An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

by

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Volume One
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Academic Section

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, Children, Adolescents and Families, and Older Adults.
Adult Mental Health Essay

How can we use psychological theory to explain “worry” and how may we approach the treatment of dysfunctional worry? Discuss with reference to the evidence base of the theory (ies) you present.

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Year 1
Introduction
Worry is a cognitive process common in normal populations. A number of different psychological theories have been developed to explain “worry”. One of the earliest definitions of worry comes from Borkovec, Robinson, Pruzinsky, and Depree (1983) who described worry as a “chain of thoughts and images, negatively affect laden and relatively uncontrollable: it represents an attempt to engage in mental problem-solving on an issue whose outcome is uncertain but contains the possibility of one or more negative outcomes.” More recently Borkovec has developed a fear avoidance model of worry in which a key feature is that worry is a conceptual and primarily verbal activity used to respond to perceived threat, and to anticipate and avoid future catastrophe. Davey (1994a) proposes that worry is a continuum, with the pathological end associated with anxiety enhancement and the exacerbation of problems, and the constructive end characterised by anxiety reduction and amelioration of problems. These theories will be briefly described and along with a review of recent experimental work supporting them. Since worry is a cardinal diagnostic feature of Generalised Anxiety Disorder (GAD), much of the research underlying worry has been carried out on subjects meeting the criteria for GAD. Therefore a description of the nature of GAD will be presented, along with an outline of the development of psychological treatments for GAD so far. Finally, a cognitive model of GAD is outlined and its treatment implication discussed.

The Nature of Worry
The Predominance of Thought
The Penn State Programme which is based at The Stress and Anxiety Disorders Institute, at The Pennsylvania State University have undertaken a great deal of research investigating worry. This research has shown that worry involves predominantly “thought” activity rather than visual imagery. Borkovec and Inz (1990) compared clients with a diagnosis of GAD, with nonanxious controls. Both groups were asked to engage in self-relaxation and in worry for ten-minute periods. During the relaxation period subjects were instructed via an intercom to close their eyes and relax, focusing their breathing and increasingly allowing their minds to wander as they relaxed. They were then given a five-minute rest period, after which they were instructed to worry in their usual fashion about a topic of current concern to them. During these phases subjects were contacted after 3, 7 and 10 minutes and asked to report whether their mental content at the time of contact was a thought, image or both, or whether they were “unsure”, and to relate the affective value of the content on a scale of pleasantness/unpleasantness and a scale of relaxation/anxiousness. The results from the study found that during the period in which subjects were asked to worry both groups showed an
increase in thought predominance and a decrease in imagery. It was also found that subjects with GAD showed greater levels of anxiety during both the relaxation and worry periods, than the control group, and there was an increase in anxiety for both groups during the worry period. These results support the theory that worry involves primarily thought or verbal activity as opposed to imaginal activity.

**Attentional Activity**

It is believed that chronic worriers devote so much in attention to the activity of worrying that there is less attentional resource remaining for other information-processing tasks. If this is correct then less processing will occur of immediately available environmental information and as a result the worrier may not experience the present moment, or learn from experiences, as much as nonworriers are able to. Molina, Borkovec, Peasley and Pearson (1998) examined the streams-of-consciousness content of GAD, dysphoric and control participants during neutral and worry periods. They were able to access this information by using think-aloud procedures which were designed to capture fluctuations in people’s spontaneous streams of thought. Subjects were asked to verbally report whatever was going through their mind during a five-minute neutral period. They were then instructed to do the same during a five-minute period in which they were to worry about a topic that was currently worrisome for them. Each participant then completed a post-streaming questionnaire. The results showed that shifting from a neutral state to a worrisome state resulted in reduced reference to, and focus on both the present moment and immediate environment.

A considerable amount of research has been undertaken on the relationship between worry and other information processing tasks. Borkovec, Ray and Stober (1998) found that many GAD clients display a preattentive bias to immediately threatening information in contrast to depressed individuals. Subjects were exposed to threat words and nonthreat words for eight seconds. They found that GAD clients explicitly recalled more of the threat words than the nonthreat words compared to their matched controls. It appears that this biased recall may be the consequence of continuous mental rehearsal of worrisome thoughts for strengthening threat-related information in memory.
Physiological Activity

A lot can be learnt about the nature and function of worry through reviewing the psychophysiological research on anxiety disorders. This research has shown that GAD clients do not show the usual sympathetic activation in response to threat or challenge that is typical of other anxiety disorders. Instead their peripheral physiology i.e. heart rate and skin conductance reveals a restriction in range of variability. Hoehn-Saric and MacLeod (1988) cited in Borkovec et al. (1998) who have reviewed this research conclude from these results “that GAD is typified by some degree of sympathetic inhibition and a resulting autonomic rigidity”. According to Borkovec et al. (1998) individuals who worry have a restricted range of peripheral physiological variability which appears to be due to a vagal (parasympathetic) deficiency. Hoehn-Seric, MacLeod and Zimmerli (1989, cited in Borkovec et al. 1998) found that at baseline patients with GAD have greater muscle tension than control subjects, but did not find any differences between groups in autonomic activity. However, when subjects were under conditions of psychological stress e.g. were given demanding cognitive tasks, GAD clients had weaker skin conductance responses and less heart rate variation than control subjects. The authors have concluded that individuals who engage in excessive worry are less likely to respond to stressful situations with an increase in autonomic arousal. Lyonfields, Borkovec and Thayer (1995) also found similar results. They carried out psychophysiological assessments of GAD clients and matched, nonanxious controls, at rest and during an induced worry period. The results showed that excessive worry may result in dysfunction in both the sympathetic and the parasympathetic systems and that an induced state of worry can phasically create a reduction in vagal tone.

Functions of Worry

Borkovec (1994) has developed a fear avoidance model of worry. This model states that worry is primarily a verbal activity which is used to respond to perceived threat and to anticipate and either prepare for or avoid future catastrophe. According to Borkovec, worry is also used to inhibit emotional processing of stressful situations.

Cognitive Avoidance of Threat

This model states that worry is a cognitive avoidance strategy used when an individual perceives threat. According to Borkovec, if an individual detects threat cues that warn of some future catastrophe, the natural fight-or-flight response is activated. However, the stimuli that they fear are not immediately present, and exist only in their minds, and therefore cannot be avoided by a motoric response. This means that the usual fight-or-flight reactions serve no purpose and can only be suppressed. It is believed that worrisome thinking may provide this
suppression. The individual shifts attention from the threat to worrisome thinking. This results in a reduction in the generation of visual imagery which in turn reduces activation of the sympathetic nervous system. Thus worry is reinforced for two reasons. Firstly, since it allows people to avoid distressing imagery it reduces unpleasant physiological reactions related to threat perception. Secondly, individuals believe they can use worry to anticipate or avoid potential future catastrophes.

Support for this model comes from a number of studies. Borkovec (1994) investigated GAD clients' beliefs about the functions of worrying. Through the use of informal questioning, they gathered information on what benefits clients thought they derived from their worrying. Through analysis of their responses the investigators found five common reasons for worrying, all of which have at their base a clear reference to the avoidance of threat. The reasons given included both potentially adaptive and maladaptive functions of worrying. These reasons were: 1) Superstitious avoidance of catastrophe, 2) Actual avoidance of catastrophe, 3) Avoidance of deeper emotional topics, 4) Coping preparation, and 5) Motivating device. Each of these reasons provide reinforcement for the activity of worrying if the individual perceives that worrying has resulted in avoidance of the expected catastrophe.

Borkovec and Roemer (1995) investigated subjective perceptions of the function of worry held by psychology students, meeting all, some or none of the diagnostic criteria for GAD. All subjects completed the Reasons To Worry Questionnaire constructed using the findings from the above study. Subjects were asked to rate the degree to which each statement represented a reason for why they worried on 1-5 point Likert scales (“not at all” to “very much”). The results showed that all subjects thought they used worry to motivate themselves to get things accomplished, to prepare for the possible occurrence of feared events, and to develop ways of avoiding or preventing such events. However the study also found some important differences between GAD subjects and the other two groups. The GAD subjects reported worry to be an effective problem-solving method to a significantly greater degree than the other subjects. The GAD group also reported that worrying made it feel like an event was less likely to occur (superstition) significantly more than non-GADs. GAD subjects also differed from the other two groups through the belief that worrying distracts themselves from “even more emotional things”.

This research indicates how individuals perceive the function of worry as being clearly related to threat avoidance. It also helps us to understand how worry can become excessive and uncontrollable. There are however some limitations to the conclusions we can draw from this
research. The reasons that subjects gave for worrying in these experiments were all post hoc explanations and therefore may merely reflect explanations that they give to themselves or others to explain the worry process and may not be directly related to the true functions of worrying.

Inhibition of Emotional Processing
According to Borkovec (1994) worry is negatively reinforced by its suppressing effects on autonomic activity and by this function results in a prevention of emotional processing. That is, worry leads to a reduction in the production of images which in turn suppress somatic/affective aspects of the experience. This process provides immediate negative reinforcement for worrying. However, in order to change the meaning of a feared stimulus emotional processing needs to take place. This can only be done if all aspects of meaning, including the physiological/affective features are accessed and experienced. Since the preclusion of emotional processing means that this does not occur during the worry process, the anxious meanings are maintained. This in turn results in maintenance of the worry process in the individual.

Evidence to support this theory comes from a study of speech anxious individuals by Borkovec and Hu (1990). Subjects were exposed to the same public speaking scene ten times. Subjects were divided into three groups and told what type of thinking to engage in just prior to presentation of the scene: either relaxed thinking, neutral thinking or worrisome thinking. The group that engaged in relaxed thinking showed a greater cardiovascular response to the initial image with a trend towards habituation upon repeated exposure. The group that engaged in neutral thinking showed significantly less reaction to the initial image with no changes over repeated exposure. The worrisome thinking group showed no cardiovascular response to any of the images, indicating a complete failure to process the emotional material contained in the images. Borkovec, Lyonfields, Wiser and Diehl (1993, cited in Borkovec 1994) replicated this study. They found that relaxed thinking during the first image presentation showed a significant correlation with cardiovascular response whereas worrisome thinking shows a significant negative correlation with cardiovascular response. Therefore the more an individual engages in worrisome thinking, the more emotional processing is prevented.

Other researchers have examined the effects of worrying after the occurrence of a stressful event. Butler, Wells and Dewick (1995) showed subjects an eight-minute gruesome video of an industrial accident. They were then asked to either “worry in verbal form”, to “imagine in
pictorial form” or to “settle down” during a 4-minute period following the film. Subjects were asked to complete ratings of mood, imagery and worry before and after the video, and record worries, imagery and accompanying discomfort about the video for the next 7 days. The results showed that immediately after exposure to the stressful stimulus, worrying about the stimulus resulted in a significant decrease in anxiety, whereas imagery resulted in a significant increase in anxiety. This provides support for the theory that worrying leads to a reduction in aversive affect and therefore may be negatively reinforcing. Results also showed that the subjects who had been asked to worry about the stressor experienced more intrusive images about the stressor during the following three days than the other two groups. The authors concluded that this was because engaging in worrisome thinking had prevented subsequent emotional processing of the film content, which had led to the maintenance of its disturbing meaning. It therefore appears that worrying before or after stressful events will inhibit adaptive processing of the material and will maintain the emotional disturbance generated by those events. Thus, it appears that worrying in this manner can be dysfunctional for the individual.

Worry as a Form of Problem-solving

Davey (1994a) has a different understanding of the functions of worry. They believe that worry is associated with adaptive, problem-focused coping strategies and an information-seeking coping style. Therefore the process of worrying can be preparational and motivational rather than merely avoidant and interfering. Davey (1994a) proposes that worry is a continuum, with the pathological end associated with unwanted, intrusive cognitions that are associated with potentially stressful events and accompanied by distressing mood states such as anxiety and the constructive end that helps to solve potential problems and reduce anxiety. Thus according to Davey’s definition, worry can be regarded as part of a problem-focused approach to life problems.

Davey, Hampton, Farrell and Davidson. (1992, cited in Davey, 1994a) investigated the relationship between worrying and problem-focused coping. They initially found no significant correlations between frequency of worrying and problem-focused coping activities. However, once levels of trait anxiety had been partialled out, worrying was found to be significantly associated with a range of problem-focused coping activities, such as information seeking and problem-solving.

Further research has shown that there seems to be a high correlation between worrying and trait anxiety. Trait anxiety has been found to be significantly related to measures of poor self-
perceived problem-solving efficacy and responsibility for negative but not positive outcomes. According to this model pathological worrying occurs as a result of an interaction between worrying and trait anxiety. Davey et al. (1992) have divided the factors that may stop the process of worrying from actually solving potential life problems into two categories: situational factors and personality factors.

Situational factors
If an individual is in a situation that is uncontrollable, for example, having a chronic, incurable illness, then the activities associated with worrying such as problem-analysis and information-seeking may actually make the situation more stressful. Miller, Leinbach and Brody (1989, cited in Davey 1994a) found that in such circumstances an information-seeking coping strategy is significantly related to hypertension. Thus in these circumstances worrying is likely to have detrimental psychological consequences and as a result perpetuate further bouts of worrying, leading to worry becoming dysfunctional.

Personality factors
In situations which are potentially controllable, worrying may still occur if the individual feels that their own coping resources will be ineffective in dealing with the situation or they define events as more threatening than they really are. Thus according to Davey (1994a) it appears that dysfunctional worrying is a function of an unjustified lack of confidence by the worrier in their problem-solving ability.

Generalised Anxiety Disorder (GAD)
In recent years worrying has been recognised as being a cardinal defining feature of GAD. GAD is a common problem. The one-year prevalence rate in a community sample was approximately 3%, and the lifetime prevalence was 5% (DSM-IV; APA, 1994). According to DSM-IV to meet the criteria for GAD an individual must show: “excessive anxiety and worry (apprehensive expectation), occurring more days than not for a period of at least six months, about a number of events or activities. The individual should find it difficult to control the worry and this should be accompanied by at least three additional symptoms out of a list of six symptoms: 1) Restlessness or feeling keyed up or on edge, 2) Being easily fatigued, 3) Difficulty concentrating or mind going blank, 4) Irritability, 5) Muscle tension, and 6) Sleep disturbance. The focus of the worry and anxiety should not be confined to another Axis 1 disorder. The symptoms must cause clinically significant distress or impairment in functioning. The disturbance must not be due to physiological effects of a substance or general medical condition.
The Nature of Worry in GAD
Research has shown that the worries of GAD patients closely resemble in content the worries of non-patients. Craske, Rapee, Jackel and Barlow (1989) compared the worries of GAD patients with non-anxious controls. They found no significant differences between content of worries or related anxiety, but they did find that GAD patients rated their worries as less controllable and less successfully reduced by corrective attempts compared with the worries of non-patients. It therefore appears that the uncontrollability of worry is central to the development of dysfunctional worry.

Psychological Treatments for GAD
A number of different treatments for GAD have been developed and evaluated. These treatments include cognitive therapy (CT), behaviour therapy (BT), cognitive-behaviour therapy (CBT), anxiety management (AMT), analytic psychotherapy (AP), applied relaxation (AR), and nondirective therapy (ND).

In CT the main focus of treatment is on identifying anxious cognitions and thinking errors and learning to switch to more helpful thoughts and reactions to stressful situations and bodily sensations. BT involves teaching patients to control symptoms through relaxation. It also involves reducing avoidance to anxiety-producing situations through graded exposure, and rebuilding confidence through engagement in pleasurable and rewarding activities. CBT involves an amalgam of these two techniques. AMT is a structured approach to treatment involving education about anxiety and learning more adaptive coping strategies. AP involves the exploration and understanding of symptoms in the contexts of the patient's current relationship, the patient's development, and in terms of the transference and resistance aspects of the therapeutic relationship. AR involves teaching the patient progressive relaxation with tension-release of the muscles and identifying early signs of arousal, and anxiety or worry as cues for relaxation. In ND therapists use supportive statements, reflective listening and empathic communications to create an accepting, non-judgemental, empathic environment, in which to facilitate allowing and accepting of affective experience (Borkovec and Costello, 1993).

Evaluation of these approaches has shown that there are advantages to some treatment approaches over others. For example, Butler, Fennell, Robson and Gelder (1991) compared CBT with BT. Results showed a clear advantage for CBT over BT at the end of treatment, and this difference was even greater at six-month follow-up, at which time 42% of CBT patients met the criteria for good outcome, compared with 5% of BT patients.
Durham, Murphy, Allan, Richard, Treliving and Fenton (1994) compared CT, AP and AMT. Patients receiving CT and AP had either 'high' (16 to 20 sessions) or 'low' (8 to 10 sessions) therapist contact. There was a highly significant difference in outcome between CT and AP, favouring CT post treatment. Patients receiving AMT showed improvements that were similar to CT, though less broadly based. No overall differences were found in outcome between 'high' and 'low' contact. At six month follow-up less AMT patients showed clinically significant change. At one year follow-up there was largely no significant differences from pre-treatment scores for patients receiving AP, but an obvious and sustained improvement in scores for patients receiving CT, in fact these patients had continued to improve since the end of treatment. This was not found to be the case for AMT patients.

Borkovec and Costello (1993) compared AR with CBT and ND. They found that AR and CBT were superior to ND at the end of treatment. Although at 12-month follow-up CBT was found to have an advantage over AR with 57.9% of CBT clients having high end state functioning versus 37.5% of AR clients and 26.7% of ND clients.

In summary, research has shown that using cognitive behavioural methods for the treatment of GAD can produce durable and consistent effects. In many cases this has been shown to have a clear advantage over other approaches. It also offers a potentially valuable alternative to anxiolytic medication. However, on average these approaches only result in modest improvements in symptoms with about 50% of patients achieving normal functioning i.e. much less effective than treatments for other anxiety disorders. The limited effects of cognitive treatments are probably due to the fact that they are not based on a specific model of GAD. They do not distinguish between normal and dysfunctional worry and as a result do not directly target mechanisms underlying problematic worry. Wells (1995) has developed a cognitive model of GAD.

Cognitive Model of GAD
Wells (1995) has developed a cognitive model of GAD that describes the processes involved in the development and maintenance of subjectively uncontrollable and aversive worry states in GAD. This model distinguishes between two types of worry: Type 1 worry which is concerned with external events and internal non-cognitive events; and Type 2 worry or ‘meta-worry’, which is concerned with negative appraisal of ones own cognitive events, particularly worry e.g. “My worries are uncontrollable” or “I will go crazy with worrying”. The model suggests that individuals who develop pathological worry hold a variety of positive and negative beliefs about worry itself which lead to a state of cognitive dissonance in the
individual. Positive beliefs are usually about the protective or coping function of worry. Negative beliefs typically concern the uncontrollability of worry, or the dangerous consequences of worrying.

