weight and FEV1. No other information will be read or recorded.

All information which is collected will be kept strictly confidential. Any information about you which leaves the hospital will have your name and address removed so that you cannot be recognised from it. Information will be stored in a locked filing cabinet.
Your GP will be informed of your participation in this study. However, they will not be provided with any other information apart from a summary of the study, once completed. As the results will have all identifying information removed there will be no way in which individuals can be identified from the summary.

If the researcher is worried about you, for example, if you become distressed, or when she looks at your answers to the questionnaires, she will discuss it with you in the first instance. If she is concerned that you might harm yourself or other people, or is worried that someone else might be harming you she may have to talk to other professionals about these issues.

- **What will happen to the results of the research study?**

The results of the research will be written up by the researcher as part of her clinical psychology doctorate. A copy of the research will be kept in the University of Surrey library. In addition, it is hoped that the research will be submitted for publication in a peer-reviewed journal. All results will be anonymous and you will not be able to be identified in any of the reports.

If you wish to receive a summary of the results please indicate this on the “Do you want to know the results?” form that you will be asked to sign if you give your consent to participate.

- **Who is organising and funding the research?**

The University of Surrey is funding the research and is being undertaken by Helen Davies, Trainee Clinical Psychologist, as part of her doctoral qualification in Clinical Psychology.

- **Who has reviewed the study?**

The Research Ethics Committee and the University of Surrey Ethics Committee have reviewed the study. They have found it to be ethically sound.

- **Contacts for Further Information**

Miss Helen Davies, Dr. Helen Davies
Trainee Clinical Psychologist, Trainee Clinical Psychologist,
Department of Psychology, Department of Psychology,
University of Surrey, University of Surrey,
Guildford, Surrey, GU2 7XH. Guildford, Surrey, GU2 7XH.
@surrey.ac.uk

This information sheet is for you to keep. If you wish to participate in the study you will have a copy of the consent form to keep as well.

Thank you for your time!

Yours sincerely,

Helen Davies
Trainee Clinical Psychologist

Dr.
Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite you to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would meet you on the day of your clinic appointment so that you can complete the questionnaires at the hospital. The researcher will be there to provide help and answer any questions you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite you to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would come to meet you on the ward and give you the questionnaires. The researcher will be there to provide help and answer any questions that you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

**An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis**

We would like to invite you to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. The researcher will contact you by phone in a week to find out if you would like to participate. If you do, she will come to visit you at home (or somewhere else, if you prefer) to give you the questionnaires. The researcher will be there to provide help and answer any questions that you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
APPENDIX D

Adolescent (age 12 years) Information Sheet
Hello,

My name is Helen Davies and I am a researcher. I want to find out how people with cystic fibrosis (CF) feel about themselves and how their body looks. So I am asking people if they want to fill in some questionnaires to let me know how they feel. Take time to decide if you want to say YES or NO to this. This sheet tells you about this study. Please read the sheet, or ask someone else to read this sheet to you. If you want more information or don't understand you can talk to your parents, or to me.

Why am I doing this?
I want to know how people with CF think about their body. I also want to know if this affects how people feel inside. With this information we can make sure that your doctors know more about how CF makes people feel. We can then help people better.

Why have I been chosen?
I have asked you to take part because you have CF and come to see the doctors at the hospital.

What will I have to do if I take part?
You will be asked to fill out some short questionnaires when you come to hospital. Or, if I come to visit you at home, you can sit down at home and do them. If you are staying on the hospital ward you can fill out the questionnaires whenever you want before you go home.

You will also look at some drawings of humans with me for five minutes. Altogether it should take no longer than 35 minutes. I will be there if you need any help. You may decide you want to sit away from mum or dad if you want to keep your answers private.

Do I have to take part?
No, it is up to you and your parents to decide. If you don't want to take part that is absolutely fine. The doctors will look after you as best they can.
anyway. If you change your mind half way through, you can stop filling in the questionnaires. You don’t have to say why you have stopped.

**What about the results?**
I will look at your results and put them together with everybody else’s results. I will then write a report. This report will not have your name or details on it and no-one will be able to tell who you are from it. If you want to know what everybody’s results show I can send you a short summary in the post or by email.

**Are there any risks in taking part?**
No, however, because some of the questionnaires ask about the way we feel about ourselves, including if we feel nervous or sad, it might be that thinking about these things makes you feel upset. If this happens you will be able to talk to me about how you feel or another psychologist. We have had special training to support people with upsetting feelings or emotions.

If, when I look at your answers on the questionnaires, I am worried that you might hurt yourself I might ask you if you want to speak to someone. You can then talk about these feelings in private if you want.

If I am worried that you might hurt yourself, or I am worried that someone else might be harming you I may have to talk to other people about these issues.

**Who will know if I take part?**
I will take your name and details off the results. This way no-one will know who filled in the questionnaires apart from me. If you want to take part I will look in your hospital notes file to write down how old you are and a few other details.

**Who can I speak to if I have any questions?**
You can also speak to your parents who have also been given an information sheet. You can also speak to me or Dr. when you come to the hospital. Your parents have our phone numbers if you want to ring us.

**This information sheet is for you to keep.**

**Thank you for reading this!**

Yours sincerely,

Helen Davies
Trainee Clinical Psychologist

Dr
Consultant
APPENDIX E

Adolescent (age 13 – 16/18 years) Information Sheet
PATIENT INFORMATION SHEET (November 2004, Version 2)

Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Hello,

My name is Helen Davies and I am a researcher. I am inviting you to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to decide whether or not you wish to take part. If you want more information you can talk to your parents or to me, the researcher.

Why am I doing the study?
As you know people with cystic fibrosis (CF) have lots of treatments to help reduce the effects of the disease. People with CF need to eat more food than their friends and take medication to help them digest their food better. Because CF affects the way the body grows I am interested in finding out whether this has any effect on the way people with CF feel. I hope that by finding out more information we can make sure that the hospitals and services can be improved.