According to the model when a GAD patient experiences a threatening stimulus, positive beliefs about worry lead them to engage in the worry process. This use of worry as a coping strategy generates its own problems. Worrying leads to a greater sense of vulnerability and danger. It increases sensitivity to threat-related information and generates a range of possible negative outcomes. These in turn lead the individual to worry more. This results in negative beliefs about worry, such as its uncontrollability, being reinforced and leads to the development of meta-worry. Some of the ways individuals behave in order to avoid the appraised negative consequences of worries contribute further to the maintenance and escalation of the problem. These responses can be divided into three groups: 1) Behavioural responses, 2) Thought control attempts, and 3) Emotional symptoms.

**Behavioural Responses**

Behavioural responses in GAD are associated with worry at the Type 1 and Type 2 level. At the Type 1 level GAD individuals avoid external threat. The role of behaviours linked to Type 2 worries aim to avoid the activation of worry itself and the negative consequences of worrying. The problem with these behaviours is that they maintain worry. Type 1 worry is maintained because they remove the opportunity to disconfirm the accuracy of the worry. Type 2 worries are preserved because the non-occurrence of catastrophe e.g. loss of mental control, is attributed to the use of the behavioural strategy.

**Thought Control Attempts**

Some individuals with GAD use worrying as a controlled rumination strategy to generate and rehearse coping responses. However, this perpetuates Type 2 worry and negative beliefs concerning the uncontrollability and consequences of worrying. Other individuals try to suppress worrying thoughts. This process may inadvertently increase the occurrence of unwanted thoughts, again increasing the sense that worry is uncontrollable.
**Emotional Symptoms**

When patients engage in worry they often experience apprehension characterised by muscle tension, uneasiness, restlessness etc. These symptoms are interpreted as evidence of loss of mental control and an increase in the sense that worry is dangerous.

**Evidence for the Model**

Wells' (1995) model proposes that the distinction between normal and pathological worry is due to the development of meta-worry. Therefore people with GAD will exhibit more meta-worry than non-worried individuals. Also according to the model, people with GAD should exhibit both positive and negative beliefs about worrying. This has been shown to be the case in a number of studies. Davis and Valentiner (2000) examined GAD clients, non-worried anxious and nonanxious individuals. Individuals in all three groups completed a number of questionnaires. The results showed that the necessity of controlling one's worry or beliefs that worry is uncontrollable are central in distinguishing the GAD clients from the other two groups. They also found that individuals with GAD exhibited significantly more positive and negative beliefs about worry than the other two groups.

**Treatment of GAD**

The initial stages of therapy involve socialisation. This involves a discussion of the role of meta-worry and counterproductive strategies in worrying. To do this the therapist may need to highlight the fact that almost everyone worries, but that worry is only a problem for some people. The aim of this is to elicit that what makes worry become a problem for some people is negative appraisals of worry, particularly its uncontrollability. Experimental techniques are used to discuss the role of counterproductive strategies. For example, thought suppression exercises may be used to demonstrate how trying not to think certain thoughts has the paradoxical effect of making those thoughts more likely. It may also be more useful to demonstrate how using a worrying style of thinking may be counterproductive as it may exaggerate the problem by increasing the range of catastrophic possibilities. The rest of therapy involves challenging the client's Type 2 worries, and negative and positive beliefs.

**Modifying Negative Beliefs about Worry**

This may be done by weighing up the evidence and counter-evidence to support the meta-worry and providing alternative explanations for this evidence. Belief in control over worry may be restored by reviewing episodes in which worry was interrupted by conflicting demands, thus counteracting appraisals of uncontrollability. Information on how common worry is may challenge meta-beliefs about worrying. Negative beliefs about worry can be
challenged by strengthening cognitive dissonance in patients. This is done by eliciting both positive and negative beliefs about worry and emphasising that they cannot coexist. Behavioural experiments may be used to test out the client’s beliefs. For example, getting the client to attempt to ‘lose control’ over worrying can demonstrate that loss of control is not possible and therefore challenge beliefs about the dangers of worrying. Experiments involving the postponement of worries can modify the patient’s belief in the uncontrollability of worrying. Once meta-beliefs have been effectively modified, positive beliefs about worry should be the focus of intervention.

**Modifying Positive Beliefs About Worry**

Verbal reattribution techniques are used to modify positive beliefs, by looking for evidence and counterevidence supporting the positive value of worrying. This can be done by getting clients to abandon worrying to see if negative events do occur. By demonstrating that worries are not always accurate representations of situations it is possible to reduce their credibility and therefore alter positive beliefs about the value of worry. The Mismatch Strategy (Wells, 1997) is used to do this. Patients are asked to write a detailed description of the content of worry and compare this to the actual events observed in the situation. This can be done either retrospectively or prospectively. The resulting mismatch is used to challenge the accuracy of worries and how useful they are as a coping strategy.

**Conclusion**

A number of different psychological theories have been developed to explain worry. Borkovec et al. (1991) have developed a fear avoidance model of worry. A key feature of this model is that worry involves predominantly thought activity, rather than visual images. The model states that individuals use worry to respond to perceived threat and either prepare for, or avoid future catastrophe. As threat is detected the individual shifts attention from the threat to worrisome thinking. This leads to a reduction in the generation of visual imagery which would normally cause activation of the sympathetic nervous system. This results in a reduction in the unpleasant physiological reactions related to threat perception therefore providing immediate negative reinforcement for worrying. However, this means that emotional processing cannot take place and the anxious meaning of the situation are maintained. This leads to further worry in the individual.

Davey (1994) proposes that worry is a continuum with the pathological end associated with anxiety enhancement and the exacerbation of problems, and the constructive end characterised by anxiety reduction and amelioration of problems. In other words, in some situations worry
can be motivating and used as a problem-solving process, but in other circumstances if the individual is in a situation that is uncontrollable, or if the situation is controllable but the individual lacks confidence in their problem-solving ability, then the process of worrying makes the situation more stressful. This in turn leads to the development of pathological worry.

Excessive or dysfunctional worry is now recognised as a cardinal feature of GAD. A number of psychological treatments have been developed for GAD. Studies have shown a clear advantage for cognitive therapy over other treatments. However, cognitive therapy still only produces modest effects, with an average of around 50% of patients attaining normal functioning at the end of treatment. Wells (1995) suggests the reason for these modest effects is that these treatment approaches fail to distinguish between normal and dysfunctional worry. Wells (1995) has developed a cognitive model of GAD. This model is based on the differentiation of two types of worry: Type 1 worry, which is worry about external events and noncognitive internal events; and Type 2 worry (meta-worry) which is focused on the nature and occurrence of one’s own cognitive events, particularly worry. The model suggests that it is the development of meta-worry that underlies dysfunctional worry, and that treatment needs to focus on modification of meta-worry, and positive and negative beliefs about worry.

This model suggests a better understanding of the development and maintenance of dysfunctional worry than previous models of worry. It accounts for existing research, as well as generating a new specific cognitive treatment for GAD. Although this treatment has yet to be evaluated in a controlled study, it appears likely that it will be more effective than previous psychological treatments for GAD.
References


People with Learning Disabilities Essay

“All challenging behaviour in individuals with learning disabilities has a communicative function and can be explained by deficits in communication skills”. Critically discuss this proposition.

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Year 1
Introduction
Challenging behaviour (CB) has most recently been described as 'culturally abnormal behaviour of such an intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities' (Emerson, 1995). There are three important aspects to this definition. Firstly, CBs are defined by their impact and not just the behaviours per se. CBs can therefore be described as any behaviour that challenges services. Thus the perception of what is challenging will vary from one group to another. Secondly, definitions of CB must take into account social norms for appropriate behaviour. Whether a behaviour is challenging will be based on complex interactions between what persons do, the setting they do it in and how their behaviour is interpreted or given meaning (Emerson, 1998). Thirdly, this definition accounts for the fact that CBs have wide-ranging personal and social consequences. For example, CBs may have immediate consequences of impairing health; impairing the quality of life of the individual, their carer and those who live or work in close proximity to the individual. They may also have longer-term consequences in the way that the community, carers, and services respond to them, such as, exclusion, deprivation, abuse, inappropriate treatment and systematic neglect (Emerson, 1998).

Prevalence of challenging behaviour
Estimates of the prevalence of challenging behaviour vary, depending on the definitions used to identify cases and how the research is carried out. Quereshi and Alborz (1992) conducted a large-scale study, to determine the prevalence of various forms of CB among the total population of people with learning disabilities (PLD) in a defined geographical location. This survey was conducted in seven District Health Authorities in the northwest of England with a total population of 1.54 million. They screened approximately 4,200 people, including adults and children with learning disabilities and found that 5.7% of these were identified as having serious CB.

Borthwick-Duffy (1994) examined the prevalence of CBs among 91,164 PLD served by the California Department of Developmental Services. People were investigated as to whether they showed one or more of four possible types of CB: aggressive behaviour, frequent and severe self-injurious behaviour (SIB), frequent SIB and property destruction. They identified 18,826 people as showing CB, that is, 14% of the population surveyed.
Prevalence rates have been shown to vary in relation to a number of risk factors. Gender is a risk factor associated with CB. Boys and men are more likely to be identified as showing CB than girls and women, particularly physical aggression and destruction of property (Rojahn, 1994, cited in Pimm, 1998). They are also more likely to demonstrate more severe CBs. There is, however, some evidence to suggest that females engage in more forms of SIB than males (Maurice and Trudel, 1982, cited in Emerson, 1995). The overall prevalence of CBs have been found to increase with age during childhood, reach a peak between the ages of 15 and 35 years, and then decline (Kiernan and Kiernan, 1994). In general, the prevalence of CBs have all been found to be positively correlated with degree of intellectual impairment (Oliver, 1993, cited in Emerson, 1995). Borthwick-Duffy (1994) in their Californian survey (see above) found that 7.6% of people with mild learning disabilities, 13.6% of people with moderate learning disabilities, 22.0% of people with severe learning disabilities and 32.9% of people with profound learning disabilities showed one or more forms of CB. CBs are also more likely to be identified in people with additional sensory impairments, for example, vision or hearing; reduced mobility or a specific impairment of communication (Emerson, 1998).

Types of challenging behaviours

Emerson and Bromley (1995) undertook a study investigating the form and function of CB in a metropolitan borough with a population of 212,000, located in the northwest of England. They identified 70 PLD who met the criteria for CB. For each of these individuals they collected detailed information of the observed CBs, including the form of the behaviours shown. They were able to divide all behaviours into four main groups: aggression; SIB; destructiveness and ‘other’ which included such behaviours as screaming, theft, inappropriate sexual and social behaviour, running away and overactivity. They found that greater severity of CBs was associated with a greater probability of the individual showing more than one form of CB.

Epidemiological estimates of SIB suggest that between 10-15% of PLD engage in some form of SIB throughout their lifetime (Borthwick-Duffy, 1994). SIB is defined as any behaviour, initiated by the individual, which directly results in physical harm to that individual. Physical harm is considered to include bruising, lacerations, bleeding, both external and internal, bone fractures, breakages and other tissue damage. SIB has been found to be most common amongst people who are very severely or profoundly learning disabled, but does also occur amongst less disabled people (Murphy, 1985, cited in Murphy and Wilson, 1985). Another behaviour classed as challenging in PLD is stereotyped behaviour. This has been defined as ‘highly consistent and repetitious motor or posturing responses which are excessive.
with respect to rate, frequency, and/or amplitude and which do not appear to possess any adaptive significance' (Baumeister 1978, cited in Murphy and Wilson, 1985). Such behaviour includes repetitive body rocking, hand flapping, finger twining, head weaving and eye-poking.

The term CB also includes objectionable personal habits, such as spitting, smearing, self-induced vomiting, pica, continuous eating and drinking, swearing and hoarding of rubbish.

**Challenging behaviour as a communicative function**

Communication defined as ‘an intentional transmission of meaning in a formal code between people that share that code’ (Coupe and Jolliffe, 1988, cited in Bradshaw, 1998), can be a key factor in understanding CB. Many PLD face extreme difficulties with communication. Bott, Farmer and Rohde (1997) observed a population of 3,662 PLD and found that those with no speech had significantly more behaviour problems than those with good speech.

The behavioural approach to understanding CB has been to view CB as functional and adaptive. That is, CB is thought of as a way through which the person exercises control over key aspects of his/her world (Emerson, 1998). Environmental consequences which maintain behaviour are termed ‘reinforcers’. Operant behaviour is established and maintained through two types of relationships between behaviour and reinforcers. These include: positive reinforcement, which refers to an increase in the rate of a behaviour as a result of the contingent presentation of a positively reinforcing event, such as social praise, food or drink; and negative reinforcement, which refers to an increase in the rate of a behaviour as a result of the contingent withdrawal, or the prevention of the occurrence, of a negatively reinforcing event, such as excessively difficult tasks, noisy or cold environments. CBs may be considered as operant behaviours learnt through these processes. That is, if CB is followed by a positively reinforcing event, such as attention, then the behaviour may become more likely to occur in the future and is thus maintained by positive reinforcement. Similarly if CB is followed by a negatively reinforcing event, such as the termination of an aversive event, for example a demand, this behaviour is more likely to occur in the future, and is thus maintained by negative reinforcement.

Precisely what stimuli act as positive or negative reinforcers depends on the individuals themselves. According to operant learning theory no a priori assumptions can be made about what particular stimuli are likely to be reinforcing for a person in a particular context. Instead positive and negative reinforcers are described functionally. That is they are defined solely in terms of the impact which their presentation or withdrawal has upon subsequent behaviour.
Derby, Wacker, Sasso, Steege, Northup, Cigrand and Asmus (1992) investigated the range of types of reward that SIB and aggressive behaviour may evoke. They found that in 48% of cases CB was maintained by demand avoidance, 34% by sensory stimulation, 24% of cases by attention, and 12% of cases by the presentation of something tangible, for example, food or drink. This concern with functional relationships also extends to the way in which behaviour is classified. Behaviours which result in the same environmental effects, for example, attracting carers' attention or the removal of an aversive stimulus, are classified as members of the same response class.

It is also important to consider the context in which behaviour occurs. Contextual factors operate in two ways. Firstly, they may provide or establish the motivational base which underlies behaviour. For example, food will only operate as a positive reinforcer if the person is denied free access to it, and if he/she has not eaten recently. In a different context, for example, if someone is satiated with food, food is unlikely to act as a positive reinforcer and may act as a negative reinforcer or punisher. That is, personal, biological, historical and environmental contexts all influence the motivational basis of behaviour by determining or establishing the reinforcing and punishing potential of otherwise neutral stimuli. Secondly, contextual factors may provide information or cues to the individual concerning the probability of particular behaviours being reinforced as a result of their previous association with variations in the probability with which particular behaviours have in the past been reinforced.

It is important to note that not all behaviour is shaped by environmental consequences. Some behaviours appear to be maintained by consequences internal to the person. Such behaviours may be thought of as examples of operant behaviour maintained by processes of automatic or perceptual reinforcement, in which the reinforcing stimuli are private or internal to the person (Lovaas, Newson and Hickman, 1987, cited in Emerson, 1998). Automatic reinforcement may be positive, that is, behaviour that leads to a positive internal state, for example, masturbation may lead to orgasm, and negative, that is, behaviour that leads to a reduction in an aversive internal state, for example, clenching your teeth may partially attenuate the pain from a sprained ankle (Emerson, 1998).

Children's and adults' CB often have an effect on their social world. For example, when an individual with learning disabilities engages in SIB, the carers who observe this frequently conclude that he/she is unhappy, uncomfortable or needs something but is unable to ask because of communication deficits. They may therefore offer comfort or food, or they may
stop making demands on the individual, feeling that it is this that is upsetting them. This leads to the individual’s behaviour being either positively or negatively reinforced as well as the carer’s behaviour being negatively reinforced if the individual then stops self-injuring. They have fallen into what Oliver (1991, cited in Murphy, 1999) has termed the SIB trap, and may be locked into a system of ‘control and counter-control’, in which the individual’s SIB will increase in frequency just as the carer’s actions will also increase in frequency. From the carer’s view the SIB has acted as a form of communicative act (Murphy, 1999). Donnellan, Mirenda, Mesaros and Fassbender (1984) have termed this the communication hypothesis. This hypothesis holds the view that many instances of CB are functionally equivalent forms of communication used when a more acceptable and effective means of expression is outside an individual’s repertoire. In this sense communication is understood as the ability to send a message to others and is derived from the pragmatics perspective that all behaviour is communicative (Watzlawick, Beavin and Jackson, 1967, cited in Donnellan et al., 1984). The theory has developed from analysis of the language of normal children. Bates (1996, cited in Carr and Durand, 1985) introduced the notion of two linguistic entities occurring before the child has acquired speech, the protodeclarative and protoimperative, which appear to function communicatively. The protodeclarative involves a variety of showing, giving and pointing behaviours in the presence of an adult and is thought to serve an attention-seeking function. The protoimperative involves the child employing a variety of nonverbal behaviours to communicate a desire for certain objects. The communication hypothesis extends this viewpoint to understand CB in PLD, that is, that the individual is engaging in challenging behaviour as a form of communicating their wishes and needs. However, it assumes that it is the functional relationship between behaviour and context, rather than the topography of behaviour alone that is indicative of its motivational source or communicative intent.

The communication hypothesis has led to the development of a number of pragmatically oriented interventions for individuals with learning disabilities and CB. These include teaching new communicative behaviours to replace the CBs; teaching other functionally related behaviours to replace CBs, and manipulating antecedents.

Functional communication training (FCT) is a behavioural intervention that incorporates a comprehensive assessment of the communicative functions of maladaptive behaviour with procedures to help teach alternative incompatible communicative responses that are functionally equivalent to the CB. If the communication hypothesis is correct, FCT should lead to a decrease in the frequency of the problem behaviour. Durand and Carr (1991) evaluated the effectiveness, maintenance and transferability of FCT as an intervention for CBs.
exhibited by three boys attending a school for children with learning disabilities. Assessment indicated that these behaviours were being maintained by escape from academic demands and social attention. The intervention involved teaching the boys alternative communicative responses that served the same attention-seeking and attention-getting functions as their CB, in order that they would replace their CB with these verbal equivalents. The results showed that not only was CB reduced for each boy, but that these changes transferred across new tasks, teachers and classrooms and were maintained for up to two years. The success of this intervention has been explained in terms of response competition and it is suggested that, as appropriate, functionally similar communicative behaviours are reinforced and strengthened, they become more efficient than CBs at eliciting the desired reinforcers.

Interventions involving the differential reinforcement of an alternative behaviour, which serves the same function as the CB, have also been found to be successful if the alternative behaviour results in reinforcement that is topographically and functionally similar to that available following the CB. Carr, Newsom and Binkoff (1980) undertook a detailed functional analysis of the behaviour of two children with learning disabilities with severely aggressive behaviour. Assessment showed that their aggression was motivated primarily by escape from demands, which, in the past had been negatively reinforced by the termination of demands. The intervention involved the differential reinforcement of an alternative nonaggressive response. It was found that as the alternative nonaggressive behaviour was strengthened, the aggressive behaviour was rendered unnecessary and a reduction in its frequency was seen.

The communication hypothesis assumes that the communicative value of behaviour is dependent on the context in which it occurs. Therefore altering the contextual or antecedent conditions will result in a variation in the rate or intensity of the behaviour (Donnellan et al., 1984). Weeks and Gaylord-Ross, (1981) investigated the influence of task difficulty on CB in three students with severe learning disabilities. Noticeably higher rates of problem behaviour occurred in demand compared to no-demand conditions, as well as difficult versus easy tasks. They found that antecedent manipulation involving simplifying tasks, decreasing the frequency of demands and using errorless learning all contributed to a decrease in escape-motivated CB.

The communication hypothesis provides an explanation as to how CBs may effectively control important aspects of individuals with learning disabilities' social world. Support for this theory comes from the work around functional communication training which shows that when PLD are taught more functionally adaptive methods of communicating they often
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exhibit a reduction in the frequency and intensity of their CBs. However this hypothesis does not explain how and why CB develops in individuals who do not have communication deficits.

Organic and neurobiological hypotheses

One theory which provides an explanation for the development of CB, in particular, SIB, in these individuals is that it arises from organic factors within the individual. Research investigating SIB has found that in general SIB is not confined to particular diagnostic categories (Murphy and Wilson, 1985). However there are two known medical conditions in which self-injury occurs frequently: Lesch-Nyhan and Cornelia de Lange syndromes. The existence of these two syndromes, both of which are congenital, provides some evidence in support of hypotheses that maintain that SIB is organic in nature. That is, SIB occurs as a result of the individual’s biological constitution and not any events in their life (Murphy and Wilson, 1985). Lesch-Nyhan syndrome is an X-linked recessive condition affecting 1 in 380,000 live births. The most prominent physical features are motor disabilities and involuntary movements. Most children affected by this condition show verbal and physical aggression towards other people and objects. Over 85% of affected children manifest compulsive SIB including biting of lips, the inside of the mouth and fingers (Turk and Hill, cited in Deb, 1998).

Individuals with Cornelia de Lange syndrome have a number of characteristic features, such as low birth weight, small stature, and facial and limb abnormalities. Associated behavioural features include moderate to severe learning disability, poor language development, stereotypic movements and overactivity. As children with Cornelia de Lange syndrome grow older, they show SIB in the form of self-hitting, biting and chewing, as well as explosive outbursts. Another syndrome where CB often occurs is Smith-Magenis syndrome. Characteristic behaviours include aggression, SIB including head-banging, hand-biting, pulling of fingernails and toenails and insertion of foreign objects into various bodily orifices. It has also been hypothesised that a number of neurobiological mechanisms may underlie CB. Recent theories have focussed on the role of three classes of endogenous neurotransmitters in modulating behaviour: dopamine, serotonin and the opioid peptides, particularly B-endorphin. The dopaminergic system is closely involved in the regulation of motor activity. There are two types of dopamine receptors D1 and D2, each of which contains further subtypes (Cross and Owen, 1989, cited in Emerson, 1995). Evidence suggests that abnormalities in the D1 receptor subsystem may be implicated in the development and maintenance of at least some forms of SIB (Emerson, 1998). People with Lesch-Nyhan syndrome, all of whom display
injurious self-biting, show a significant deficiency in dopamine pathways in certain areas of
the brain and decreased levels of dopamine and its metabolites in the central nervous system

The serotonergic system is closely linked with a number of processes including arousal,
appetite control, anxiety and depression. Research evidence suggests there may also be a link
between serotonin and aggression and some forms of ‘obsessional’ SIB (Schroeder and
Tessel, 1994). Evidence suggests that serotonergic agonists or reuptake inhibitors, such as
fluoxetine, can reduce OCD in individuals without learning disabilities and SIB in people with
severe learning disabilities (Markowitz, 1992).

Opioid peptides are structurally and functionally related to the opioid alkaloids morphine and
heroin and play an important role in pain control. One particular opioid peptide, B-endorphin,
is released in times of pain and stress in human beings. B-endorphins have the greatest
analgesic properties, and may produce a euphoric mood state. Sandman (1990/1991, cited in
Emerson, 1995) has proposed two models in which B-endorphins are related to SIB. The first
model, the congenital opioid excess model, states that excess opioid activity leads to
permanently raised pain thresholds. The second model, proposes that SIB leads to the release
of B-endorphins, which through its analgesic and euphoria-inducing properties, acts as an
automatic reinforcer for the SIB. Sandman (1990/1991, cited in Emerson, 1995) found that
following an episode of SIB in an individual an increased level of B-endorphins are found in
their cerebral spinal fluid.

Another theory which explains the development of SIB is that a person may begin to self-
injure as a side effect of a minor illness, for example, the SIB may be an attempt to relieve an
irritation or an internal pain. It is assumed that these behaviours then develop into SIB and are
maintained for other reasons. Although the evidence for this theory does not come from the
literature on individuals with learning disabilities, de Lissovoy (1963) found a larger
proportion of a group of normal infants who head banged had experienced middle ear
infections than a control group of normal infants who did not head bang.

Recently it has been suggested that SIB may occur as a response to frontal lobe epilepsy.
Chung and Cassidy (2001) investigated the relationship between CB and epilepsy in PLD.
They examined nineteen patients using the Disability Assessment Schedule and the Aberrant
Behaviour Checklist. Information on their epilepsy was collected from medical records. The
results suggested that epileptic patients tended to display more CB than non-epileptic patients.
They also found that epileptic patients were significantly more irritable than non-epileptic patients.

**Environmental hypothesis**

Another explanation for CB has been derived from human ecology, that is, the study of the interaction of people with their environment. Considerations of ecological factors in relation to CB come from two areas of research. Firstly, it is argued that particular aspects of early family life predict the development of CB (Murphy, 1999). Niñara, Meyers and Mink (1980) examined the rates of CB amongst children with learning disabilities. They found that discontinuities in upbringing, care that was below the basic level, family discord and instability, or disorganisation in the home were linked to increased CB in young adults with mild developmental disability and conduct disorder in young adults without a learning disability.

To date no research has been carried out looking at the features of family life on the development of CB in individuals with severe learning difficulties, however it has been hypothesised that they would be the same as those mentioned above.

The second area of research has investigated the effects of the individual’s immediate environment on CB. It has been shown that the prevalence of SIB is found to be higher in restrictive or institutional settings. Harris (1993) surveyed aggressive behaviour amongst PLD in a single health district. The lowest rate of aggressive behaviour was found amongst those in day facilities (9.7%) and the highest rate amongst individuals residing in hospitals (38.2%). Three explanations have been given for this finding. Firstly, individuals with severe learning disabilities are more likely to be admitted to institutional settings and less likely to be discharged back to the community. Secondly, individuals who exhibit SIB are more likely to be admitted to institutional settings and be excluded from community placements. Thirdly, the levels of material and social deprivation as well as patterns of staff-client interaction that are common to institutional settings may help to sustain or shape SIB (Emerson, 1990).

Mansell (1995) examined the behaviour of staff towards 18 residents, prior to their transfer from hospital or special units designed for individuals with CB, to a number of staffed houses. The results showed that staff-resident interaction averaged 7% of time in hospital wards, 8% in the specialist units and 24% in the staffed houses. It was also found that levels of engagement in non-social and social activities combined averaged 12% in the hospital wards, 15% in the special units and 31% in the staffed houses. The low levels of stimulation in
institutional settings may result in positive adaptive behaviour not being recognised and reinforced. Positive behaviour may therefore be extinguished, resulting in a more frequent occurrence of maladaptive behaviour (Pimm, 1998).

These findings have led to a number of research projects being carried out in the UK examining the effects of deinstitutionalisation on people’s quality of life, skills and behaviour. Roy, Abdalla, Smee, Fallon, Simon, Blincoe, Hayes, Shaw, and Marsh, (1994) evaluated a resettlement programme involving the move of three men with learning disabilities and behaviour disorder from a large learning disability hospital to a residential service in the community. They found that following the move they showed an increase in engaged behaviour, a decrease in disturbed behaviour and a decrease in violent incidents. They also found that these men were better integrated into the community and had a better quality of life.

In Cardiff towards the end of the 1970s a jointly funded comprehensive community-based service called NIMROD was set up, for all PLD in a defined area. This consisted of a staffed residential service using ordinary community housing, to which 22 clients were transferred. Twelve of these clients were male, with 64% rated as presenting with severely CBs. Following the move it was found that the prevalence of CBs did not diminish, although there was an increase in quality of life and skills acquisition, as well as increases in resident’s contact with community amenities and friends (Felce, Lowe and de Paiva, 1999).

Research looking at the effect of an individual’s environment on their CB has found that for some individuals deinstitutionalisation has led to a reduction in CBs at the same time as adaptive behaviours and engagement levels increase. However this is not the case for all individuals who are resettled in the community. This may be because for some individuals their CB is serving a self-stimulatory function and therefore a move to the community, which leads to an increase in material and social stimulation, would result in these individuals showing a decrease in their CBs. However, for those individuals whose CB serves the function of avoiding/escaping from demands, a move to a community setting, where there is likely to be an increase in demands, would be likely to result in an increase in CBs.

**Psychiatric disorders**

While CB and psychiatric illness are not synonymous, many people with severe learning disabilities have dual diagnoses of mental health problems (Borthwick-Duffy, 1994). Studies
on the prevalence of psychiatric disorders amongst PLD have shown that rates are much higher than those found in the general population (Borthwick-Duffy, 1994).

In people with mild, and to some extent, moderate learning disabilities, symptoms of psychiatric illness are essentially the same as those seen in people without learning disabilities (Bouras and Drummond, 1992). However, the diagnosis of mental health problems in individuals with severe and profound learning disabilities can be extremely difficult, particularly when individuals have language or communication deficits, or difficulties in organising their thinking processes coherently (Pimm, 1998). This is because psychiatric and emotional problems tend to be highly individualistic in these individuals (Eaton and Menolascino, 1982, cited in Bouras and Drummond, 1992) and might present as behavioural problems (Reiss, 1985, cited in Bouras and Drummond, 1992).

According to Emerson, Moss and Kiernan (1999) there are three possible ways in which psychiatric disorders may be associated with CB. Firstly, it is thought that some examples of CB among individuals with severe learning disabilities may represent atypical presentations of psychiatric disorder. For example, some forms of SIB may be atypical presentations of obsessive-compulsive disorder (OCD) amongst individuals with severe learning disabilities (King, 1993). Secondly, CB may be a secondary feature of psychiatric disorder in PLD (Emerson et al., 1999). For example, individuals with depression, who are unable to verbalise their feelings may instead exhibit a variety of clinical features, including hysterical fits, agitation, and disturbances of physiological functions such as sleep and appetite (Reid, 1982, cited in Emerson et al., 1999). Thirdly, it is possible that some forms of CB may involve the operation of behavioural process in the context of an underlying psychiatric disorder (Emerson et al., 1999). In other words, an underlying biological condition, such as, psychiatric illness may change the valence of otherwise neutral environmental events, thereby establishing a motivating condition for the expression of CB. For example, an individual with depression may not wish to participate in any social activity, thus establishing this as a negative reinforcer. If they have previously learned that CB can terminate what has become an aversive event, the person is likely to engage in higher levels of CB.

**Psychodynamic hypothesis**

A number of psychodynamic explanations of SIB have been put forward. Firstly, it is suggested that some individuals may find it more difficult than others to differentiate themselves from the external world. SIB is said to represent a manifestation of ‘poor ego identity’ and serves to differentiate the ego from the outside world (Green, 1967, cited in Murphy and Wilson, 1985).
Another psychodynamic explanation suggests that SIB is used to obtain relief from feelings of emptiness, depersonalisation and unreality, to exert control over one's body, to move guilt onto others, or may be a non-verbal expression of the individual's distressed emotional state (Conn and Lion, 1983, cited in Murphy and Wilson, 1985).

A more recent psychodynamic theory focuses on the concept of 'secondary handicap'. In this theory the disabled person uses challenging behaviour as a defence against the feelings engendered by a personal awareness of their disability. The individual may either exaggerate their initial disability or adopt a further 'secondary' handicap as a coping mechanism (Sinason, 1986). It is thought that SIB may serve to distract others from making too many demands on them, or may serve to block or minimise memories of deeply upsetting traumatic events in the past (Sinason, 1992).

These theories will not be discussed further as there is limited evidence to support them. This is because the constructs underlying them are very broad, for example, emotional trauma, and loosely defined or difficult to objectify, for example, ego boundaries, therefore making it difficult to conduct research evaluating them.
Discussion
There are a number of different models available that attempt to explain the development and maintenance of CB. However it seems that none of these models alone can provide a full explanation of challenging behaviour. The communication hypothesis proposes that CB is functional and adaptive and used by individuals with deficits in communication as a way of enabling them to exercise control over key aspects of their world, for example, to gain access to attention or to avoid demands. This hypothesis assumes that behaviour problems are social-communicative in nature and therefore predicts that an intervention programme focusing on teaching individuals alternative, communicative responses that are functionally equivalent to the CB should lead to a decrease in the frequency of the problem behaviour. The literature on functional communication training has found this to be the case and therefore supports this prediction. It seems that the communication hypothesis therefore goes some way to understanding the development and maintenance of challenging behaviour, however it cannot explain the existence of challenging behaviour in PLD who do not have deficits in communication. This may be explained by the biological model, which argues that biological factors may contribute to the appearance of CBs in PLD, for example, in Lesch-Nyhan and Cornelia de Lange syndrome. But, although theses factors may occasionally be seen as sufficient they are never necessarily present for particular challenging behaviours. Equally, it was argued that ecological factors appear to be important in understanding challenging behaviours, although again these are not necessarily always present. These are just three of the many proposed factors involved in the genesis and maintenance of CB. It is important to note that these factors are not incompatible. There are, for example, demonstrations of effective behavioural treatments of SIB in people with Lesch-Nyhan syndrome (Bull and La Vecchio, 1978, cited in Murphy, 1999). There are also a number of services where ecological and operant views have been integrated (Emerson, 1990). It therefore seems that in order to fully understand CB it is necessary to develop an integrated model that would take into account all of these factors and their interactions. That is, that the way these factors interact is likely to be bi-directional, continuous and progressive. It is therefore vital for future research attempting to identify the factors which underlie the acquisition and maintenance of CB not to become clouded by too rigid an adherence to a particular psychological, medical or ecological perspective.
References


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Murphy, G. and Wilson, B. (1985) The development and maintenance of self-injurious behaviour in individuals who are mentally handicapped or autistic. In: *Self injurious behaviour: a collection of published papers on prevalence, causes, and treatment in people who are mentally handicapped or autistic*. Pp 90-102, BIMH Publications


Anxiety disorders in childhood are fundamentally different from anxiety disorders in adulthood. Discuss with reference to the theory and treatment of two anxiety disorders.
Introduction
Fear is the natural response to a stimulus which poses a threat to well-being, safety or security. This response includes cognitive, affective, physiological, behavioural and relational aspects (Herbert, 1994, cited in Carr, 1999). At a cognitive level, the stimulus or situation is construed as threatening or dangerous. At an affective level, there are feelings of apprehension, tension and uneasiness. At a physiological level, autonomic arousal occurs so as to prepare the person to neutralise the threat by fighting or fleeing from danger. With respect to behaviour the individual may either aggressively approach and confront the danger, or apprehensively avoid it (Carr, 1999). Fears and anxieties in children are a normal part of growing up and are seen as normal emotions which play important protective and adaptive functions during development. In adults, moderate levels of fear can serve as a regulatory function, helping individuals monitor behaviour. However, for some these fears intensify and persist over time. Too much fear or anxiety can be maladaptive, causing significant distress, impairment in functioning, or both. It is at this stage that an individual would warrant both a clinical diagnosis of anxiety disorder and clinical attention (Barratt, 1998).

In order to determine whether there is a fundamental difference between anxiety disorders in children and adults, two anxiety disorders will be referred to: panic disorder (PD) and post traumatic stress disorder (PTSD). A number of different theories have been used to try to understand the development and maintenance of these two disorders, however the focus here will be on cognitive theories and treatments for these disorders as these predominate the literature on anxiety disorders.

PD in adults
Panic attacks (PAs) are defined as rapid-onset, discrete periods of intense fear or discomfort, characterised by at least four symptoms from a list of thirteen somatic and cognitive anxiety symptoms. In order for an individual to receive a diagnosis of PD according to DSM-IV (APA, 1993) the individual must experience an occurrence of one full-symptom unexpected PA followed by either four attacks occurring within any four-week period or any fear of having another attack (anticipatory anxiety) for at least one month. DSM-IV (APA, 1993) divides PD sufferers into two groups, PD with agoraphobia (PDAG) and PD without agoraphobia.

The lifetime prevalence of PD in the general population is about 6-12% (Craske, Rapee and Barlow, 1992), and six-month prevalence is estimated to be 0.6-1% (Hoen-Saric and McLeod,
In adults, the disorder is approximately two to three times more prevalent in females (Robins, Helzer, Weissman, 1984).

Cognitive model of PD (Clark, 1986)
The cognitive theory of panic states that "individuals who experience PAs do so because they have a relatively enduring tendency to interpret a range of bodily sensations in a catastrophic fashion. The sensations that are misinterpreted are mainly those involved in normal anxiety responses, for example, palpitations, breathlessness, dizziness, but also include some other sensations. The catastrophic misinterpretation involves perceiving these sensations as indicative of immediately impending physical or mental disaster. A wide range of stimuli can provoke attacks. External stimuli, such as a situation in which an individual has previously experienced a PA, can provoke an attack, but it is more often internal stimuli, such as thoughts, images, or bodily sensations. If these stimuli are interpreted as a threat, a state of apprehension occurs, which is itself associated with a wide range of bodily sensations. If these anxiety-induced sensations are themselves interpreted in a catastrophic fashion, a further increase in apprehension occurs, which produces more bodily sensations, leading to a vicious cycle that culminates in a PA" (Clark, 1986).