Why have I been chosen?
I have asked you to take part because you have CF. In total I hope to get 60 adolescents and adults to participate.

Do I have to take part?
It is up to you to decide whether or not you take part in this project. You do not have to take part if you don't want to. Your choice will not have an affect on the help you are receiving. If you change your mind halfway through, you can stop filling in the questionnaires. You don't have to give a reason for stopping.

What will I have to do if I take part?
You will be asked to fill out some short questionnaires when you come to your clinic appointment. Or, if I come to visit you at home, you can sit down at home and do them. If you are on the hospital ward you can fill out the questionnaires whenever you want before you go home.

You will also look at some line drawings of human figures with me for five minutes. Altogether the questionnaires and body drawings task should take no longer than 35 minutes. I will be there if you need any help. You may decide you want to sit away from mum or dad if you want to keep your answers private.
What are the possible benefits of taking part?
Although there are no specific benefits to taking part in this study it is hoped that the results of this study will help us to better understand this area. This will mean we can give better help to adults and children with CF.

What are risks of taking part?
There are no known risks to taking part in this study. However, because some of the questionnaires ask about the way we feel about ourselves, including if we feel nervous or sad, it might be that thinking about these things makes you feel upset. If this happens you will be able to talk to me about how you feel or another psychologist. We have had special training to support people with upsetting feelings or emotions.

If when I look at your answers on the questionnaires I am worried that you might hurt yourself I might ask you if you want to speak to someone. You can then talk about these feelings in private if you want.

Will my answers be kept private?
All information will have your name and address removed so that no-one can tell who you are. The questionnaires will have a number instead of your name. No-one will see your answers apart from me. If you want to take part in the project I will look in your medical file to write down your age, gender, ethnicity, height, weight and FEV₁. No other information will be read or recorded.

If I am worried that you might hurt yourself, or I am worried that someone else might be harming you I may have to talk to other professionals about these issues.

What will happen to the results of the project?
I will write a report. This report will not have your name or answers on it and no-one will be able to tell who you are from it. If you want a copy of a summary of the results I can email or send you one.

Who can I speak to if I have more questions?
You can speak to Helen Davies, Trainee Clinical Psychologist, or Dr. , Consultant, if you have any questions. Or you can speak to your parents who have also been given an information sheet. Your parents also have some further contact details of people to speak to if they have any complaints or worries.

This information sheet is for you to keep. If you wish to take part in the study you will have a copy of the consent form to keep as well.

Thank you for reading this!

Yours sincerely,

Helen Davies
Trainee Clinical Psychologist

Dr
Consultant
APPENDIX F

Parents Information Sheet
PATIENT INFORMATION SHEET (November 2004, Version 2.)

- Study title

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

- Invitation paragraph

Your child is being invited to take part in a research study. Before you decide it is important for you and your child to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with your son or daughter and others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you would like your son or daughter to take part.

Thank you for reading this.

- What is the purpose of the study?

People with cystic fibrosis (CF) have an extensive treatment regime in order to try and counteract the effects of the disease. One part of this regime is to take enzyme supplements and eat a high calorie diet. We know that all individuals think about their body and how it looks. We also know that how we think about our body has an important impact on our self-esteem and feelings of well-being. As CF impacts upon the way the body grows and develops and due to the pressures of the treatment regime, we are interested in finding out whether this has any impact on the psychological experience of people with CF.

We are interested in finding out how people with CF view their body and how they feel in themselves. At the moment there is very little research in this area. We hope that if we have more information and a greater understanding about the psychological impact of these factors we can help to inform services that people with CF use.

- Why has your child been chosen?

Your child has been chosen to participate because they have been diagnosed with CF. In total we hope to get 60 adolescents and adults to participate.

- Does your child have to take part?

It is up to you and your child to decide whether or not to take part. If your child does decide to take part you will be given this information sheet to keep and will both be asked to sign a consent form. If your child does decide to take part they are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care they receive.
• What will happen to your child if they take part and what will they have to do?

Your child will be asked to complete a questionnaire pack on the day of their clinic appointment or home visit. If they are on the hospital ward they can complete the questionnaires whenever it is convenient before their discharge. They will also complete a task where they will be asked to look at some line drawings of human figures. This task only takes about five minutes. The researcher will make an appointment with you and your child. This will be either on the day of the clinic appointment, home visit or whilst they are in hospital. Altogether the questionnaires and body drawings task should take no longer than 35 minutes. Your child will only have to complete the questionnaires and body drawings task once.

• What are the possible disadvantages and risks of taking part?

There are no known risks to taking part in this study. However, because some of the questionnaires ask about anxiety, depression and self-esteem, it might be that thinking about these things is distressing for your child. If they become upset by answering the questionnaires, they will be able to talk about these issues with the researcher or another clinical psychologist in confidence.

If, when we analyse your son or daughter’s answers on the questionnaires, we are concerned that they are at risk of hurting themselves or are very low or depressed we might contact you and your child to raise this concern. Together with the researcher, or another psychologist, your child can then discuss these issues in confidence. If you also feel worried about your son or daughter following their participation in the study you can speak to the researcher, or clinical psychologist, in confidence.

• What are the possible benefits of taking part?

Although there are no direct clinical benefits to taking part in this study it is hoped that your child’s contribution and the results of this study will help us to better understand this area. In the long-term it is hoped that this information can help us give patients, like your son or daughter, a better service and understand their needs better.

• What if new information becomes available?

It is unlikely that new information will become available but if this happens the researcher will tell you and your son or daughter about it. She will contact you and discuss with you and your child whether your child wants to continue in the study. If you and your son or daughter decide to withdraw there will be no impact on the standard of care they receive. If your child decides to continue in the study you will both be asked to sign an updated consent form.

• What if something goes wrong?

It is extremely unlikely that any of the questionnaires being used will cause your son or daughter any harm. However, if you wish to complain, for whatever reason, about the study, or the way you have been treated, the normal NHS complaints mechanisms may be available to you.

• Will your child’s taking part in this study be kept confidential?

If your son or daughter takes part in the research a small amount of information from their medical records will be recorded. The information that will be recorded will be their age, gender, ethnicity, height, weight and FEV₁. No other information will be read or recorded.

All information which is collected will be kept strictly confidential. Any information about your child which leaves the hospital will have their name and address removed so that they cannot be recognised from it. Information will be stored in a locked filing cabinet.
Your child's GP will be informed of their participation in this study. However, they will not be provided with any other information apart from a summary of the study, once completed. As the results will have all identifying information removed there will be no way in which individuals can be identified from the summary.

If the researcher is worried about your child, for example, if they become distressed, or when she looks at their answers to the questionnaires, she will discuss it with your son or daughter in the first instance. If she is concerned that your child might harm themselves or other people, or is worried that someone else might be harming your child she may have to talk to other professionals about these issues.

- **What will happen to the results of the research study?**

The results of the research will be written up by the researcher as part of her clinical psychology doctorate. A copy of the research will be kept in the University of Surrey library. In addition, it is hoped that the research will be submitted for publication in a peer-reviewed journal. All results will be anonymous and your child will not be able to be identified in any of the reports.

If you wish to receive a summary of the results please indicate this on the “Do you want to know the results?” form that you and your child will be asked to sign if they give their assent to participate.

- **Who is organising and funding the research?**

The University of Surrey is funding the research and is being undertaken by Helen Davies, Trainee Clinical Psychologist, as part of her doctoral qualification in Clinical Psychology.

- **Who has reviewed the study?**

The Research Ethics Committee and the University of Surrey Ethics Committee have reviewed the study. They have found it to be ethically sound.

- **Contacts for Further Information**

  Miss Helen Davies,  
  Trainee Clinical Psychologist,  
  Department of Psychology,  
  University of Surrey,  
  Guildford,  
  Surrey, GU2 7AX

  Dr.  
  Consultant,

This information sheet is for you to keep. If your child wishes to participate in the study you will have a copy of the consent form to keep as well.

Thank you for your time!

Yours sincerely,

Helen Davies  
Trainee Clinical Psychologist

Dr  
Consultant
APPENDIX G

Adolescent Invitation Letters
Dear

**An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis**

We would like to invite you to take part in our study. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and how they feel about themselves. It is hoped that the results will provide a better understanding of the issues and therefore better services to people with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would meet you on the day of your clinic appointment so that you can fill in the questionnaires at the hospital. The researcher will be there to provide help and answer any questions that you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 2 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite you to take part in our study. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and how they feel about themselves. It is hoped that the results will provide a better understanding of the issues and therefore better services to people with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would come to meet you on the ward and give you the questionnaires. The researcher will be there to provide help and answer any questions that you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 2 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite you to take part in our study. The study is about body image and the way we view ourselves. We are asking you to participate because you have cystic fibrosis. With your help we would like to find out more about people with CF, their body image and how they feel about themselves. It is hoped that the results will provide a better understanding of the issues and therefore better services to people with CF in the future.

The study involves you completing a questionnaire pack. You will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. The researcher will phone your mum or dad or the person looking after you in a week to find out if you would like to take part. If you do, she will come to visit you at home (or somewhere else, if you prefer) to give you the questionnaires. The researcher will be there to provide help and answer any questions that you may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 2 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
APPENDIX H

Parent Invitation Letters
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite your child to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking your child to participate because they have cystic fibrosis. With their help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves your son or daughter completing a questionnaire pack. They will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would meet your child on the day of their clinic appointment so that they can fill in the questionnaires whilst they are at the hospital. The researcher will be there to provide help and answer any questions that your son or daughter may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite your child to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking your child to participate because they have cystic fibrosis. With their help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves your son or daughter completing a questionnaire pack. They will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. It is hoped that the researcher would come to meet your child on the ward and give them the questionnaires. The researcher will be there to provide help and answer any questions that your son or daughter may have.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

We would like to invite your child to participate in our study. The study makes up part of the researcher's doctorate to gain her Clinical Psychology qualification. The study is about body image and the way we view ourselves. We are asking your child to participate because they have cystic fibrosis. With their help we would like to find out more about people with CF, their body image and psychological wellbeing. It is hoped that the results will provide a better understanding of the issues and therefore better services to individuals with CF in the future.

The study involves your son or daughter completing a questionnaire pack. They will also need to take part in a short task looking at drawings of human figures. Altogether it should take no longer than 35 minutes to complete everything. The researcher will contact you by phone in a week to find out if your child wants to participate. If they do, she will arrange a time convenient to you to visit you at home (or elsewhere, if you prefer) to give them the questionnaires.

We have enclosed an information sheet about the study for you to read and discuss with family and friends. Please also feel free to contact the researchers to discuss any questions that you may have. Contact details for the researchers can be found on page 3 of the information sheet.

Many thanks for your time.

Helen Davies
Trainee Clinical Psychologist
APPENDIX I

Adult Consent Form
CONSENT FORM  October 2004 V. 1

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Name of Researcher:

Miss Helen Davies,
Trainee Clinical Psychologist,
Department of Psychology,
University of Surrey,
Guildford, Surrey, GU2 7XH.
@surrey.ac.uk

Miss Helen Davies
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford, Surrey, GU2 7XH
@surrey.ac.uk

Please initial box

1. I confirm that I have read and understand the information sheet dated November 2004 (version 2) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

3. I understand that a small amount of information (my age, gender, ethnicity, height, weight and FEV1 only) will be gained from my medical notes by the responsible researcher from the University of Surrey. I give permission for this individual to have access to my records.