The cognitive theory of panic accounts for PAs that are preceded by a period of heightened anxiety and for those that are not, and instead appear out of the blue. For both types of attack it is argued that the critical event is the misinterpretation of bodily sensations. In attacks preceded by a period of heightened anxiety, these sensations are usually a consequence of the preceding anxiety, which in turn is due to anticipating an attack or some other anxiety-evoking event unrelated to panic. In attacks not preceded by elevated anxiety, the misinterpreted bodily sensations are initially caused by a different emotional state such as anger or excitement, or by innocuous events such as exercising or drinking too much coffee. In such attacks patients frequently fail to distinguish between the triggering sensations and the subsequent panic and so perceive the attack as having no cause and coming out of the blue.

Once an individual has developed a tendency to catastrophically interpret bodily sensations, three other factors contribute to the maintenance of PD. Firstly, individuals with PD selectively attend to bodily events and this increased bodily focus can contribute to a lowered threshold for perceiving bodily sensations. Secondly, panic patients develop situational safety-behaviours aimed at preventing feared catastrophes. These responses prevent disconfirmation of belief in catastrophe and can intensify bodily symptoms, making catastrophe more believable. Finally, individuals with PD tend to avoid anxiety-provoking situations, therefore
restricting the opportunity to realise that anxiety does not tend to lead to catastrophe (Wells, 1997).

Treatment for PD in adults

According to the cognitive theory of panic, it should be possible to treat naturally occurring PAs by helping patients to reduce their tendency to interpret bodily sensations in a catastrophic fashion. Cognitive behaviour therapy (CBT) aims to reduce anxiety by teaching patients how to identify, evaluate, control, and modify their negative danger-related thoughts and associated behaviours, in response to somatic cues (Craske, Rapee and Barlow, 1992). CBT involves a wide range of cognitive and behavioural procedures to help patients change their misinterpretations of bodily sensations and to modify the processes that tend to maintain misinterpretations. Cognitive techniques used include reviewing a recent PA to derive the vicious circle model, identifying and challenging patients’ evidence for their misinterpretations, substituting more realistic interpretations, and restructuring images. Behavioural procedures involve inducing feared sensations, through a number of techniques, such as hyperventilation, in order to demonstrate the true cause of the panic symptoms, patients are then instructed to drop safety-behaviours and enter feared situations in order to allow them to disconfirm their negative predictions about the consequences of their symptoms (Clark, 1996). Recent trials of CBT for PD have observed panic-free rates of 71-87%, averaging 83% in short-term trials. Short-term gains are generally maintained even after therapy is discontinued (Brown and Barlow, 1995). Meta-analyses suggest that CBT is certainly as effective as, if not more effective, than pharmacotherapy (Chambless and Gillis, 1993, cited in Ballenger, 1999), and cognitive techniques combined with exposure treatment are the treatment of choice for panic disorder (Roth and Fonagy, 1996).

PD in children and adolescents

While the existence of PAs and PD is well established in the adult population, much interest currently exists regarding the prevalence of these phenomena in children and adolescents. A number of different studies have been carried out to determine prevalence rates of PD in children and adolescents. These studies have led researchers to conclude that there is little reason to doubt the occurrence of PD in children and adolescents. However, this does not answer the question of whether PD has the same clinical presentation in children and adolescents as that found in adults.
Panic disorder in adolescents

King, Ollendick, Mattis, Yang and Tonge (1997, cited in Ollendick, 1998) investigated PD in 649 unselected Australian youth between twelve and seventeen years of age. They reported that 16% of the subjects had experienced at least one full-blown PA in their lifetime. About twice as many girls as boys reported full-blown PAs. The most frequently endorsed symptoms were trembling, dizziness/faintness, pounding heart and sweating. Cognitive symptoms were reported less frequently than somatic symptoms. Fear of dying was reported by 38.7% of the sample, and fear of going crazy or losing control by 56.7% of the sample. Subjects were also asked about events or situations in which their panic usually occurred. The most frequently endorsed situations were being separated from someone important or walking alone at night, however approximately 21% of subjects indicated that their PAs typically occurred unexpectedly or “out of the blue”. Ollendick (1995) found that four adolescents meeting full criteria for PDAG also reported elevated levels of anxiety sensitivity on the Childhood Anxiety Sensitivity Index, a measure of the tendency to interpret anxiety symptoms as dangerous and to react fearfully to related bodily sensations. It therefore appears that adolescents do experience cognitive symptoms, although with less frequency than physiological symptoms, and are able to make the catastrophic misinterpretations necessary to evidence a true PA, and that these symptoms are experienced as spontaneous. That is, the clinical presentation of PD in adolescents is very similar to that found in adults and in this sense appear to be consistent with the cognitive model. However, there is limited research investigating whether adolescents are concerned about future PAs, avoid anxiety-provoking situations, selectively attend to bodily sensations and engage in safety behaviours. It is therefore important that further research is carried out addressing these areas.

Panic disorder in children

As noted above, many studies have shown that panic and related symptomatology occur in children. However, Nelles and Barlow (1988) have argued that spontaneous PAs as described by the cognitive model of panic (Clark, 1986), are rare or nonexistent in children. This argument was based upon work undertaken by Bibace and Walsh (1977, cited in Ollendick, 1998) who defined a developmental progression of children’s conceptions of the causes of physical illnesses. They proposed that very young children aged two to six years engage in “phenomenism”, that is, they attribute the cause of illness to phenomena present in the immediate environment, but which the child has no direct physical contact with; children aged seven to ten years are able to differentiate between what is internal to the self and what is external, and view illness as being caused by an external stimulus that contaminates the body through physical contact, that is “internalisation”. The next stage reflects the greatest degree
of differentiation between the internal world and the external environment. “Physiological” explanations denote the source of illness as manifested within internal physiological structures, although external events may serve to trigger malfunctioning. “Psychophysiological” classifies the most sophisticated explanation of illness. This involves identifying internal structures and processes as causing illness, but also recognises the role of psychological factors.

Based on this model, Nelles and Barlow (1988) concluded that children’s cognitive responses are dominated by notions of external causality and they therefore lack the ability to catastrophically misinterpret somatic symptoms, prior to reaching the psychophysiological stage, evident in adolescence. However, contrary to these ideas, it is possible that even though children may perceive the inhalation of germs as causing their panic, they may still interpret the meaning of their panic symptoms as signalling they may be dying or losing control, and therefore although they do not identify internal, psychological factors as causing their panic, they may still interpret their symptoms as catastrophic. There is also evidence that although physiological and psychophysiological conceptions of illness are most typical of adolescent thinking, they are not necessarily restricted to this group. Mattis and Ollendick (1997) tested this out by exploring cognitive responses to somatic symptoms of panic in eight, eleven and fourteen-year-old children. They administered the Bibace and Walsh (1980) Conceptions of Illness Questionnaire and a Panic Attribution Checklist. The results found that the majority of children at each age level reported psychophysiological conceptions for the somatic symptoms of panic.

According to DSM-IV criteria for PD, PAs must occur spontaneously. The presence of spontaneous PAs have only recently begun to be reported in preadolescence and it is currently believed that spontaneous PAs are rare in prepubertal children (Dummit and Klein, 1994).

Research has shown that PAs and PD do occur in children, although, less frequently than in adolescents. Mattis and Ollendick (1997) found that some children aged eight to fourteen are cognitively capable of making catastrophic misinterpretations of body sensations, however it remains to be determined whether children under eight years also have this capability. It has also been shown that a small number of children experience PAs spontaneously, although Ollendick (1998) reported that most PAs in children are associated with particular events and not “unexpected or out of the blue”. It therefore appears that the cognitive model of panic is better able to account for PAs in older children and adolescents, rather than younger children. However, a more complete understanding of the cognitive manifestations of PAs and PD
among children needs to be investigated further, in particular looking at the developmental progression in children’s cognitive responses to panic symptoms.

_Treatment of PD in children and adolescents_

Most of the literature on the treatment of PD in youngsters consists of either case studies, or small uncontrolled trials, with patients consisting of adolescents. Ollendick (1995) treated four adolescents with PDAG, aged 13-17 years with an adapted version of CBT. Treatment involved information about the nature of panic, progressive muscle relaxation, breathing retraining, cue-controlled relaxation and applied relaxation, self-instruction training, problem-solving training and graded situational exposure. Results showed that PAs were eliminated, and agoraphobic avoidance was reduced. Patients were also more confident about coping with future PAs. Gains were maintained at six-month follow-up.

It therefore appears that CBT is useful in treating PD in adolescents, as long as it is tailored to meet the patient’s developmental level. No controlled treatment outcome studies have been conducted investigating CBT in children with PD. If children do have the cognitive capability to misinterpret bodily sensations, then CBT tailored to meet the child’s developmental level, may be appropriate. If however PD is phenomenologically different in children, due to different developmental cognitive levels, as has been suggested, then it may be that purely behavioural interventions, based on exposure-based approaches to the management of PD in adults, are more appropriate. This would involve providing an explanation of PD and a rationale for treatment, that can be comprehended by children. Parental support would be enlisted in order to help youngsters develop relaxation and self-instructional coping skills. Relaxation can involve either progressive muscle relaxation, or visualisation. Treatment would then involve developing exposure programmes for both feared internal somatic signs of hyperarousal in order that children learn that internal signs of arousal are not indicative of impending danger. Once exposure to internal arousal has been completed, exposure to feared external stimuli may be conducted. As yet no controlled trials have been carried out investigating treatments of PD in children. Further research therefore needs to be undertaken investigating these.

_PTSD in adults_

PTSD is a common reaction to traumatic events such as assault, disaster or severe accidents. DSM-IV criteria (APA, 1994) state the individual must have been exposed to a traumatic event that is out of the range of normal human experience, and their response to this event must have also involved intense fear, helplessness, or horror. Symptoms include persistently
reexperiencing the traumatic event, persistent avoidance of stimuli associated with it (including thoughts) and persistent symptoms of increased arousal, that were not present before the trauma. Symptoms must be present for at least one month.

The lifetime prevalence of PTSD was reported to be 1% in the general population (Helzer, Robins and McEvoy, 1987, cited in Tarrier, Pilgrim, Sommerfield, Faragher, Reynolds, Graham and Barrowclough, 1999), however rates vary depending on the traumatic event. For example, Kilpatrick and Resnick (1993, cited in Roth and Fonagy, 1996) in a retrospective study, note that 35% of rape victims report symptoms of PTSD. Curran, Bell, Murray, Loughrey, Roddy and Rocke (1990) reported that 50% of the survivors of the Enniskillen bombing in Ireland had symptoms of PTSD.

Cognitive model of PTSD (Ehlers and Clark, 1999)
PTSD is classified as an anxiety disorder, despite it being a disorder in which the problem is a memory for an event that has already happened. It is argued that individuals who go on to suffer persistent PTSD do so because they process the traumatic event and/or its sequelae in a way which produces a sense of serious current threat. According to the cognitive model of PTSD this is as a result of two key processes. Firstly, individual differences in the appraisal of trauma and/or its sequelae, may lead to a sense of current threat. This threat can be either external, for example, individuals may draw negative conclusions about their safety and the meaning of the world, or more commonly, internal, for example, a threat to one’s view of oneself as a capable person. Negative appraisals of one’s behaviour, emotions or thoughts during the trauma can also have long-term implications. Negative appraisals of the trauma sequelae, including interpretation of one’s initial PTSD symptoms, interpretation of other’s reactions and appraisals of the consequences that the trauma has in other life domains, may themselves produce a sense of current threat. Secondly, it is believed that individual differences in the nature of the trauma memory can lead to a sense of current threat. Individuals with PTSD often find that they have difficulty in intentionally recalling a complete memory of the trauma, giving rise to symptoms such as memory blanks (Foa and Riggs, 1993, cited in Ehlers and Clark, 2000). They may also find that they experience a high frequency of involuntarily triggered intrusive memories of the event in a vivid and emotional way. It is proposed that persistent PTSD is associated with a failure to elaborate and integrate the trauma memory into the individual’s broader base of autobiographical memories. It is also believed that in persistent PTSD S-S and S-R associations are particularly strong for traumatic material. Therefore distinct stimuli that were present before or during the traumatic event therefore become associated with the default prediction of danger to oneself, and cue-driven
memories may elicit strong affect without recollection of the trauma itself. Individuals with persistent PTSD are also more likely to notice cues associated with the trauma.

Once activated, the perception of current threat is accompanied by intrusions and other reexperiencing symptoms, symptoms of arousal, anxiety and other emotional responses. The perceived threat also motivates a series of behavioural and cognitive responses, such as avoidance and safety-seeking behaviours. These strategies maintain the disorder in three ways. Firstly, they may directly increase specific PTSD symptoms. Secondly, they may prevent change in the appraisal of the traumatic event. Finally, safety-behaviours prevent disconfirmation of negative appraisals. Other behavioural and cognitive responses include use of alcohol or medication to control anxiety, giving up or avoiding activities that were important before the traumatic event, rumination about the trauma and its consequences, and dissociation when reminded of the trauma.

A number of factors are likely to increase the likelihood that an individual will make negative appraisals of the trauma and/or its sequelae. These include cognitive processing during the trauma; characteristics of the trauma, such as duration and predictability; previous experiences of trauma and coping styles used during these events; low intellectual ability; prior beliefs, and state factors, such as alcohol consumption or fear.

Treatment for PTSD in adults
According to the cognitive model of PTSD (Ehlers and Clark, 1999) the central goal of therapy for PTSD is to “put the trauma in the past”. In order to do this changes need to be made in three areas. Firstly, the trauma memory needs to be elaborated and integrated into the context of the individual’s preceding and subsequent experiences. Secondly, problematic appraisals of the trauma and/or its sequelae need to be modified. Finally, dysfunctional behavioural and cognitive strategies need to be dropped. A number of cognitive–behavioural interventions have been developed to address these issues. CBT involves exposure, focusing on the trauma per se, cognitive restructuring (CR), focusing on the meaning and the emotional consequences of the trauma, or a combination of both. The aim of imaginal exposure (IE) is to produce habituation of emotional responses. Patients are instructed to close their eyes and relive the trauma imagining it as vividly as possible and describe it aloud using the present tense. Patients are asked to rate their levels of distress at regular intervals to help identify hot spots. Reliving is repeated as many times as possible during the session. Sessions may be audiotaped so that the patient can listen to the tapes in between sessions. Reliving may also be done through writing down a detailed account of the event (Resick and Schnicke, 1993, cited
in Ehlers and Clark, 2000). Treatment may also involve in vivo exposure to avoided reminders of the trauma.

CR aims to be emotion-focused and elicit patients' beliefs about the meaning of the event and the attributions they made following it, taking into account their previous belief system. Maladaptive cognitions and patterns of emotions are identified and modified. Behavioural experiments may be used to provide evidence to contradict beliefs. Patients are also encouraged to drop safety-behaviours that may be preventing negative cognitions from being modified.

Evidence from controlled studies suggests that therapies involving imaginal exposure (IE) and/or CR are effective in reducing PTSD symptoms. Tarrier et al. (1999) compared the effectiveness of IE and CT in the treatment of PTSD. The results showed a significant improvement over treatment that was maintained at follow-up for both treatments. No significant differences were found between treatments. The current treatment of choice appears to be a combination of cognitive techniques and exposure (Roth and Fonagy, 1996).

**PTSD in children and adolescents**

It was first thought that some of the symptoms necessary for a diagnosis of PTSD were developmentally inappropriate for younger people, and that the younger the child, the less appropriate the diagnosis. However, work with children with PTSD has shown that they do show the tripartite symptoms seen in adults, although it appears that cardinal symptoms may manifest differently at different ages, and a range of other reactions is also common (Yule and Williams, 1990, cited in Smith, Perrin and Yule, 1998). Most children are troubled by repetitive, intrusive thoughts about the event. In young children these may be expressed through repetitive play and drawing in which themes or aspects of the trauma are expressed, or through trauma-specific re-enactment. Although there appears to be little evidence of emotional numbing in children, some children show loss of interest in activities, become socially more withdrawn, and show loss of affect. Preschool children show more regressive behaviour, as well as more anti-social and destructive behaviour. Sleep disturbances and nightmares, without recognisable content, are common. Vivid flashbacks are not uncommon. Many children become very alert to danger in their environment and tend to avoid trauma-related stimuli and reminders of the event. Separation difficulties are frequent, even among teenagers. Many children become more irritable and angry. Child survivors often experience a pressure to talk about their experiences, but also find it very difficult to talk with their parents...
and peers. Children also report a number of cognitive changes, such as, concentration difficulties or memory problems. Many children feel that the world is a much more dangerous place. In addition, a range of other reactions is also common, including depression and anxiety, particularly in adolescents, and prolonged grief reactions.

Like adults, not all children exposed to a traumatic event go on to develop PTSD (Schwarz and Kowalski, 1991, cited in Smith, Perrin and Yule, 1998). According to the cognitive model of PTSD adults who go on to develop PTSD do so because of individual differences in the appraisal of the trauma and/or its sequelae, and individual differences in the trauma memory. This raises the question of whether this model of PTSD can be used to account for differences in the aetiology and maintenance of PTSD in children and adolescents.

Although developed from the work with traumatised adults, there is emerging evidence that individual differences in processing emotional reactions, including the role of threat appraisal, attributional processes, and attitudinal changes central to cognitive accounts of PTSD in adults are also important factors in children. Stallard, Velleman and Baldwin (1998) investigated PTSD in children involved in road traffic accidents. They found that the personal meaning of the event for the child, previous experience of trauma and the appraisal of threat to life were significantly related to the development of PTSD. Moradi, Taghavi, Doost, Yule, and Dalgleish, (1999) carried out a modified Stroop colour-naming task on children and adolescents with PTSD, aged nine to seventeen. The findings indicated a specific attributional bias to trauma-related material in children and adolescents with PTSD. Joseph, Brewin, Yule and Williams (1991) provide further evidence that attributional processes in children can mediate symptoms. They investigated attributions of sixteen adolescent survivors of the Jupiter ship disaster. The results showed that more internal and controllable attributions were related to intrusive thoughts and feelings of depression one year after the accident. Johnson, Foa, Jaycox and Rescorla (1996, cited in Smith, Perrin and Yule, 1998) reported evidence of attitudinal changes in children who survived an earthquake, which were related specifically to PTSD symptomatology. These findings are consistent with the adult literature regarding shattering of pre-trauma assumptions.

Although there is evidence that the form of PTSD varies with age, there are too few studies to examine whether children of different ages are at different risk of developing PTSD. Keppel-Benson and Ollendick, (1993, cited in Yule, 2001) argue that very young children may be protected from strong emotional reactions because of their limited cognitive capacity. That is, children’s awareness of the possible serious consequences of any event will be related to both
their understanding of causality and their understanding of the concept of death. Based on Piaget's theories of child development, it was first believed that children do not completely understand death until they reach age thirteen (Yule, Perrin and Smith, 1999). It is now believed that children as young as four can have partial, and sometimes complete understanding of death. Therefore if these children are involved in a traumatic event, since they are aware of their own mortality they may go on to develop PTSD. However other children of the same age may not appreciate the dangers they faced, and so may be protected from developing PTSD.

It was also questioned whether children who are traumatised before they have developed expressive language can have memories that affect their development. However it is now believed that although verbal memories cannot be accessed prior to about 2½ to 3 years, pre-verbal children have non-verbal memories that affect their behaviour and adjustment (Yule, 2001).

In summary, children and adolescents who survive a life-threatening disaster show a wide range of symptoms which tend to cluster around re-experiencing, avoidance and increased arousal. These symptoms are very similar to those seen in adults with PTSD, although it appears that there are some differences in their presentation depending on the child's developmental stage. There is therefore some evidence to support the use of the cognitive model of PTSD for children and adolescents, however it is also important to take into account children's cognitive developmental stage, as this will influence their ability to negatively appraise the traumatic event and/or its sequelae. In order to gain a fuller understanding of the aetiology and course of PTSD in childhood, further research needs to be carried out investigating the long-term course of PTSD in children and adolescents, particularly preschool children, the way in which children explain and ascribe meaning to traumatic events, descriptions of their post-traumatic attitudes towards the world and themselves, and changes in information processing.

Treatment of PTSD in children and adolescents

As yet there have been few randomised-controlled studies investigating effectiveness of treatment for PTSD in children and adolescents. Treatment approaches are predominantly cognitive-behavioural and appear to consist of adaptations of approaches used with adults (Yule, 1991, cited in Yule, 2001). CBT begins with the provision of information about the effects of trauma, and a rationale for treatment, to both parents and the child. As with adults CBT uses imaginal or in vivo exposure, to facilitate emotional processing of the traumatic
material. The clinician assists the child to recall the event and re-experience all relevant thoughts and emotions in a safe and trusting environment. For many children, talking about the traumatic event may be too difficult, and other means of accessing traumatic memories may be found, such as asking children to draw their experiences, or play can be used with younger children. Exposure takes the same format as in adult work, although children are frequently taught coping skills, such as relaxation, positive self-talk or imagery, and problem-solving before exposure is carried out. Psychoeducation of parents and teachers about PTSD and their inclusion in treatment assists in fostering a therapeutic milieu (Seedat, Kaminer, Lockhart and Stein, 2000). For example, parents may be asked to reward the child’s use of positive coping behaviours in between treatment sessions. Parents are also given regular feedback on the child’s progress and are prepared for any short-term increases in PTSD symptoms. Intervention may also include components to treat other common reactions such as sleep disturbance, separation anxiety, anger and conduct problems, prolonged grief reactions, and generalised anxiety. In older children and adolescents, cognitive restructuring may be used to counter misattributions of predictability, causality and responsibility. Work with younger children may address any misunderstandings about the causes of the event (Smith, Perrin and Yule, 1998).

Where there are large numbers of children involved in a traumatic event, group treatments are the preferred treatment. The aims of such therapeutic groups include the sharing of feelings, boosting the children’s sense of coping and mastery, and sharing ways of common problem-solving.

Controlled treatment and case studies provide support for the effectiveness of CBT in individual, parent and child, or group format. There is general consensus that CBT in the form of prolonged therapeutic exposure and cognitive restructuring is the “first-line” treatment for PTSD in children and adolescents (Perrin, Smith and Yule, 2000). However there is a need for further treatment-outcome studies of PTSD in children and adolescents.

Discussion
Cognitive models have been used to attempt to explain the development and maintenance of different anxiety disorders in adults. These models have led to the development of specific assessments and empirically supported interventions. Recent research has investigated whether these models can be successfully applied to children and adolescents with anxiety disorders. It has been found that that the cognitive model of panic is better able to account for PAs in older children and adolescents, rather than younger children. CBT is therefore an
appropriate treatment for PD in adolescents, as long as it is tailored to meet the patient's developmental level. Whereas it seems that purely behavioural interventions, are more appropriate for younger children.

Research has shown that there is some evidence to support the use of the cognitive model of PTSD for children and adolescents. However it may not be able to explain PTSD in very young children. Treatment for PTSD in children and adolescents are predominantly cognitive-behavioural and appear to consist of approaches used with adults, adapted to meet the child's developmental level.

In summary, it appears that some cognitive theories of anxiety disorders can be used to account for those disorders in both children and adolescents, whereas other theories may only be applied to older children and adolescents, and it may be more appropriate to understand the disorder in terms of a developmental model, rather than a cognitive model. As a result certain adult treatments may be administered to children and adolescents effectively, as long as they are adapted to meet the patient's developmental level, whereas other treatments may be inappropriate for some children. In order to gain a more complete understanding of whether adult theories and treatments of anxiety disorders can be applied to children and adolescents, further research needs to be carried out investigating the aetiology and course of these disorders, in particular addressing the developmental progression in children's cognitive abilities, as well as investigating more controlled treatment trials in this area.
References


'Dementia cannot be cured. It takes its course'. Critically evaluate with a discussion of known theories of causes and treatment approaches.

July 2002

Year 2
Introduction
Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is a disturbance of multiple higher cortical functions, including memory, thinking, language, and judgement, in someone of previously normal intellect. The primary requirement for a diagnosis of dementia is evidence of a decline in both memory and thinking which is sufficient to impair personal activities of daily living, such as washing, dressing, eating, personal hygiene, and toilet activities (ICD-10). The impairment of memory typically affects the registration, storage, and retrieval of new information, but previously learned and familiar material may also be lost, particularly during the later stages of the dementia. (ICD-10). In addition to a declining memory there must also be one of the following symptoms: spatial disorientation, language disturbances, reduced practical abilities, and personality changes (Gustafson, 1996). Alongside this there may also be impairment of thinking and reasoning capacity, and a reduction in the flow of ideas. The processing of information may also be impaired, so that, the individual finds it increasingly difficult to attend to more than one stimulus at a time. There may also be a number of behavioural and psychological symptoms, including aggression, agitation, wandering, screaming, sleep disturbances, sexual inhibition and apathy (Dunkin and Anderson-Hanley, 1998). In order for a diagnosis of dementia to be made, consciousness must not be clouded and symptoms must have been evident for six months (ICD-10).

The clinical features described above are known as primary symptoms of dementia, since they are believed to be more directly determined by localisation and severity of brain damage. However, there may also be secondary symptoms of dementia. These include other psychiatric features, such as anxiety, depression, suspiciousness, delusions and obstinacy. This group of symptoms appear to be more related to the patient’s reaction and adaptation to the cerebral disorder, rather than the disorder itself (Gustafson, 1996).

Dementia is predominantly a disorder of later life. Its prevalence and incidence rise sharply with advancing age. It has been estimated that dementia affects approximately 5% of people over the age of 65, and 20% of those over 80 (Terry and Katzman, 1983, cited in Midence and Cunliffe, 1996), with around 400,000 sufferers in the United Kingdom (O’Brien and Ballard, 2001). There are a number of different types of dementia, including Alzheimer’s Disease (AD), Vascular Dementia, and Lewy body-type dementia. AD is the most common form of dementia, accounting for more than half of all cases of dementia. AD is usually insidious in onset and develops slowly but steadily over a period of years. This period can be as short as two to three years, but can occasionally be considerably longer (ICD-10). AD usually begins
after age 65, however, its onset may occur as early as age 40. Early behavioural manifestations of AD include memory decline. Subsequently, there may be transient confusion, deficits in intellectual and general cognitive functioning, language deficits and changes in personality (Bradshaw and Mattingley, 1995). This essay will largely focus on AD, since it is the most frequent cause of dementia in Western societies (Erkinjuntti, 1999).

**The biomedical model of dementia**

At present the biomedical model is the dominant model for understanding dementia. According to the biomedical model of AD, there are characteristic changes in the brains of patients with AD. This involves a marked reduction in the population of neurons, particularly in the hippocampus, substantia innominata, locus ceruleus, and temporoparietal and frontal cortex. Neuroimaging of the patient with AD may reveal atrophy of the brain, such as enlarged ventricles and sulci, and narrowed gyri, although these features are not always present. Neuronal loss is the main neuropathologic feature underlying the symptoms of AD. Microscopically, AD is characterised by the presence of senile plaques and neurofibrillary tangles (NFTs). These plaques are extracellular deposits of filamentous B-amyloid, a protease cleavage product of amyloid precursor protein. NFTs are formed intracellularly by the abnormal rearrangement of microtubule-associated proteins, such as tau (Zurad, 2001). Both NFTs and senile plaques may also be present to some degree in the brains of elderly persons without dementia. However, they are usually relatively diffuse and consist of relatively benign deposits of B-amyloid, whereas in patients with dementia, the plaques assume a compact B-pleated conformation and subsequently become associated with dystrophic neurites. These later stage plaques are thought to represent a more neurotoxic form (Zurad, 2001).

The biomedical model of AD also proposes that many neurotransmitter systems are affected in AD. However, degeneration in the cholinergic system occurs earlier and more consistently than in other systems, and these changes appear to be closely correlated with the presence of plaques and NFT. Markers for cholinergic neurons, such as, choline acetyltransferase and acetylcholinesterase (AChE), which are enzymes responsible for the synthesis and degradation of acetylcholine (ACh), respectively, are deceased in the brains of persons with AD. This occurs particularly in the cortex and hippocampus, areas of the brain involved in cognition and memory. The resultant decrease in ACh-dependent neurotransmission is thought to lead to the functional deficits in AD (Zurad, 2001).

Other neurochemical changes found in the brain of patients with AD include significant increases in levels of Butyrylcholinesterase (BuChE), an enzyme, like AChE, that degrades
ACh. This enzyme, found only at low levels in the normal brain, is also more widely
distributed in the brains of patients with AD. In addition, BuChE is also thought to play a
causative role in senile plaque maturation. It is these alterations in the cholinergic systems that
occur in patients with AD that are thought to be the key factors in the cognitive and functional
deficits associated with the disease (Zurad, 2001).

Evidence for the biomedical model
The biomedical model assumes a causal relationship between neuropathology and dementia.
Evidence for this model comes from examinations of brains of patients with AD. Research has
found that in patients with AD there is massive cell loss in the hippocampus, which is
concerned with memory; the amygdala, which is concerned with emotion and personality; the
olfactory areas, causing the problems in the sense of smell which often appear early on in AD,
and in the entorhinal limbic system, which connects to the hippocampus. There is also
extensive cell loss in cortical areas, including the parietal cortex, causing spatial problems and
anosognosia; the temporal cortex, leading to agnosia and aphasia, as well as memory deficits,
and the frontal cortex, causing strategic difficulties, executive and social problems (Bradshaw
and Mattingley, 1995). It has also been shown that the loss of cholinergic transmission
progresses at the same rate as the disease advances (Doody, 1999).

Further evidence for the role of the cholinergic system in AD comes from Winkler, Suhr,
Gage, Thal and Fisher (1995, cited in Doody, 1999) who reported that experimentally
inducing a cholinergic deficiency resulted in cognitive impairment, which was reversible with
cholinergic therapy.

Medical treatment for AD
The discovery of the role of the cholinergic system in cognition led to the hypothesis that
pharmacological enhancement of cholinergic function, by enhancing or maintaining central
concentrations of ACh, may alleviate the cognitive symptoms of dementia. This can be
achieved through cholinergic agents, either cholinesterase (ChE) inhibitors, or by cholinergic
agonists. Within the past three years three cholinesterase inhibitors: donepezil, rivastigmine,
and galantamine, have been licensed in the United Kingdom for use in mild to moderate AD.
These compounds represent symptomatic treatments and have been shown in several large,
randomised, placebo-controlled trials to improve cognitive function, global outcome, and
activities of daily living (ADL). There is also growing evidence that they may also improve
non-cognitive symptoms, such as psychosis and apathy (O'Brien and Ballard, 2001). Due to
shortage of space only one of these will be discussed further: Donepezil.
Donepezil, also known as Aricept, is a piperidine-based anticholinesterase. Donepezil was specifically designed for the symptomatic relief of AD. To date, there have been a number of randomised-controlled trials investigating its efficacy. Since the clinical manifestations of dementia are threefold, that is, cognitive impairment, non-cognitive features, such as, psychiatric symptoms and behavioural disturbances, and ADL, measurements of drug efficacy need to take into account changes in these three domains. Rogers et al. (1998) carried out a 24-week, double-blind, placebo-controlled trial of Donepezil in 473 patients with AD. The results showed that cognitive function, as measured by the AD assessment scale (ADAS-cog), was significantly improved in the 5- and 10- mg/d Donepezil groups, as compared with placebo at weeks 12, 18, and 24 (p<0.0001). They also reported improvements in global functioning and in ADL in these two groups, although there was no difference between drug doses. At the end of the study they carried out a 6-week placebo washout phase. During this phase they found that there was no significant difference on the outcome measures between the three groups. However this treatment did have some drawbacks, in that a number of patients reported cholinergic side effects, such as diarrhoea, nausea, and vomiting. Although these were transient and generally mild. Overall the authors concluded that Donepezil is a well-tolerated drug that improves cognition and global function in patients with mild to moderate AD. Further studies have been carried out on Donepezil and the magnitude of change has been similar in each of the studies, that is, around three points on active drug compared with placebo on the ADAS-Cog, which is highly statistically significant. These outcome studies also provide further support for the biomedical model of AD, particularly the role of ACh.

As well as being highly efficacious, Donepezil is also well absorbed and results in predictable dose-related plasma concentrations. It has a long half-life of approximately 70 hours, permitting once-daily dosing. However, it is only effective whilst the drug is being taken and once discontinued, all effects will be lost (Doody, 1999).

There have also been a number of trials of other pharmacologic treatments of AD. A 2-year double-blind, placebo-controlled study was conducted using both vitamin E and a monoamine oxidase inhibitor. Treatment with one or both of these agents resulted in significant delays in time to death, rates of institutionalisation, and loss of ADL (Shadlen and Larson, 1999, cited in Zurad 2001). Anti-inflammatory agents also appear to have a role in the treatment of patients with AD. Several retrospective studies have found that patients treated with these agents for diseases such as arthritis have a reduced risk of developing AD. In a randomised, double-blind trial of 44 patients with AD, treated with an anti-inflammatory agent, the results
showed significantly increased cognitive performance for the treatment group, compared with placebo (Rogers, Kirby and Hempelman, 1993, cited in Zurad, 2001).

Oestrogen has also been used to treat AD. Results from an open-label study suggest that oestrogen can improve cognitive function in patients with AD (Small, 1998, cited in Zurad, 2001). Gingko biloba, which is thought to have neuroprotective properties, has also been shown to produce benefits in one study (Burns, Russell and Page, 1999).

**Criticisms of the biomedical model**

According to Kitwood (1990) the biomedical model has certain fundamental flaws as a basis for explaining the dementing process. Correlations between the degree of dementia and the extent of neuropathological change established at postmortem leave ‘some 80% of the variance unexplained in moderate or severe dementia’ (Kitwood, 1989). There have also been cases of persons who have gone through the whole course of a dementing illness as classically described, but whose brains at postmortem showed no neuropathology beyond what would be typical for a person with no impairments (Homer, Honavar and Lantos, 1988, cited in Kitwood, 1999). Some people with dementia, have also been observed to, under certain conditions, deteriorate in their functioning very much faster than can be attributed to the consequence of progressive degeneration of nervous tissue. For example, following entry to a nursing home, a person may show a sudden decline in functioning. This may happen over a period of months, whereas changes in typical neurodegeneration, is likely to occur over a number of years. A third factor that provides evidence that the biomedical model cannot sufficiently explain the dementing process is the phenomenon of stabilisation, that is, the virtual arrest of deterioration under certain conditions (Bell and McGregor, 1991, cited in Kitwood 1999). Kitwood (1999) also describes a process called “rementing” whereby the patient with dementia recovers part of their abilities previously lost. Sixsmith, Stillwell and Copeland (1993) observed improvements in cognition and functional abilities, as well as a reduction in social disturbance in individuals in supportive, person-centred environments.

**Malignant social psychology**

Kitwood (1990) has therefore developed an interactionist model of dementia that he believes is better able to explain the heterogeneity of behaviour in dementia, than the biomedical model. This model states that although the underlying pathology eventually leads to a degrading incapacity, prior to this, both environmental and psychogenic factors influence the rate and pattern of change seen in the individual, thus providing an explanation for the individual differences seen in the behaviour of those with dementia.
Kitwood (1990) described a “malignant social psychology” (MSP) around the person with dementia, which comprises negative attitudes and practices. He believes that this is a significant non-biological influence on dementia, which results in the patient with dementia feeling depersonalised, disempowered and stigmatised. Kitwood (1999) has argued that this MSP leads to a reduced function in people with dementia, and perhaps even increases in the rate of decline and neurological impairment. According to Kitwood (1999), dehumanisation, objectification and invalidation form the core of the MSP and are unfortunately pervasive throughout dementia care.

In his model of dementia (1993), Kitwood acknowledged a complex interaction between five factors, which result in dementia. These factors are personality, that is, resources for action; biography, that is, the person’s life story; physical health, neurological impairment and the social psychology that surrounds the person with dementia from day to day. Kitwood contended that the symptomatic presentation of dementia in an individual arises from a complex interaction from all these factors, but that the progression of dementia depends primarily on the interplay between neurological impairment and social psychology.

Kitwood (1990) proposed two fundamental equations: firstly, that dementia is compounded by the effects of neurological impairment and of MSP. Secondly, that neurological impairment in an elderly person attracts to itself MSP. That is, anyone with dementia may be distressed or devalued by the actions of those who care for them, those alongside whom they live, as well as by those who care for them. For example, those in formal care are liable to some degree of “institutionalisation maintenance”, while experiencing a social world that is little more than a group of strangers (Stokes, 2000).

Kitwood (1990) stated that the consequences of MSP may be devastating, and yet ‘the MSP is so much a part of the taken-for-granted world of later life that it generally passes unnoticed’. Kitwood (1990) even proposed that MSP might play a role in bringing about neurological impairment. In other words he believed that the psychological aspects of an environment may be as “dementogenic” as physical factors.

One of the most devastating consequences of MSP is the destruction of personhood in the individual with dementia. For personhood to be maintained “an individual needs not only to be in a relationship with others, but also to be accorded status... In terms of social status, it requires an acknowledgement of one’s subjectivity and uniqueness as an individual” (Kitwood, 1994, cited in Stokes, 2000). While a cognitively intact person can attempt to avoid
such malignancy, and replenish their personhood elsewhere, individuals with dementia and therefore lowered competence and interaction are more susceptible to their environmental influences (Woods, 1996, cited in Stokes, 2000).