4. I agree to take part in the above study.

Name of Patient Date Signature

Researcher Date Signature

1 copy for patient; 1 copy for researcher;
APPENDIX J

Adolescent Consent Form
CONSENT FORM October 2004 V. 1

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Miss Helen Davies, Trainee Clinical Psychologist, Dr. [Name], Consultant, Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7AX
@surrey.ac.uk

1. I confirm that I have read and understand the information sheet dated November 2004 (version 2) for the above study and have had the opportunity to ask questions.

2. I understand that my child’s participation is voluntary and that they are free to withdraw at any time, without giving any reason, without their medical care or legal rights being affected.

3. I understand that a small amount of information (my child’s age, gender, ethnicity, height, weight and FEV1 only) will be gained from their medical notes by the responsible researcher from the University of Surrey. I give permission for this individual to have access to my records.

4. I give agreement for my child to take part in the above study.

Name of PatientDateSignature

Name of Parent / Legal GuardianDateSignature

ResearcherDateSignature

1 copy for patient; 1 copy for parent / legal guardian; 1 copy for researcher;
APPENDIX K

‘Do you want to know the Results?’ Adult Form
DO YOU WANT TO KNOW THE RESULTS?

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Miss Helen Davies, Trainee Clinical Psychologist, Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH. @surrey.ac.uk

Dr. Clinical Psychologist,

I wish to be provided with a summary of the results from the study

Please circle

YES / NO

If yes..... please indicate how you would like to be contacted with the summary of results:

☐ By post (please give postal address)

☐ By email (please give email address)

Name of Patient ___________________________ Date ___________ Signature ___________

Researcher ___________________________ Date ___________ Signature ___________
APPENDIX L

‘Do you want to know the Results’ Adolescent Form
DO YOU WANT TO KNOW THE RESULTS?

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Miss Helen Davies, Trainee Clinical Psychologist, Dr. , Consultant, Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7AX
@surrey.ac.uk

Please circle

I wish to be provided with a summary of the results from the study YES / NO

If yes..... please indicate how you would like to be contacted with the summary of results:

☐ By post (please give postal address) ☐ By email (please give email address)

........................................................................................................
........................................................................................................
........................................................................................................
........................................................................................................

Name of Patient Date Signature

Name of Parent / Legal Guardian Date Signature

Researcher Date Signature
APPENDIX M

GP Letter (Adults and Adolescent)
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Your patient, ......................................................., has today taken part in the above study. The study has been found to be ethically sound by the Research Ethics Committee and University of Surrey Ethics Committee.

You will be sent a copy of the summary of the results following completion of the study (approximately December 2005). Please do not hesitate to contact me if you would like to know more details about the study. You can do this by emailing me at: @surrey.ac.uk, or by writing to me at: PsychD Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH.

Yours faithfully,

Helen Davies
Trainee Clinical Psychologist
Dear

An Exploratory Study of Body Image, Body Dissatisfaction and Psychological Adjustment in Individuals with Cystic Fibrosis

Your patient, ..........................................., has today taken part in the above study. The study has been found to be ethically sound by the Research Ethics Committee and University of Surrey Ethics Committee.

You will be sent a copy of the summary of the results following completion of the study (approximately December 2005). Please do not hesitate to contact me if you would like to know more details about the study. You can do this by emailing me at: @surrey.ac.uk, or by writing to me at: PsychD Department of Psychology, University of Surrey, Guildford, Surrey, GU2 7XH.

Yours faithfully,

Helen Davies
Trainee Clinical Psychologist
APPENDIX N

Demographic Information Sheet (Adult and Parent Version for Adolescent)
**DEMOGRAPHIC INFORMATION SHEET - Adult**

For participant to complete:

<table>
<thead>
<tr>
<th>HOSPITAL: (Circle)</th>
<th>Hospital</th>
<th>Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>AGE:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEX: (circle)</td>
<td>Male</td>
<td>Female</td>
</tr>
</tbody>
</table>

**PLEASE CIRCLE THE ETHNIC GROUP WHICH BEST APPLIES TO YOU:**

<table>
<thead>
<tr>
<th>A) WHITE</th>
<th>B) MIXED</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. British</td>
<td>4. White and Black Caribbean</td>
</tr>
<tr>
<td>2. Irish</td>
<td>5. White and Black African</td>
</tr>
<tr>
<td>3. Other White background</td>
<td>6. White and Asian</td>
</tr>
<tr>
<td></td>
<td>7. Other Mixed background</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C) ASIAN or ASIAN BRITISH</th>
<th>D) BLACK or BLACK BRITISH</th>
</tr>
</thead>
<tbody>
<tr>
<td>8. Indian</td>
<td>12. Caribbean</td>
</tr>
<tr>
<td>11. Other Asian background</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>E) CHINESE or OTHER ETHNIC GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>15. Chinese</td>
</tr>
<tr>
<td>16. Any other ethnic group</td>
</tr>
</tbody>
</table>

For researcher to complete:

**PARTICIPANT NUMBER:**

**HEIGHT cm:**    **WEIGHT kg:**    **BMI:**

**FEV<sub>1</sub> % PREDICTED IN 1 SECOND:**

**GP:**   Name
          Address
          Postcode

**CDRS: Current:**
          Ideal:
DEMOGRAPHIC INFORMATION SHEET - Adolescent

For parent to complete:

HOSPITAL: (Circle) Hospital

AGE OF CHILD:

SEX OF CHILD: (circle) Male Female

PLEASE CIRCLE THE ETHNIC GROUP WHICH BEST APPLIES TO YOUR CHILD:

A) WHITE
1. British
2. Irish
3. Other White background

B) MIXED
4. White and Black Caribbean
5. White and Black African
6. White and Asian
7. Other Mixed background

C) ASIAN or ASIAN BRITISH
8. Indian
9. Pakistani
10. Bangladeshi
11. Other Asian background

D) BLACK or BLACK BRITISH
12. Caribbean
13. African
14. Other Black background

E) CHINESE or OTHER ETHNIC GROUP
15. Chinese
16. Any other ethnic group

For researcher to complete:

PARTICIPANT NUMBER:

HEIGHT cm: WEIGHT kg: BMI:

FEV₁ % PREDICTED IN 1 SECOND:

GP: Name
    Address
    Postcode

CDRS: Current:
    Ideal:
APPENDIX O

Body Satisfaction Scale
Body Satisfaction Scale (Hatfield & Sprecher, 1986)

Please rate your feelings of satisfaction for each of the following items related to yourself using the six point scale:
1. Extremely dissatisfied
2. Quite dissatisfied
3. Somewhat dissatisfied
4. Somewhat satisfied
5. Quite satisfied
6. Extremely satisfied

Please rate your feelings of satisfaction for each of the following items related to yourself using this six-point scale:

<table>
<thead>
<tr>
<th></th>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Height</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hair</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ears</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nose</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mouth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Teeth</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Voice</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chin</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Complexion (Skin)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall facial</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
attractiveness       |                        |                   |                       |                   |                |                     |
### Research Dossier: Major Research Project

<table>
<thead>
<tr>
<th>Area</th>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shoulders</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chest or breasts</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hands</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Size of abdomen</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(size of tummy)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Buttocks</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hips (upper thighs)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Legs and ankles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feet</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General muscle tone</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall body appearance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
APPENDIX P

Role of Cystic Fibrosis in Body Satisfaction Questionnaire - Adult
**Role of Cystic Fibrosis in Body Satisfaction Questionnaire - Adult**

Please read and answer the following questions which ask about how you see the way you look:

1. How satisfied are you with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

2. How much do you think your cystic fibrosis has affected how satisfied you are with your weight?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

3. How much do you think your cystic fibrosis has affected how satisfied you are with your height?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

4. How much do you think your cystic fibrosis has affected how satisfied you are with your physical appearance?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

**Here are some questions asking about how you think your partner (or if not partner, parents) see the way you look:**

5. How satisfied do you think your partner or parents are with your weight?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

6. How satisfied do you think your partner or parents are with your height?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

7. How satisfied do you think your partner or parents are with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)

**Here are some questions asking about how you think your friends see the way you look:**

8. How satisfied do you think your friends are with your weight?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

   (Please circle the response that best applies to you)
9. How satisfied do you think your friends are with your height?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Quite satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

(Please circle the response that best applies to you)

10. How satisfied do you think your friends are with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Quite satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

(Please circle the response that best applies to you)

Here are some questions asking about you think your doctor sees the way you look:

11. How satisfied do you think your doctor is with your weight?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Quite satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

(Please circle the response that best applies to you)

12. How satisfied do you think your doctor is with your height?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Quite satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

(Please circle the response that best applies to you)

13. How satisfied do you think your doctor is with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely satisfied</th>
<th>Quite satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Somewhat satisfied</th>
<th>Quite satisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

(Please circle the response that best applies to you)

These are some questions asking about your body and how the way you look affects you:

14. Do you have any of the following?

<table>
<thead>
<tr>
<th>Gastrostomy</th>
<th>Portacath</th>
<th>Sores</th>
<th>Scars</th>
<th>Other</th>
<th>N/A</th>
</tr>
</thead>
</table>

(Please circle the responses which apply to you; If N/A skip to Question 16.)

If other, please state any other physical difficulties that you have:

...........................................................................................................................................................................................................................................................................................................

...........................................................................................................................................................................................................................................................................................................

15. If you are bothered by any of these, please state how much:

(Please tick the appropriate box)

<table>
<thead>
<tr>
<th>Gastrostomy</th>
<th>Portacath</th>
<th>Sores</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all</td>
<td>Not at all</td>
<td>Not at all</td>
<td></td>
</tr>
<tr>
<td>Very little</td>
<td>Very little</td>
<td>Very little</td>
<td></td>
</tr>
<tr>
<td>A little</td>
<td>A little</td>
<td>A little</td>
<td></td>
</tr>
<tr>
<td>Quite a lot</td>
<td>Quite a lot</td>
<td>Quite a lot</td>
<td></td>
</tr>
<tr>
<td>Very much</td>
<td>Very much</td>
<td>Very much</td>
<td></td>
</tr>
</tbody>
</table>

316
Research Dossier: Major Research Project

Scars

Not at all  | Very little  | A little  | Quite a lot  | Very much

Other

Not at all  | Very little  | A little  | Quite a lot  | Very much

Please State:

Other

Not at all  | Very little  | A little  | Quite a lot  | Very much

Please State:

Other

Not at all  | Very little  | A little  | Quite a lot  | Very much

Please State:

16. Is there any part of your body that you are not happy with?
   YES / NO
   If yes, please list all the parts of your body you are unhappy with:

17. Do you feel that you look different to other adults who are the same age as you?
   YES / NO
   If yes, please state in what way you feel you look different:

18. Is there anything you avoid doing because of your physical appearance?
   YES / NO
   If yes, please list all the things you avoid doing:

19. Is there anything you do because of your physical appearance? (For example, some people avoid wearing certain clothes, or alter the amount they eat)
   YES / NO
   If yes, please list everything you do:

20. Do you think that the way you look affects your relationships with other people?
   YES / NO
   If yes, please list all the reasons:

21. Do you think that the way you look affects your relationships with intimate partners?
   YES / NO
   If yes, please list all the reasons:
APPENDIX Q

Role of Cystic Fibrosis in Body Satisfaction Questionnaire - Adolescent
**Role of Cystic Fibrosis in Body Satisfaction Questionnaire - Adolescent**

Please read and answer the following questions which ask about how you see the way you look:

1. How satisfied are you with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

2. How much do you think your cystic fibrosis has affected how satisfied you are with your weight?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

3. How much do you think your cystic fibrosis has affected how satisfied you are with your height?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

4. How much do you think your cystic fibrosis has affected how satisfied you are with your physical appearance?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

Here are some questions asking about how you think your parents see the way you look:

5. How satisfied do you think your mother is with your weight?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

6. How satisfied do you think your mother is with your height?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

7. How satisfied do you think your mother is with your physical appearance?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

8. How satisfied do you think your father is with your weight?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*

9. How satisfied do you think your father is with your height?

<table>
<thead>
<tr>
<th>Extremely dissatisfied</th>
<th>Quite satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat dissatisfied</th>
<th>Quite dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
</table>

*(Please circle the response that best applies to you)*
10. How satisfied do you think your father is with your physical appearance?