This model challenges the determinism and pessimism that pervade the accepted “medical-disease” model of dementia (Stokes, 1996). It provides a framework for understanding dementia, which also includes behavioural ecology, and therefore generates greater explanatory power than is offered by the biomedical model. This model also highlights the need for an understanding of the person’s life-story, of his/her preferences, interests, values, relationships, achievements, and disappointments. It provides the potential means to slow down the rate of behavioural decline through identifying elements of a social psychology that make for well-being, for example, the provision of quality care settings (Stokes, 1996). Kitwood (1999) stated that when this is consistently done for half an hour, then the person gains enough confidence and security to cope well for the next two or three hours that follow, as if personhood has temporarily been restored. Kitwood (1999) gives five examples of such processes: holding, validation, facilitation, celebration and timulation. Holding is a metaphor for providing a safe and steady place where powerful and frightening emotions can be experienced, without the person being overwhelmed by the terror of disintegration or annihilation. This may well also involve physically holding the person with dementia (Kitwood, 1999). The second of these processes, validation means to accept the reality and “personal truth” of another’s experience, often in contrast to those who would dismiss it as unreal or of no account. This process is now widely used in dementia care, and will be discussed in more detail later. Facilitation refers to enabling the person to do things they might not otherwise be able to do, by providing the parts of the action schemata that are missing. For example, responding to a gesture in a way that evokes a further response, so that a solitary gesture is transformed into a complete action in the social world. Celebration involves the individual with dementia and their carer being together and doing something they enjoy, such as, dancing, having a good meal or walking. Timulation involves the direct and pleasurable stimulation of the senses, in a way that accords with the values of the person with dementia, for example, massage or the creation of a personal conversation through music. It is hypothesised that the direct involvement of the senses is a form of reality orientation (Kitwood, 1999). Again, this will be discussed further, later.

The above five processes are techniques of interacting with persons with dementia. However, each one demands something profound from the caregiver, something that may entail personal
change on their part. A number of more formal, structured interventions have also been
developed for working with individuals with dementia.

**Psychosocial treatments for dementia**

Psychological approaches to dementia range from quite specific interventions in attempts to
resolve clearly definable behaviour problems to more general approaches, including reality
orientation, reminiscence therapy and validation therapy. Behavioural interventions begin
with a detailed analysis of the specific problem behaviour and the context in which it occurs,
and then aim to change the person’s behaviour by altering triggers and/or consequences of the
behaviour. Behavioural interventions have been used to alter a number of different
behaviours, such as, wandering and self-stimulatory behaviour, suspicious and accusatory
verbalisations, and self-care skills (Midence and Cunliffe, 1996). However, there are few
reported studies of behavioural interventions on people with dementia.

Reality orientation (RO) involves providing accurate information aimed at orientating the
person to their surroundings. There are two different forms of RO, twenty-four-hour RO and
RO sessions. Twenty-four-hour RO involves a number of changes to the environment, with
clear signposting of locations around the ward or home, extensive use of notices and other
memory aids, and a consistent approach by all staff in interacting with the person with
dementia. RO sessions, which aim to improve cognition in dementia, are structured group
sessions, involving small numbers of patients and staff, meeting regularly, often several times
a week for about half an hour. These sessions involve a wide variety of activities and
materials to engage the patients with their surroundings, to maintain contact with the wider
world and to provide cognitive stimulation and memory training. A typical session would
begin with going over basic information, such as the names of participants, day, date, time and
place. This would be followed by a discussion of a current relevant theme of interest.
Throughout the session there would be a tangible focus, this could be a white-board for the
current information, or pictures or objects appropriate to the theme (Woods, 1999). This
would also involve the use of external memory aids, such as diaries or notebooks (Spector,
Orrell, Davies and Woods, 2001). Studies have shown that there is strong evidence that RO
results in increased scores on measures of verbal orientation. More recently it has been
proposed that RO may result in more wide-ranging improvements in cognition. However, as
yet it has not been shown to result in any changes in function and behaviour. Zanetti et al.
(2002) carried out RO with 38 mild-to-moderately demented outpatients. The intervention
consisted of four patients meeting daily, for one hour, five days a week for a month. Sessions
involved repetitive stimulation of patients’ autobiographical and semantic memory, attention,
language and orientation. The group discussed different issues and patients were encouraged to participate. Following RO they found a significant improvement in patients’ scores in overall cognitive functioning.

Another common intervention for dementia is reminiscence therapy (RT), in which, patients are encouraged to share memories, stimulated by newspaper files, photographs, films and other resources (Midence and Cunliffe, 1996). Thornton and Brotchie (1987) suggested that one of the main aims of RT is to challenge staff attitudes towards patients, by increasing the degree of staff-patient interaction and increasing the staff’s knowledge about the patients’ past experiences. Other goals of RT include increased communication and socialisation, and providing pleasure and entertainment. It can be implemented either on an individual or a group basis, and may be structured or free-flowing, with the focus on a relaxed positive atmosphere (Woods, 1999). Outcome research on RT is inconclusive. Baines, Saxby and Ehlert (1987, cited in Woods, 1999) compared RT and RO groups in a residential-home setting, with residents having a moderate to severe degree of cognitive impairment. They found some effects on cognitive and behavioural function following RT in a group of residents who had previously responded well to a month of RO. The residents showed a reduction in scores on a problem behaviour rating scale, as well as an increase in verbal orientation. However, other studies have reported no changes in cognitive or behavioural function following RT.

Validation therapy (VT) is widely used in the dementia care field. It is centred on the recognition of the individuality of the person with dementia and respect for their value as a person, and focuses more on the emotional communication of the person, rather than on cognitions. The aim of validation therapy is to empathically reflect and validate the person’s view of reality, with behaviour seen as likely to be resulting from a person’s life experience and unresolved conflicts, rather than on more immediate causes in the current environment (Feil 1993, cited in Woods, 2001). VT encourages carers to listen respectfully and sensitively to the feelings expressed, without being confrontational and to provide a safe, containing environment where strong emotions can be expressed and validated. In other words, validating and supporting the feelings of disoriented persons in whatever time or place is real to them, even though this may not correspond to the here and now reality. It is believed that responding at a cognitive level and correcting the person, may well miss an underlying key issue for the person with dementia. Painful feelings from the past that are expressed, acknowledged and validated in this way are thought to decrease in strength, whereas if ignored or not expressed they are believed to heighten. Specific techniques include many
aspects of nonverbal communication, such as, touch, eye contact, tone of voice, as well as music and reminiscence (Woods, 2001). There are only very few published outcome studies involving VT and findings from these are inconclusive.

Resolution therapy (ReT) is similar to VT in that it aims to understand the emotional communication of the person with dementia, through empathic listening skills. However it places less emphasis on unresolved issues from the past and focuses more on identifying feelings related to making sense of the current situation or expressing a current need. ReT involves many counselling skills, such as, warmth, acceptance, and reflective listening, to determine the underlying meaning or need. The intervention begins by focusing on the feelings of the person, then acknowledges them, both verbally and nonverbally, and then meets the need of the person through modifying the environment or the pattern of care. Again, there are few outcome studies measuring the efficacy of ReT.

Sensory integration therapy (SIT) is becoming increasingly popular in the treatment of dementia patients. It is based on the hypothesis that elderly people with dementia experience sensory deprivation and unchanging input, which may lead to increased confusion. A variety of methods have been used, including touch, bright lights, music and pets. Lord and Garner (1993, cited in Woods, 1999) evaluated the effects of music therapy on a group of patients with AD. They reported that the intervention group showed better recall of personal information, as well as improvements in their mood and social interaction. One form of SIT, "Snoezelen", aims to increase the amount of sensory stimulation through the use of changing coloured lights and visual effects, relaxing armchairs and cushions, pleasant smells, a vibrating cushion and a bubble machine. Evaluation of "Snoezelen" has shown that it results in increased relaxation, improved mood, and decreased agitation during the session, and may significantly reduce disturbed behaviour in the longer term (Woods, 1999).

A number of cognitive rehabilitation techniques have also been employed with persons with dementia, including reducing the cognitive load, external memory aids and enhancing new learning. It has been hypothesised that if cognitive demands can be reduced on the person, their retained abilities may be used more effectively. This can be done through environmental adaptations, such as simplifying the locating of important rooms through clear signposting, reducing the number of irrelevant and distracting sources of stimuli and making use of well-learned associations. External memory aids can also help to reduce the cognitive load, by removing the need for effortful, self-initiated cognitive processes and providing support for the person in cuing and prompting retrieval of information. Memory aids may include
watches, diaries and specially made booklets or wallets containing relevant pictures and information (Post, 2001). For aids to be effective they need a high degree of specificity and need to be placed so that the person will encounter the cue at the relevant time. The person with dementia may also need specific training to use the cue. Memory aids have been shown to be effective in a number of studies. Josephsson et al. (1993, cited in Woods 1999) used memory aids to reduce the load on the person’s memory and to support retrieval in daily living tasks in four patients with dementia. They found that the memory aids resulted in improvements in task performance.

It is thought that rates of forgetting are relatively unimpaired after the first ten minutes or so, so that if material can be adequately registered, retention is feasible. Several techniques to achieve this initial learning have been described. Spaced retrieval involves the learning of one item at a time, with the retrieval period being gradually increased each time the person correctly retrieves the item and reduced if the person is unable to retrieve the item. The next item is taught once the first item has been fully established (Woods, 1999). It is thought that this is able to enhance learning in patients with AD. For example, Camp, Foss and O’Hanlon (1996, cited in Woods, 2001) were able to teach patients with dementia to use a calendar listing activities using spaced retrieval.

Another way to enhance learning is through errorless learning, where the conditions of learning shape and prompt the correct response, so that learning proceeds without the person making errors. It is thought that when errors are made during learning, these interfere with the memory for the correct response, and so hinder performance (Woods, 1999). Procedural learning, where encoding proceeds through a motor act, or practice of a sequence of movements, has also been shown to be effective, even where the degree of dementia is severe (Woods, 1999). Priming, where exposure to an item enhances processing of that, or a related, item has also been shown to aid learning in patients with dementia (Woods, 1999).

Discussion
In summary, there are a number of interventions that result in either improving symptoms in patients with dementia or in stabilising patients at their current functioning level. Acetylcholinesterase inhibitors, such as Donepezil have shown varying levels of efficacy in slowing or reversing decline in the three key domains of AD: ADLs, behaviour and cognition. These have been shown to be safe and effective treatments in a number of randomised controlled trials. However, although they can improve function in the short-term, their effects are at best described as modest and at present these drugs are also only suitable for patients
Older Adults Essay

with a mild to moderate degree of impairment and are only effective whilst the drug is being taken.

A number of psychosocial interventions for persons with dementia have also been developed, such as, reality orientation, reminiscence therapy and cognitive rehabilitation, which have also been shown to result in symptomatic improvement in both cognitive and behavioural function in patients with AD. It has also been shown that changing the social environment, in which a person with dementia lives, provides the potential means to slow down the rate and pattern of decline seen in the individual. However, again the effectiveness of these interventions is far from satisfactory and many of these interventions are limited to patients who are at the earlier stages of dementia, whilst their cognitive abilities are intact.

It therefore needs to be acknowledged that although there are currently a number of treatments available for persons with dementia, these are only management techniques, and are not curative. They at best, only delay the progression of the dementia and to date, no treatments have been developed that are able to restore the integrity of the brain or reverse the progressive decline once the dementia is apparent.
References


Clinical Section

This section contains summaries of clinical 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, plus one specialist placement. The five clinical case reports are submitted in full in Volume Two of this portfolio, along with placement contracts, supervisor evaluation forms and full records of clinical activity.
Summary of Clinical Experience
**Placement Summaries**

**Adult Mental Health Placement** - Springfield Hospital; Morden Medical Practice

**Client demographics**
- Individual work with 9 clients (4 male, 5 female) ranging in age from 17 to 69
- Group work with clients whose ages ranged from 18 to 65

**Presenting problem / Issues**
- Depression
- Schizophrenia
- Bipolar affective disorder
- Panic disorder
- Bereavement
- Chronic pain
- Anger management

- Social phobia
- Obsessive compulsive disorder
- Self-harm
- Eating disorder
- Bullying
- Drug abuse

**Settings**
- CMHT outpatient; inpatient; GP practice

**Assessment procedures**
- Assessment interviews; Questionnaires: Maudsley Obsessive Compulsive Inventory;
  Neuropsychological assessment using WAIS-III, WMS-R

**Interventions**
- Solution focussed; Cognitive therapy; Cognitive behaviour therapy

**Other experience**
- Carried out Service Related Research Project
- Observed supervisor running an advice clinic in the GP practice
- Met with and observed work of other professionals (CPN, GP, social worker)
- Sat in and contributed to ward rounds

**People with Learning Disabilities Placement** - Catford Team for People with Learning Disabilities

**Client demographics**
- Individual work with 7 clients (5 male, 2 female) ranging in age from 4 to 69

**Presenting problem / Issues**
- Obsessive compulsive disorder
- Absconding from home
- Depression
- Psychosis

- Challenging behaviour
- Sibling issues
- Bereavement
- Feeding difficulties

**Settings**
- Community based outpatients; Home visits

**Assessment procedures**
- Assessment interviews; Functional analysis; Neuropsychological assessments using
  WAIS-III
Interventions
• Cognitive behaviour therapy; Behaviour therapy; Supportive counselling; Staff support

Other experience
• Visits to various services for people with learning disabilities including group homes and day centres
• Met with and observed work of other professionals (CPN, occupational therapist, physiotherapist, social worker, speech therapist, care worker)
• Observed a funding panel meeting for Lewisham Partnership
• Attended care-planning meetings
• Observed a number of screenings of patients referred to the psychology team

Children, Adolescents and Families Placement - Bexley CAMHS

Client demographics
• Individual work with 8 clients (4 male, 4 female) ranging in age from 4 to 14

Presenting problem / Issues
• School phobia
• Social phobia
• Bullying
• Dyspraxia
• Behaviour problems
• Anger management
• Stealing
• School difficulties
• Family difficulties
• Secondary enuresis
• Stealing
• Issues related to being taken into foster care

Settings
• Community based outpatient; Home visits

Assessment procedures
• Assessment interviews; Neuropsychological assessments using WISC-III, WORD, FRT

Interventions
• Cognitive behaviour therapy; Cognitive therapy; Behaviour therapy; Systemic therapy; Supportive counselling; Psychoanalytic psychotherapy

Other experience
• Met with and observed other professionals including (Family therapist, child psychiatrist, social worker, educational psychologist, health visitor)
• Regularly observed family therapy sessions and was part of a reflecting team
• Attended weekly team meetings

Older People Placement - Springfield Hospital

Client demographics
• Individual work with 8 clients (all female) ranging in age from 67 to 92

Presenting problem / Issues
• Anxiety
• Depression
• Chronic pain
• Loss and adjustment issues
• Challenging behaviour
• Memory impairment


Settings
- Community outpatient; Day unit; Inpatient; Home visits

Assessment procedures
- Assessment interviews; Functional analysis; Questionnaires: HADS, BAI, Worrying Thoughts Questionnaire, BDI-II, Life Satisfaction Scale, Geriatric Depression Scale; Neuropsychological assessments using WAIS-III, WMS-III, BADS, COWAT, Clock Drawing Test, MMSE, CAMDEX, MEAMS, AMIPB, RMT, Hayling and Brixton

Interventions
- Cognitive behaviour therapy; Solution focussed; Behaviour therapy

Other experience
- Attended Psychology department team meetings and presentations, Older Adult team meetings, day hospital ward rounds and referral meetings
- Met with and observed other professionals (CPN, psychiatrists, occupational therapists)

Specialist Placement in Paediatric Psychology - Great Ormond Street Hospital

Client demographics
- Individual work with 8 clients (7 male, 1 female) ranging in age from 8 to 15

Presenting problem / Issues
- Behaviour problems
- Soiling
- Anxiety
- Depression
- Sibling issues
- Chronic pain
- Needle phobia
- Low self-esteem

Settings
- Hospital based outpatient; Inpatient

Assessment procedures
- Assessment interviews; Questionnaires: Child Behaviour Checklist, Parent Behaviour Checklist, Children’s Depression Inventory, State Trait Anxiety Inventory, Self-Perception Profile for Adolescents

Interventions
- Cognitive behaviour therapy; Behaviour therapy

Other experience
- Attended ward rounds, psychosocial meetings, case conferences, planning meetings, weekly Paediatric Psychology team meetings and weekly Paediatric Psychology presentations
- Met with and observed other professionals (Paediatrician, clinical nurse specialist, play therapist, physiotherapist, dietician, speech and language therapist, social worker)
- Attended the national psychosocial Cystic Fibrosis conference
Clinical Case Report Summaries
Adult Mental Health Case Report Summary

Cognitive Behaviour Therapy for a 48-Year Old Man with Obsessive-Compulsive Disorder

March 2001

Year 1
Some of the details of this case have been changed to maintain client confidentiality.

Reason for Referral
Jamie, a forty-eight year old gentleman was referred to Psychology by his GP for obsessive-compulsive disorder (OCD).

History of Presenting Problem
Jamie began experiencing a number of obsessive compulsive symptoms one year prior to his referral following an accident at work in which he sustained a head injury. Jamie also reported he had been experiencing short-term memory problems and social anxiety for the same length of time.

Assessment
The assessment involved interviews with Jamie that covered information about the nature and course of his OCD, as well as coping strategies that he employed. In addition, the Maudsley Obsessive Compulsive Inventory (MOCI) was administered. During the assessment phase, information was also gathered about Jamie's family, medical and psychiatric history, employment history and relevant life events. Further information was collected regarding Jamie's short-term memory problems and social anxiety.

Formulation
Jamie's OCD was formulated within the Cognitive Model of OCD (Wells and Matthews, 1994). Following intrusive thoughts Jamie would engage in both mental and behavioural checking, as well as ruminating. Jamie reported that these behaviours resulted in a reduction in worry and discomfort, and it was therefore hypothesised that engaging in such behaviours reinforced his beliefs about the beneficial effects of checking and ruminating, thereby increasing the likelihood of him engaging in such behaviours in the future. It was also hypothesised that Jamie's memory problems resulted from his tendency to focus on internally generated events, rather than due to a specific cognitive impairment.