- Extremely dissatisfied
- Quite dissatisfied
- Somewhat dissatisfied
- Somewhat satisfied
- Quite satisfied
- Extremely satisfied

(Please circle the response that best applies to you)

Here are some questions asking about you think your doctor sees the way look:

11. How satisfied do you think your doctor is with your weight?

- Extremely dissatisfied
- Quite dissatisfied
- Somewhat dissatisfied
- Somewhat satisfied
- Quite satisfied
- Extremely satisfied

(Please circle the response that best applies to you)

12. How satisfied do you think your doctor is with your height?

- Extremely dissatisfied
- Quite dissatisfied
- Somewhat dissatisfied
- Somewhat satisfied
- Quite satisfied
- Extremely satisfied

(Please circle the response that best applies to you)

13. How satisfied do you think your doctor is with your physical appearance?

- Extremely dissatisfied
- Quite dissatisfied
- Somewhat dissatisfied
- Somewhat satisfied
- Quite satisfied
- Extremely satisfied

(Please circle the response that best applies to you)

These are some questions asking about your body and how the way you look affects you:

14. Do you have any of the following?

- Gastrostomy
- Portacath
- Sores
- Scars
- Other

(Please circle the responses which apply to you)

If other, please write down any other physical difficulties that you have:

- ........................................................................
- ........................................................................
- ........................................................................

15. If you are bothered by any of these, please state how much:

(Please tick the appropriate box)

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Very little</th>
<th>A little</th>
<th>Quite a lot</th>
<th>Very much</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gastrostomy</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Portacath</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sores</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Scars</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
16. Is there any part of your body that you are not happy with?

YES / NO
If yes, please list all the parts of your body you are unhappy with:

17. Do you feel that you look different to other young people who are the same age as you?

YES / NO
If yes, please state in what way you feel you look different:

18. Is there anything you avoid doing because of your physical appearance?

YES / NO
If yes, please list all the things you avoid doing:

19. Is there anything you do because of your physical appearance? (For example, some people avoid wearing certain clothes, or alter the amount they eat)

YES / NO
If yes, please list everything you do:

20. Do you think that the way you look affects your relationships with other people the same age as you?

YES / NO
If yes, please list all the reasons:
APPENDIX R

Shape and Weight Based Self-Esteem Scale (SAWBS) – Adult
SAWBS INVENTORY – Adult

OUR OPINION OF OURSELVES IS BASED ON HOW WE FEEL ABOUT OUR DIFFERENT PERSONAL ATTRIBUTES

STEP 1: Please read through the list below and PLACE AN “X” on the line next to each attribute that is important to how you have felt about yourself in the past four weeks.

STEP 2: Now, look over the attributes you have selected, and RANK ORDER them in terms of how much your opinion in the past four weeks has been based on each attribute. The numbers should not necessarily reflect how satisfied you have been with the attribute, but rather how important the attribute has been to how you feel about yourself.

STEP 3: Using the attributes you selected, DIVIDE THE CIRCLE below so that the size of each section is a reflection of how much your opinion of yourself in the past four weeks has been based on the attribute (larger pieces should indicate that a greater part of yourself has been based on that attribute, for example). Place the letters corresponding to the attributes inside the pieces of the circle.

- A: Your intimate or romantic relationships  
  e.g., as reflected in the level of closeness you feel in close relationships
- B: Your body shape and weight  
  e.g., your actual current shape and weight
- C: Your competence at school/work  
  e.g., as reflected by grades or work evaluation
- D: Your personality  
  e.g., warmth, level-headedness, openness, self-control
- E: Your friendships  
  e.g., as reflected by the number or quality of friendships
- F: Your face  
  e.g., how “good looking” you are
- G: Your personal development  
  e.g., your sense of morality, ethics or spirituality
- H: Your competence at activities other than school/work  
  e.g., your competence in music, sports, hobbies
- I: Other  
  Please describe: ...........................................................................

EXAMPLES:

YOUR CIRCLE:
APPENDIX S

Shape and Weight Based Self-Esteem Questionnaire (SAWBS) - Adolescent
SAWBS INVENTORY – Adolescent

WHAT MATTERS MOST TO HOW YOU FEEL ABOUT YOURSELF?

STEP 1: Which parts matter? Look at the list below. Pick out the parts about you that are most important to how you feel about yourself. Place an “X” on the line next to the parts that are important to you.

STEP 2: Of the parts you picked, which part matters most? Put a 1 in the box next to that part. Put a 2 in the box next to the second most important part, and continue doing this until you have ranked all the parts where you have put an “X”.

STEP 3: Using the parts you chose, divide the circle at the bottom into pieces, with each part corresponding to a piece of the circle. (The part that you rated as “1” should have the biggest piece). Place the letters corresponding to the parts inside the circle pieces.

☐ A: Getting along with grown-ups
   e.g., parents or your teachers

☐ B: Your body shape and weight
   e.g., what your body feels and looks like

☐ C: Your intelligence
   e.g., how clever you are at figuring things out and how good you are at school

☐ D: Your personality
   e.g., your nature, outgoing, shy, friendly etc.

☐ E: Getting along with your friends
   e.g., what kind of friend you are

☐ F: Your face
   e.g., what your face looks like and how “good looking” you are

☐ G: Your religion or spiritual beliefs
   e.g., your religious feelings or feelings in nature

☐ H: How good you are at a hobby, music or sport
   e.g., musical instrument, hobby or sport

☐ I: Other
   Please describe:

EXAMPLES: 

YOUR CIRCLE:
APPENDIX T

Rosenberg Self-Esteem Scale
ROSENBERG SELF-ESTEEM SCALE (RSES)

Below is a list of statements dealing with your general feelings about yourself.

If you **strongly agree** with the statement, circle **SA**.
If you **agree** with the statement, circle **A**.
If you **disagree** with the statement, circle **D**.
If you **strongly disagree** with the statement, circle **SD**.

<table>
<thead>
<tr>
<th></th>
<th>1. STRONGLY AGREE</th>
<th>2. AGREE</th>
<th>3. DISAGREE</th>
<th>4. STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>I feel that I’m a person of worth, at least on an equal plane with others.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>2.</td>
<td>I feel that I have a number of good qualities.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>3.</td>
<td>All in all, I am inclined to feel that I am a failure.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>4.</td>
<td>I am able to do things as well as most other people.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>5.</td>
<td>I feel I do not have much to be proud of.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>6.</td>
<td>I take a positive attitude toward myself.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>7.</td>
<td>On the whole, I am satisfied with myself.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>8.</td>
<td>I wish I could have more respect for myself.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>9.</td>
<td>I certainly feel useless at times.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
<tr>
<td>10.</td>
<td>At times I think I am no good at all.</td>
<td>SA</td>
<td>A</td>
<td>D</td>
</tr>
</tbody>
</table>
APPENDIX U

Hospital Anxiety and Depression Scale (HADS)
Hospital Anxiety and Depression Scale (HADS)

Name: 

Clinicians are aware that emotions play an important part in many illnesses. If you: clinician knows about these feelings he or she will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Ignore the numbers printed at the edge of the questionnaire.

Don't take too long over your replies, your immediate reaction to each item will probably be more accurate than a long, thought-out response.

A) I feel tense or 'wound up'
   - Most of the time
   - All of the time
   - Often
   - Sometimes
   - Rarely
   - Nearly all the time
   - Very often

B) I get a sort of frightened feeling as if something awful is about to happen
   - Very often
   - Occasionally
   - Rarely
   - Nearly all the time
   - Very often

C) I have lost interest in my appearance
   - Definitely
   - Somewhat
   - Rarely
   - Nearly all the time
   - Very often

D) I feel as if I am slowed down
   - Nearly all the time
   - Very often
   - Sometimes
   - Rarely
   - Very often

E) I can laugh and see the funny side of things
   - As much as I always could
   - Not quite as much now
   - Definitely not as much now
   - Hardly at all

F) Worrying thoughts go through my mind
   - A great deal of the time
   - Most of the time
   - Often
   - Sometimes
   - Very little
   - Nearly all the time
   - Very often

G) I feel cheerful
   - Never
   - Not much
   - Sometimes
   - Most of the time
   - Hardly at all
   - Nearly all the time
   - Very often

H) I can sit at ease and feel relaxed
   - Definitely
   - Usually
   - Sometimes
   - Not often
   - Hardly at all

Now check you have answered all the questions.

TOTAL

This form is photocopied. Any other records have been destroyed. NFER-Nelson Ltd, Ashford, Kent. TEL: 01233 628888. FAX: 01233 628893. E-MAIL: info@nfer.co.uk. www.nfer.co.uk. Printed in the UK. © NFER-Nelson 2007.
APPENDIX V

Contour Drawing Rating Scale (CDRS)
Contour Drawing Rating Scale (Thompson & Gray, 1995)
## RESEARCH LOG

<table>
<thead>
<tr>
<th>Research Skill /Experience</th>
<th>Description of How Research Skill/Experience Acquired</th>
<th>Date Research Skill Acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Formulating and testing hypotheses and research questions</td>
<td>Formulation and testing of hypotheses and research questions have been carried out during the three years for the Service Related Research Project (SRRP), Qualitative Research Project (QRP) and the Major Research Project (MRP).</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Carrying out a structured literature search using information technology and literature search tools</td>
<td>Literature searches have been carried out for all essays, case reports, clinical work, and research projects. Literature searches required use of computerised databases, including Medline, PsycInfo, Web of Knowledge and Internet search engines. The process required accurate and continuing amendment of search terms.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Critically reviewing relevant literature and evaluating research methods</td>
<td>All literature that was read was reviewed critically, for all academic, clinical and research work. This involved examining research methodologies and measures in relation to specific hypotheses and questions and assessing the usefulness of conclusions.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Formulating specific research questions</td>
<td>Formulating specific research questions was required for the SRRP, QRP and MRP. This required a process of examining research evidence and literature and creating questions, continually modifying these until a strong focused question could be arrived at.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Writing brief research proposals</td>
<td>Brief research proposals were written for the SRRP and MRP, which required summary of important concepts and an action plan indicating how the research would be carried out.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Writing detailed research proposals/protocols</td>
<td>Detailed research proposals and protocols were written for the SRRP and MRP, which aided the process of gaining ethical approval and effective collection of data.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Obtaining approval from a research ethics committee</td>
<td>For the MRP the NHS COREC procedures were followed in order that the research study achieved ethical approval. This involved writing a detailed ethics application, attending the meeting and following up the committee’s suggestions and requirements.</td>
<td>During year two and three</td>
</tr>
</tbody>
</table>