Jamie reported that when he was in a social situation he would become preoccupied by negative thoughts concerning evaluation by other people. It was hypothesised that as a result his attention to external aspects of the social situation was depleted, making it more difficult for him to be objective regarding his interpersonal performance and assuming that his self-generated perception of his performance reflected the way others perceived him. Jamie had also reported employing a number of safety behaviours in order to prevent social catastrophe.
It was assumed that these behaviours were perpetuating his belief about his negative performance and therefore maintaining his social anxiety.

**Intervention**
Since Jamie had reported his OCD to be his main problem, it was agreed that this would be the main focus of therapy, and that the social phobia would be addressed at a later stage. It was also decided that since Jamie was undergoing formal cognitive testing with a private neurologist for litigation purposes, that formal memory testing would not be undertaken. The intervention aimed to help Jamie to modify the dysfunctional appraisals and beliefs regarding his intrusions. In addition, behavioural experiments were used to challenge beliefs about the consequences of not engaging in safety-seeking behaviours. Jamie was also taught some stress management techniques including relaxation, time management and forward planning. Once Jamie felt that his obsessive-compulsive symptoms were more under control, the social anxiety was addressed. The role of safety-behaviours and self-focussed attention on his performance was highlighted.

**Outcome and prognosis**
At the end of the intervention, Jamie reported that he was no longer bothered by intrusions about his safety, that he felt more in control and more optimistic about his future. As a result he felt more confident and no longer employed any safety behaviours. Jamie’s total obsessional score on the MOCI had dropped from seventeen to nine. Jamie also reported that throughout the intervention he had noticed some improvement in his memory. He stated that although he was still experiencing occasional memory impairment, he was no longer worried about it. He also reported that he felt more confident interacting socially. Jamie felt that his improvement in performance without his safety behaviours was in itself reinforcing and that this meant that he was likely to maintain these improvements. Jamie was offered a follow up appointment, which he declined, stating that he should take “ownership” for his difficulties, and that he felt equipped to deal with any future difficulties.
People with Learning Disabilities Case Report Summary

The Assessment and Management of a Four-Year old Boy with Autistic Spectrum Disorder and Feeding Problems

September 2001

Year 2
Some of the details of this case have been changed to maintain client confidentiality

Reason for referral
Alex, a four-year old boy with a diagnosis of autistic spectrum disorder, was referred for persistent feeding difficulties.

Presenting problem
Alex’ parents’ main concern was the limited amount of food types that he would eat. They reported that he would only eat digestive biscuits, quavers crisps, as long as they were not broken, pureed fruit, chocolate, yoghurt and ice cream. Alex would also eat tinned spaghetti if it was liquidised, for his evening meal for three or four days at a time but would then refuse to eat any cooked food for at least two weeks. During these phases if Alex’ parents put any food in front of him, he would push it away and become very agitated. Alex also drank excessive amounts of milk. Alex’ parents reported that he was very sensitive to smell, colour and texture, and would decide what foods he would eat according to these factors. Alex would not take any medicines when he was ill. Alex also refused to feed himself, despite the fact he had done so in the past without any encouragement.

Assessment
The assessment procedure included interviews with Alex’ parents. In addition, Alex and his parents’ behaviour was observed at home on two separate occasions. This provided specific information regarding the frequency, duration and severity of the problem behaviours, without being influenced by Alex’ parents perception of the problem. No formal assessment tools were administered as part of the assessment process. However, Alex’ mother agreed to complete diaries of all food and drink presented to, and consumed by Alex during the two week assessment period. Information regarding developmental details was gathered from Alex’ medical notes.

Formulation
It was hypothesised that Alex’ difficulties were as a result of an interaction between psychological, familial and social factors. It was believed that the rigidity of behaviour and difficulty adjusting to new experiences seen in autistic spectrum disorders and the fact that Alex was frequently ill, suffering from very high temperatures when he was very young, disrupted the weaning process making it difficult for Alex’ mother to introduce solid foods into his diet. From a behavioural perspective it was hypothesised that Alex’ early feeding difficulties had led to him develop a classically conditioned aversive response to food at an
early age and that his current feeding problems were being maintained by both positive and negative reinforcement.

**Intervention**
A behavioural intervention that aimed at increasing acceptance of new foods and self-feeding, through small, graduated steps was implemented, alongside parent education regarding Alex' feeding difficulties and behaviour management. This involved didactic training of behaviour management strategies in relation to Alex' feeding difficulties and the rationale for them. Alex' mother was sequentially instructed in the use of differential attention, contingent privileges and setting realistic expectations at mealtimes. She was also instructed in the use of description and verbal praise of appropriate behaviours. Alex' mother was also encouraged to only give Alex milk at bedtime and limit the amount of food he received in between mealtimes. She was advised that initially meals presented to Alex should be small, with the aim of systematically increasing portion sizes over time. Due to the difficulties frequently experienced in autism attending to, regulating and understanding auditory input, an individualised picture activity schedule was implemented as part of the intervention to communicate to Alex the sequence of events that would occur during the intervention. A supportive counselling approach was adopted, through which Alex' mother's longstanding difficulties, anxieties and frustrations with feeding Alex, were recognised and accepted.

**Outcome and Prognosis**
By the end of the intervention, Alex' mother reported that he would have cereal everyday for breakfast and would eat liquidised solids every evening, which he would regularly ask for when he got home from nursery. He was also feeding himself one hundred percent of the time. This information was supported by the feeding diaries kept by Alex' mother. There was no difference in the texture of the foods eaten by Alex, however Alex' mother stated that he seemed less anxious and more confident around food and that he was trying new things more readily. Less disruptive and more appropriate feeding behaviours were observed during mealtimes. Alex' mother reported that she felt less worried about his eating and nutritional intake. Prior to the end of therapy, it was agreed that since the family had not met all of their goals, they would continue to be seen by the clinical psychologist supervising the intervention.
Children, Adolescents and Families Case Report Summary

The cognitive assessment of a twelve-year-old boy with behaviour difficulties

April 2002

Year 2
Some of the details of this case have been changed to maintain client confidentiality

Reason for referral
Charlie was a twelve-year old boy, who was referred for a psychometric assessment by a child psychiatrist who worked within the same child and adolescent mental health service. Both Charlie and his mother were concerned about his behaviour. Charlie’s mother felt that his behaviour difficulties were due to attention deficit hyperactivity disorder (ADHD), whereas the child psychiatrist thought they were more likely to be as a result of a specific learning disability.

Presenting problem
Charlie’s behaviour difficulties occurred both at home and at school, however at the time of assessment they were presenting more of a problem at school. Reported behaviour difficulties at school included being fidgety, having poor concentration, being rude and verbally abusive to teachers, and getting into trouble during unstructured time. Charlie also had difficulty concentrating at school and understanding new concepts. Reported behaviour difficulties at home included engaging in dangerous behaviours and temper tantrums. He also reportedly needed to be told to do something a number of times before he would respond. In addition, Charlie’s memory was reportedly not very good, and he often found it difficult to absorb new information and understand a chain of commands.

Assessment
The assessment procedure included interviews with Charlie and his mother to gain information regarding his behaviour, his understanding of his difficulties, his developmental and medical history, education, and family background. Based on this information, it was hypothesised that Charlie had an undiagnosed specific learning disability, resulting in low self-esteem, poor peer relationships and behaviour problems. It was felt that the psychometric assessment to test out this hypothesis should be carried out by the trainee clinical psychologist and not referred on to educational psychology at this stage because of the associated emotional and behavioural difficulties. A number of psychometric tests were selected to test this hypothesis: the Wechsler Intelligence Scales for Children (WISC-III) was selected to establish Charlie’s level of general intellectual functioning and to establish a profile of his strengths and weaknesses; the Wechsler Objective Reading Dimensions (WORD) was used to establish whether there was any evidence of a SpLD; The Revised Rutter Scales for School-Age Children (parent and teacher versions) were administered to provide more information about Charlie’s behaviour; the Birleson Depression Scale was administered to formally assess
whether Charlie was clinically depressed; the Spence Children’s Anxiety Scale was administered to assess Charlie’s level of anxiety and the Self-Perception Profile was administered to establish whether Charlie presented with significantly poor self-esteem. The Family Relations Test (FRT) was administered to gather more information about Charlie’s relationships with his family, since Charlie reported having relationship difficulties with some family members.

Results and discussion
In contrast to the concerns from the referrer, Charlie’s results showed that his general cognitive abilities were within the average to high average range for his age, and that there was no evidence to support the hypothesis that Charlie had a specific learning disability. It was therefore concluded that factors other than cognitive factors accounted for his behaviour difficulties. During testing Charlie always appeared motivated to perform well and try his hardest on all tests. However, he was observed to have poor concentration and attend to irrelevant or distracting stimuli in the environment, and to have difficulty sustaining his attention for more than one hour. In addition, his mother and teacher both reported attention and concentration difficulties, in a number of different situations. His mother also described him engaging in dangerous and impulsive behaviours, as well as constantly fidgeting and having excessive amounts of energy. It was suggested that this information, alongside the inability to foresee the consequences of his behaviour, meant that it was more likely that Charlie’s behaviour difficulties resulted from ADHD, and that this would also explain the academic difficulties that Charlie experienced.

Charlie was not found to be anxious or depressed, but was found to have low self-esteem in a number of different domains, including school, his body image and his father. Charlie’s results on the FRT indicated that he had a poor relationship with his family, particularly his father and younger brother.

Recommendations
The above information was feedback to Charlie, his mother and the referrer with recommendations that Charlie should be referred to a specialist ADHD service in order for him to have a more in-depth multidisciplinary assessment. This was felt necessary since it was felt that Charlie was a complex case. Due to Charlie’s results on the FRT it was also recommended that a family assessment should be carried out to further understand family dynamics. It was felt that this would also provide information on how Charlie’s behaviour difficulties have impacted on his family and the way they viewed him. This was important
because relationships within his family may have been either maintaining or exacerbating Charlie’s behaviour difficulties.

Although Charlie did well on most aspects of memory during the psychometric assessment, since both Charlie and his mother reported short-term memory problems at the initial assessment, it was recommended that Charlie undergo further testing, specifically examining different aspects of memory, to rule out a specific memory impairment.
Older Adults Case Report Summary

A report of a neuropsychological assessment of a 67-year-old Asian woman complaining of memory problems

September 2002

Year 2
Some of the details of this case have been changed to maintain client confidentiality

**Reason for referral**
Elaine was a sixty-seven year old Asian woman who reported a deterioration in her memory. She was initially assessed by a clinical psychologist working in a CMHT, who concluded that her memory impairment was not due to a functional psychiatric problem. As a result she was referred to the older adults service, for an extended assessment of her difficulties.

**Presenting problem**
Elaine reported a one to two year history of poor short-term memory, which had gradually got worse over the last six months. Reported difficulties included putting things down in her flat and later not being able to remember where she had put them and going shopping and either forgetting what to buy, or losing her shopping on the way home. Elaine also reported that she found it difficult to attend to more than one stimulus at a time. Although she had no difficulty remembering names of family members, she did find it difficult remembering the names and faces of new people she met. Elaine also reported that she had difficulty spelling previously familiar words and finding her way home.

**Assessment**
Interviews were conducted with Elaine and one of her sons to gain information regarding her current difficulties, her personal, psychiatric and medical history, and her social situation. Relevant information reported during the initial assessment included the fact that Elaine was born in Sri Lanka and moved to the United Kingdom in 1993. Her first language was Tamil, although she spoke English well. Following initial assessment a number of hypotheses were developed to account for Elaine’s difficulties. These were that Elaine’s difficulties were due to either Alzheimer’s disease or Vascular dementia, that her difficulties were resulting from her being depressed, or that her difficulties were age-related. Several neuropsychological tests were selected to test out these hypotheses. The Wechsler Adult Intelligence Scale-Third Edition (WAIS-III) was used to establish Elaine’s level of general intellectual functioning, a profile of her strengths and weaknesses, and to see whether there had been a decline from her estimated premorbid level of functioning. The Wechsler Memory Scale-Third Edition was used to evaluate Elaine’s memory impairment. Traditionally the National Adult Reading Test (NART) is used to provide a estimate of premorbid functioning, however, because English was not Elaine’s first language, the use of the NART was deemed invalid. The Behavioural Assessment of the Dysexecutive Syndrome (BADS) was chosen to assess for difficulties in executive functioning. The Controlled Oral Word Association Test (COWAT) was chosen to
test for speech and verbal comprehension deficits and the Clock Drawing Test was used to screen for visuoconstructive deficits. The Beck Depression Inventory and Beck Anxiety Inventory were administered to evaluate psychopathology.

Results and discussion
Caution was exercised when interpreting the results since cultural and language factors may have led to an underestimate of Elaine’s abilities. Although it was difficult to determine whether there had been a decline in general intellectual functioning from premorbid estimates, the results did indicate that Elaine did not have difficulty with recall of information after a delay or difficulty encoding and retrieving information. Nor did not have impaired working memory or learning, attention and concentration difficulties, or difficulty with speech production. Her results also showed that her abstract reasoning was intact. Although Elaine had reported memory difficulties, the results from testing did not support this. There was some indication that Elaine had visual memory difficulties relative to her verbal abilities, although these differences were not clinically significant. Elaine’s performance on the CDT and the Block Design subtest of the WAIS-III also indicated some difficulties, although it was unclear whether these were due to a visual-spatial impairment or other difficulties. Her results on the BADS indicated some difficulties with executive functioning, although this was not supported by the information obtained during the clinical assessment. Elaine scored highly on both formal assessments of depression and anxiety.

Although, the results from this assessment cannot rule out the development of organic cognitive impairment, it was concluded that there was insufficient evidence to support a diagnosis of either Alzheimer’s disease or Vascular dementia. Given the finding that Elaine attained high scores on the measures of depression and anxiety, it was proposed that Elaine’s difficulties were most likely to be age-related and that these were exacerbated by her low mood, causing further cognitive impairment. However, it was not possible to be conclusive about this, based on the findings.

Recommendations
The above findings were feedback to Elaine, informing her that she appeared to be functioning within the normal limits of someone her age, and that there was insufficient evidence to support a diagnosis of an organic cognitive impairment. It was also recommended that Elaine should be offered additional support or counselling in relation to any current concerns, and that the neuropsychological assessment should be repeated in one year, to determine whether there has been any further decline in Elaine’s cognitive abilities.
Specialist Case Report Summary
(Paediatric Psychology)

The Assessment and Management of a Nine-Year old Boy with Cystic Fibrosis and Behaviour Problems

April 2003

Year 3
Specialist Placement Case Report Summary

Some of the details of this case have been changed to maintain client confidentiality

Reason for referral
Greg was a nine-year old boy with a diagnosis of Cystic Fibrosis (CF). He was referred to Psychology by his paediatrician following concerns raised by his mother regarding his behaviour.

Presenting problem
Reported behaviour difficulties included non-compliance, not listening to his parents, interrupting them during adult-adult conversations and engaging in attention-seeking behaviour. Greg’s mother also noted that he was very “clingy” towards both parents, making it increasingly difficult for them to go out as a family. Greg’s mother reported that his behaviour was worse during school time and that there was always a significant improvement in his behaviour during school holidays.

Assessment
The assessment procedure involved interviews with Greg’s mother to gain information regarding the types and frequency of behaviour problems, as well as information about how Greg’s parents had previously attempted to deal with his behaviour difficulties. Information was also obtained regarding Greg’s developmental and medical history, and his family and educational background. In addition, Greg’s mother completed the Child Behaviour Checklist (CBCL) and the Parent Behaviour Checklist. Greg’s mother also kept a three-column diary of the three main problem behaviours identified, during the assessment period. This provided more precise information regarding Greg’s behaviour, as well as related antecedents and consequences. Greg’s mother was frequently tearful during the assessment and so was asked to complete the Beck Depression Inventory to provide a measure of her perception of her own personal adjustment.

Formulation
It was hypothesised that the aetiology and maintenance of Greg’s difficult behaviours reflected the complex interplay between biological, psychological and familial factors. It was hypothesised that Greg’s diagnosis of CF and the experience of having a chronic illness served as a predisposing factor for his behaviour difficulties. From a behavioural perspective it was believed that Greg’s behaviour was being maintained by both positive and negative reinforcement.
Intervention
A behavioural intervention that aimed to reduce the frequency of problem behaviours and increase the frequency of positive behaviours was implemented, alongside parent education regarding behaviour problems and a problem-solving framework which makes sense of their children’s problems and the pattern of interactions within which they are embedded. The intervention was carried out in two phases. During the first phase Greg’s mother was taught to be a more effective reinforcing agent in order to increase positive behaviours. During the second phase, Greg’s mother was trained in techniques to decrease noncompliance and behaviour problems.

Outcome and Prognosis
In total, Greg’s mother was seen for seven sessions over five months. Following these sessions, Greg’s mother reported that she was unable to continue attending due to time constraints. The therapist reviewed the intervention to date and any changes to Greg’s behaviour, and agreed to write a letter to Greg’s mother summarising the intervention to date. Greg’s mother reported that as a result of the intervention she understood more about Greg’s behaviour and the factors underlying and maintaining it. She also stated that there had been a small improvement in his behaviour, for example, he was interrupting less, he appeared to be more aware of his own behaviour and its impact on others, and he was going to bed at the expected time. However, she did not feel that there had been any improvement in the frequency of positive behaviours. The outcome measures administered during the initial assessment were not readministered because the therapist was not aware that Greg’s mother did not wish to continue with the intervention.

During the intervention Greg had only been able to make very small improvements in his behaviour and it was felt that these would not be sustained beyond the end of therapy. Reasons for this are discussed.
Research Section

This section contains three pieces of work. The Service Related Research Project was carried in Year one, during the Adult Mental Health Placement. The Major Research Project was carried out in Years two and three. The research log book was recorded over the three years.
Service Related Research Project

An audit of patients' understanding of the role of the clinical psychologist and of a psychology service in a primary health care setting

June 2001

Year 1
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<tr>
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<th>Page Number</th>
</tr>
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Acknowledgements: With thanks to Jane Street for her support and supervision, and also thanks to the Medical Centre for allowing and supporting this project.
Abstract

An exploratory survey of patients attending a GP practice in South London was undertaken. Aims were to establish patients' understanding of the role of the clinical psychologist and of a psychology service in a primary care setting; their attitudes towards it, and factors influencing their decision to use it or not. The measure used was a questionnaire developed through careful consideration of previous research and of existing questionnaires addressing similar issues, as well as consultation with experienced professionals. Thirty-five of forty-one (85%) participants completed the questionnaire. Data analysis comprised of simple frequencies, content analysis and nonparametric tests. Findings indicated that the majority of participants did not know about the advice clinic and had a very circumscribed view of the role of the clinical psychologist. One third of people thought that there was no stigma attached to seeing a clinical psychologist. The majority of participants reported that they would now use the advice clinic if they felt they needed to. This decision was independent of their demographic status. It is suggested that it is necessary to increase knowledge about the advice clinic and the role of the clinical psychologist amongst patients of the GP practice. The advice clinic should be extended, possibly to outside normal surgery hours, to reduce the waiting list and ease clients' access to the service. A protocol should be established for GPs regarding referrals to the advice clinic.
Introduction

It has been estimated that up to 25% of the general population will suffer from some form of psychological problem in their lifetime, but that only 7% of those identified as having a mental health problem are actually referred to specialist mental health services (Goldberg and Huxley, 1980, 1992). This therefore leaves a large proportion of the population who currently do not have access to clinical psychologists or psychiatrists.