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333
<table>
<thead>
<tr>
<th>Research Skill /Experience</th>
<th>Description of How Research Skill/Experience Acquired</th>
<th>Date Research Skill Acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considering issues related to ethical practice in research, including issues of diversity, and structuring plans accordingly</td>
<td>Ethical issues in research were considered for the MRP and also for the SRRP and QRP. It was very important to explore how issues such as reading ability and cultural differences could be accommodated by the research in order that the research be as accessible and representative as possible. In particular, issues around confidentiality and consent were thought through and plans about how these would be achieved constructed. Plans were also devised, in collaboration with supervisors, for potential situations, such as if serious psychopathology were disclosed by participants during the course of the MRP.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Obtaining appropriate supervision for research</td>
<td>During the process of formulating research questions contacts with individuals known to specialise in the field of the research were made. Obtaining and negotiating research interests and the focus of research questions, as well as levels of involvement and supervision times was required in obtaining appropriate supervision.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Obtaining appropriate collaboration for research</td>
<td>Obtaining appropriate collaboration for the research project was vital from individuals working with and providing the care for potential participants in order that the project could progress. This involved a process of consultation and negotiation with specific services and professionals, building good working relationships.</td>
<td>During year two and three</td>
</tr>
<tr>
<td>Collecting data from research participants</td>
<td>This required a process of identifying participants and recruitment, which needed organisation and forward-planning. It also involved spending time with research participants, discussing with them the research, what their involvement would be and helping them with completion of research questionnaires.</td>
<td>During year three</td>
</tr>
<tr>
<td>Choosing appropriate design for research questions</td>
<td>An appropriate research design was chosen on the basis on what was required by the research question and also by the potential participants for all research projects during the three years.</td>
<td>During year one and three</td>
</tr>
<tr>
<td>Writing patient information and consent forms</td>
<td>Information sheets and consent forms were created for adolescents and adults. It was important to ensure that information sheets and consent forms were easily understandable and had the relevant information included.</td>
<td>During year two and three</td>
</tr>
<tr>
<td>Research Skill /Experience</td>
<td>Description of How Research Skill/Experience Acquired</td>
<td>Date Research Skill Acquired</td>
</tr>
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</tr>
<tr>
<td>Devising and administering questionnaires</td>
<td>The MRP required appropriate questionnaires to be reviewed, piloted and administered. Ensuring that one of the questionnaires for adults was appropriately designed required expert-sampling.</td>
<td>During year two and three</td>
</tr>
<tr>
<td>Negotiating access to study participants in applied NHS settings</td>
<td>In conjunction with supervisors individuals who provided care for potential participants were contacted and with these individuals the details of the research were discussed and plans for how to best access patients were facilitated.</td>
<td>During year two</td>
</tr>
<tr>
<td>Setting up a data file</td>
<td>Databases were set up for the SRRP and the MRP in SPSS. This required careful examination of variables that needed to be included and how best to code such data. It also required accurate data input.</td>
<td>During year one and three</td>
</tr>
<tr>
<td>Conducting statistical data analysis using SPSS</td>
<td>Statistical analysis was conducted in SPSS for the SRRP and MRP. This needed knowledge of how to utilise many different aspects of the computer programme to perform the required statistics.</td>
<td>During year one and three</td>
</tr>
<tr>
<td>Preparing quantitative data for analysis</td>
<td>Data screening, checking properties of the data, reviewing outliers and transformations of data were required so that data was ready for quantitative analysis. This was carried out for the SRRP and MRP.</td>
<td>During year one and three</td>
</tr>
<tr>
<td>Choosing appropriate quantitative data analysis</td>
<td>For the SRRP and MRP appropriate data analysis had to be chosen. This required examination of assumptions of statistical tests, the properties of the data and attention to the hypotheses and research questions that needed to be investigated.</td>
<td>During year one and three</td>
</tr>
<tr>
<td>Summarising results in figures and tables</td>
<td>Summarising results in figures and tables has been carried out throughout academic, clinical and research work. It required synthesis of important information in a clear, coherent and understandable way.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Conducting semi-structured interviews</td>
<td>Semi-structured interviews were organised and carried out with research participants during the QRP. This included creating the interview schedule based upon the research question. Research interviews also followed principles of the ‘counselling interview’.</td>
<td>During year two</td>
</tr>
<tr>
<td>Transcribing and analysing interview data using qualitative methods</td>
<td>Transcription and analysis of interviews using qualitative methods, including interpretative phenomenological analysis, was required for the QRP.</td>
<td>During year two</td>
</tr>
<tr>
<td>Research Skill /Experience</td>
<td>Description of How Research Skill/Experience Acquired</td>
<td>Date Research Skill Acquired</td>
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</tr>
<tr>
<td>Choosing appropriate qualitative analyses</td>
<td>On the basis of the research questions and aims of the QRP, qualitative analyses procedures were reviewed and chosen through examining relevant literature and consultation with supervisors.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Interpreting results from quantitative and qualitative data analysis</td>
<td>During the SRRP and MRP quantitative analysis had had to be interpreted. This required an ability to understand and interpret the output from statistical analysis and relate the findings in the context of relevant literature. For the QRP interpretation of transcriptions had to reflect the data collected, following formalised procedures for analysis.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Presenting research findings in a variety of contexts</td>
<td>The background to the current research, including a review of current findings, research hypotheses, questions, methodology and design were presented to the National Psychosocial Cystic Fibrosis Conference in May 2005 in London using a PowerPoint presentation.</td>
<td>During year three</td>
</tr>
<tr>
<td>Producing a written report on a research project</td>
<td>Reports required planning and a process of writing and reviewing drafts. Reports required synthesis of relevant literature, statistical analyses and interpretation with conclusions drawn and the clinical relevance elucidated.</td>
<td>During year one, two and three</td>
</tr>
<tr>
<td>Defending own research decisions and analyses</td>
<td>The viva will provide a chance for the defence of research decisions and analyses. In addition, the conference presentation called for an ability to defend the MRP to colleagues and experts in the field.</td>
<td>During year three</td>
</tr>
<tr>
<td>Submitting research reports for publication in peer-reviewed journals or edited book</td>
<td>The MRP will be prepared for submission for publication in an appropriate peer-reviewed journal, following any revisions required by the viva.</td>
<td>During year three</td>
</tr>
<tr>
<td>Applying research findings to clinical practice</td>
<td>Applying research findings to clinical practice is critical to enhancing the development of evidence-based practice. It required the interpretation of research findings within the context of previous literature whilst noting research limitations and considering practical aspects of application to real-world settings.</td>
<td>During year one, two and three</td>
</tr>
</tbody>
</table>