There are a number of variables which influence whether or not an individual comes into contact with mental health services. Firstly, approximately 18% of individuals do not consult their General Practitioner (GP) about their psychiatric or psychological problems (Bebbington, Marsden, and Brewin, 1999). Cochrane (1983) suggested that factors that might prevent an individual from consulting their GP might include not acknowledging that there is something wrong, not recognising the problem as emotional in origin, or not believing that the problem can be overcome. Warr and Payne (1982, cited in Brown and Cochrane 1999) also suggested that individuals experiencing mental health problems may try natural coping strategies to overcome them, such as self-medication, smoking, eating, drinking alcohol or talking to friends or a priest. Another factor that prevents potential clients from approaching services is a wish to avoid being labelled by others as “mad” (Cheston and Schmidt, 1994).

For those individuals with mental health problems that do consult their GPs, there are still a number of factors influencing whether their GP will refer them to specialist mental health services. According to Goldberg and Huxley’s filter model (1980), a patient has to pass through a number of filters in order to arrive at the specialized mental health care level (Figure 1). The framework for this model consists of five levels, each one corresponding to a stage on the pathway to psychiatric care. Goldberg and Huxley postulated a set of four filters between each of these five levels. The first filter is the decision of the individual to consult their GP. Goldberg and Huxley (1980) suggested that although many patients with psychological problems do consult their GPs, the consultations might be for other reasons. Many depressed patients do not mention their depressive symptoms, but confine their complaints to the doctor to the associated somatic symptoms. The second filter represents the recognition of the problem by the GP. A variety of research evidence suggests that GPs may detect as few as a third to a half of the psychiatric problems which are presented (Goldberg and Huxley, 1992). The third filter represents whether the GP decides to treat the patient within the practice or to refer them on to specialist services. According to the model only 7% of patients are ever referred to specialist services. The fourth filter refers to whether an individual receives care from specialised mental health services on an outpatient or inpatient basis.
Even if individuals are referred to secondary services in order to see a clinical psychologist, they may still not receive the help they need. For example, individuals may not be able to attend their appointment as specialist services tend to operate during office hours. Also psychology services tend to have long waiting lists. Seager (1991) has described the "standard" referral system and waiting list as creating a double bind. In other words, clients are given the message "you can't help yourself, but we can't help you for the present either". Howells (1996) believes that being placed on a waiting list can be adverse for some clients, as it encourages chronicity and the development of the sick role.

One way to overcome these problems and improve access for individuals experiencing mental health problems to specialist services has been for psychologists to move from working within secondary services to primary care. This allows psychologists to see clients earlier and to reach as many people as possible before problems become entrenched or severe. In an attempt to address these issues, a clinical psychologist, Jane Street (1993) set up an "Advice Clinic" at a medical centre in South London. Clients are not formally referred to this clinic, but rather self-refer by "booking in" a one-off, half-hour session with the clinical psychologist. The aim of this clinic is to provide a fast, effective, flexible and acceptable service to adult clients who would not normally be referred to secondary services; who were ambivalent about the benefits of a psychological approach, or who did not want to discuss their difficulties with their GP (Street, 1994). The service was originally advertised by a poster in the waiting room, but subsequently it has relied on "word of mouth" publicity or occasionally via an informal suggestion by a GP. The service was evaluated for client satisfaction using the Client Satisfaction Questionnaire (Nguyen, Attkisson and Stegner, 1983). The results showed that the majority of participants (89.4%) rated all aspects of the service as either "good" or "excellent" (Chapman, 1999).

In summary, research has shown that only 7% of individuals with psychological difficulties actually receive help from specialist mental health services (Goldberg and Huxley, 1980, 1992). This is due to a number of factors, such as individuals not consulting their GPs; individuals may not be referred to secondary services when they do consult their GP, or even if individuals are referred they may have a long wait or may be unable to attend their appointments. The advice clinic at the medical centre was set up to try to overcome all of these difficulties and increase access for patients to specialist psychology services. It has been shown that clients attending the advice clinic are satisfied with the services they receive,
however no information is available about those who do not attend, and the reasons why they do not attend.

**Aims and research questions**

This study was set up to determine whether patients within the medical centre know about the advice clinic and whether those patients who know about it would use it; what factors would make them more or less likely to use it, and to investigate how patients at the practice generally understand the role of a clinical psychologist.
Figure 1: Filter model of treatment seeking for mental health problems (Goldberg and Huxley, 1980, 1992)

People with mental health problems in the general population (100%)

Do not consult their GP (18%)

Filter 1: Consultation (82%)
  - Undetected do not complain to GP or GP does not detect (46%)

Filter 2: Detection (36%)
  - Detected but not referred on (29%)

Filter 3: Referral (7%)

Referred to specialist mental health services (7%)

LEVEL 1

LEVEL 2

LEVEL 3

LEVEL 4 (outpatients)

LEVEL 5 (inpatients)
Method

Setting
The research was carried out in a GP practice in a suburban area of South London. The practice has seven partners and serves a population of 11,700. During the time the research was carried out a clinical psychologist and a trainee-counselling psychologist were in post in the practice.

Procedure
Participants were approached by the trainee clinical psychologist in the waiting room immediately after they had checked in to see their GP. Because the purpose of the study was explained in person, if several people arrived at the same time, it was only possible for the researcher to approach one of them at a time. Participants were given an information letter and a questionnaire about the advice clinic (see Appendix A & B). The information letter described the aims of the study and explained that the purpose of the questionnaire was to assist in the planning of future service provision. Participants were left alone to decide whether they wished to complete the questionnaire or not, whilst they were waiting to see their GP. During this time the trainee clinical psychologist was available in the reception area in case there were any questions regarding the research and all participants were informed of this. Participants then either completed the questionnaire and returned it to a box on the reception desk, or returned it to the same box blank.

Measure
The questionnaire (Appendix B) was designed to elicit participants' knowledge of the role of the clinical psychologist and of the advice clinic, their attitudes towards it, and factors affecting their decision to use it or not. The questionnaire consisted of twelve closed and fourteen open-ended questions. It was developed after careful consideration of previous research and of existing questionnaires addressing similar issues (Cocksedge, 1997; Hughes, Midence and Jackson, 1996) as well as by discussion among the researchers, followed by consultation with experienced professionals working in this field. At the end of the questionnaire the following sociodemographic details were recorded: age; sex; marital status; ethnicity; employment status and children.
The sample

Participants were patients of the GP practice who were attending the practice to see their GP. Participants were only included if they were there to use 'normal' GP surgery sessions, not special clinics. Participants were only asked to participate if they were visiting the GP themselves, and not if they were accompanying someone else. This was to ensure that they were registered at the GP practice. Participants were excluded from the study if they were below age 18, if they were private patients or temporary residents.

Data

All data was collected in one day at the GP practice. In all forty-one questionnaires were handed out.
Results

Thirty-five of the forty-one questionnaires administered were returned completed. This represented an 85% response rate.

**Demographic details**

The average age of participants was 32 years (range 18-67; SD 12.9). Twenty-three participants were female and nine were male, three did not report their demographic details. Table 1 summarises the participants’ demographic details.

**Table 1. Demographic details**

<table>
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<tr>
<th>Demographic details</th>
<th>Frequency</th>
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<tr>
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### Demographic details

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<th>How many children</th>
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<td>One</td>
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</tr>
<tr>
<td>Two</td>
<td>6</td>
<td>17</td>
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<td>Three</td>
<td>2</td>
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<td>Four</td>
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<td>6</td>
</tr>
<tr>
<td>Six</td>
<td>1</td>
<td>3</td>
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</table>

1) *Did participants know about the advice clinic?*

Only five participants (14%) knew about the advice clinic before reading the information letter that described the research. Of these, three were informed by their GP, one by the practice nurse and one by another patient. Two of these participants had used the advice clinic themselves. Only one participant gave a reason for attending, which was depression. Of these two participants, one stated that they would use the advice clinic again, as they needed ongoing psychological help, the other participant reported that she would not use the advice clinic again because she felt she had to wait too long for an appointment.

Three participants knew other people who had used the advice clinic. Two participants named family members and one participant stated this was a friend. The reasons given for attending the advice clinic were depression and family problems. Two participants felt that these people would use the advice clinic again and one was not sure.

2) *Would participants use the advice clinic?*

Fourteen participants (40%) reported that now they knew about the advice clinic they would use it, three (9%) reported that they would not use it and seventeen (49%) were not sure. No significant differences were found in participants decision to use the advice clinic, between those who were working or not working; participants who were married/cohabiting and those who were single/separated/divorced/widowed; younger (18-40 years) or older (41-67 years) participants; and participants with children or with no children (see Table 2).
Table 2. Factors influencing whether participants reported they would use the advice clinic, would not use it or were not sure

<table>
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<th>Chi-Square value</th>
<th>df</th>
<th>p-value</th>
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<tr>
<td>Working vs not working</td>
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<td>1</td>
<td>0.667</td>
</tr>
<tr>
<td>Married/cohabiting vs single/separated/divorced/widowed</td>
<td>2.306</td>
<td>1</td>
<td>0.129</td>
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<tr>
<td>Children vs no children</td>
<td>3.028</td>
<td>1</td>
<td>0.082</td>
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<tr>
<td>Younger vs older</td>
<td>0.202</td>
<td>1</td>
<td>0.653</td>
</tr>
</tbody>
</table>

3) What factors would make participants more or less likely to use the advice clinic?

a) What would stop participants from using the advice clinic?

Reasons that would stop someone from using the advice clinic fell into three categories. Two participants (6%) reported worries about confidentiality, two participants (6%) reported not understanding exactly what the clinic is for, and two participants (6%) reported not wishing to talk to a stranger or preferring to talk to friends. Seven participants (20%) felt that nothing would stop them from using the advice clinic now that they knew about it.

b) What would make it easier for participants to use the advice clinic?

Reasons that participants gave that would make it easier for them to use the advice clinic fell into three categories. Nine participants (26%) felt that having more information about the service would make it easier for them to use the advice clinic. Two participants (6%) made comments referring to issues of confidentiality. Two participants (6%) reported knowing the clinical psychologist and liking their characteristics would influence their decision.

c) How would participants feel if their GP suggested they make an appointment at the advice clinic?

Thirteen participants (37%) reported they would feel either fine or relieved. Five participants (14%) reported that they trusted their GP's opinion. Only two participants (6%) reported they would feel either worried or would not like it.

4) Participants' perceptions of the role of the clinical psychologist and psychology services

Table 3 indicates the types of problems that participants thought a clinical psychologist could help someone with. The majority of participants thought clinical psychologists could help people with depression or anxiety. Very few people thought clinical psychologists could help people with chronic pain, social skills or lack of assertiveness.
Table 3. Psychological and/or other health problems indicated by participants that clinical psychologists could help someone with

<table>
<thead>
<tr>
<th>Psychological and/or other health problems</th>
<th>Frequency</th>
<th>%</th>
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</thead>
<tbody>
<tr>
<td>Depression</td>
<td>29</td>
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</tr>
<tr>
<td>Anxiety</td>
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<td>74</td>
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<tr>
<td>Response to trauma</td>
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<td>63</td>
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<tr>
<td>Fears and phobias</td>
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<td>57</td>
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<tr>
<td>Post natal depression</td>
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<tr>
<td>Suicidal ideas</td>
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<td>OCD</td>
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<tr>
<td>Self harm</td>
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<td>49</td>
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<tr>
<td>Eating disorders</td>
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<tr>
<td>Sleep problems</td>
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<td>Bereavement</td>
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<tr>
<td>Schizophrenia</td>
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<tr>
<td>Family problems</td>
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<tr>
<td>Alcoholism</td>
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<tr>
<td>Memory problems</td>
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<td>37</td>
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<tr>
<td>Relationship</td>
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<td>37</td>
</tr>
<tr>
<td>Sexual abuse</td>
<td>13</td>
<td>37</td>
</tr>
<tr>
<td>Worries about children</td>
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<td>37</td>
</tr>
<tr>
<td>Dementia</td>
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<td>34</td>
</tr>
<tr>
<td>Work worries</td>
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<td>34</td>
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<tr>
<td>Drug misuse</td>
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<td>34</td>
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<tr>
<td>Sexual difficulties</td>
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<td>Carer problems</td>
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<td>Violence/aggression</td>
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<td>Physical health</td>
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<td>26</td>
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<tr>
<td>Chronic pain</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Social skills</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Lack of assertiveness</td>
<td>6</td>
<td>17</td>
</tr>
</tbody>
</table>

Participants were asked why someone would see a clinical psychologist. The reasons given fell into three categories. Five respondents (14%) commented on individuals not being able to deal with the problem themselves. Two respondents (6%) felt this was to try to understand the cause of their problem. Four respondents (11%) reported any problem that contributed to distress, difficulty or led someone to be concerned.
Where would you usually go for help/support?
Prior to the research only six participants (17%) had sought professional help for a personal problem. Two people had seen their GP, two a clinical psychologist, one a psychiatrist and one a counsellor. The reasons given for seeking professional help were depression, family problems, and panic and anxiety attacks. Table 4 indicates where participants would go for help or support if they had a personal problem. The majority of people reported they would go to either their family or friends. Very few people reported that prior to the research they would have sought help from a clinical psychologist or counsellor.

Table 4. Where participants would usually go for help/support

<table>
<thead>
<tr>
<th>Where participants go for</th>
<th>Frequency</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>21</td>
<td>60</td>
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<tr>
<td>Friends</td>
<td>20</td>
<td>57</td>
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<tr>
<td>GP</td>
<td>13</td>
<td>37</td>
</tr>
<tr>
<td>Religious person</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Self-help books</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Counselling Psychologist</td>
<td>3</td>
<td>9</td>
</tr>
<tr>
<td>Practice nurse</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Counsellor</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Internet</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Preference of venue expressed for seeing a clinical psychologist
Twenty-five participants (71%) reported that they would like to see a clinical psychologist at their GP practice, whereas only ten participants (29%) would like to be seen at a health centre, seven (20%) at home and only one participant (3%) at a general hospital.

Stigma
Thirteen participants (37%) felt that there was no stigma attached to seeing a clinical psychologist. Nine participants (26 %) felt there was still a stigma attached to seeing a clinical psychologist, and eight (23%) were not sure. Five participants did not respond. These responses did not influence whether participants would now use the advice clinic ($x^2=1.044$, p=.593).

1 Adds up to more than 100% because on the questionnaire participants could tick more than one box
Discussion

Participants' knowledge of and attitudes towards the advice clinic

The study found that very few people knew about the advice clinic prior to reading the information letter. Once they had been informed about the advice clinic the majority of participants said they would use it if they felt they needed to. Previous research has found that certain factors, such as marital status or employment status, influence whether individuals are likely to be seen by specialist mental health services (Brown and Cochrane, 1999). However this study found that the decision to use the advice clinic was independent of these factors and it therefore appears the advice clinic is able to overcome some of the difficulties experienced by patients in accessing specialist psychology services.

Thirty-seven per cent of respondents reported that they would feel either fine or relieved if their GP suggested that they make an appointment at the advice clinic, and that they would attend as they “trusted their GP’s opinion”. However, according to Goldberg and Huxley (1992) GPs may detect as few as a third to a half of the psychiatric or psychological problems which are presented. It may therefore be beneficial for a protocol to be established for GPs regarding referrals to the advice clinic.

Participants' perceptions of the role of the clinical psychologist

The majority of participants had a very circumscribed view of the role of the clinical psychologist and were not aware of the range of difficulties that a clinical psychologist could help with. If those individuals do not see themselves as having a specific psychological diagnosis, or do not wish to recognise their problem as being emotional in origin, they may not seek the help they need.

Participants also exhibited a lack of knowledge regarding different models of working employed by clinical psychologists, as well as the range of services offered, such as family therapy or group work. There was also no recognition of the wider role of clinical psychologists’ work, such as consultancy, research or health promotion and prevention programmes. It may be that this lack of knowledge leads individuals to believe that the problem cannot be overcome by psychological help and as a result they do not approach services for help.
The majority of respondents expressed a preference for seeing a clinical psychologist at their GP practice. Although the research did not establish the reasons for this preference of venue, it does provide support for the current location of the advice clinic.

Cheston and Schmidt (1994) found that many potential clients are prevented from approaching services as they wish to avoid being labelled by others as “mad”. This study found that only just over one third of participants felt that there was no stigma attached to seeing a clinical psychologist. Although these beliefs did not seem to influence participants’ decision to use the advice clinic it is still important to reduce this associated stigma. This has partially been addressed by allowing patients to be seen at the GP practice rather than another venue, such as an outpatient psychiatric hospital where patients attach more stigma (Crawford, 1987).

Stigma associated with mental health services can be reduced through education. Salter and Byrne (2000) suggest that one way to do this is through the use of the media. They believe that while TV, radio and newspapers often perpetuate unhelpful stereotypes of mental illness, if properly harnessed they may also be used to challenge prejudice, inform and initiate debate, and so help to combat stigma associated with mental illness.

**Critical evaluation and limitations**

The sample used for the study was very small. However, as the research focussed specifically on people who were attending GP clinics there is no reason to think that this sample is not representative of the GP practice’s population. Six participants returned their questionnaires blank, although the reasons for this are not known, it is not expected that this would have biased the sample.

A number of participants returned questionnaires without giving information on background characteristics. The reasons given for this was that they were called to see their GP before they had completed the questionnaire. The provision of stamped addressed envelopes to return questionnaires was considered but as research shows that the response rate can go as low as 40% for postal questionnaires (Fife-Schaw, 1992), it was decided not to use this method of data collection as it was more likely to produce a lower response rate.

It was not possible to check the reliability and validity of the questionnaire because time constraints meant that it was not possible to do a pilot study.
Feedback of results

A copy of the report will be sent to the clinical psychologist who runs the advice clinic. This will be followed up by a phone call to discuss the implications of the research and presentation of the research to the practice if required.

Conclusion and service implications

Overall it appears that the advice clinic is able to provide easy access to psychology services to large numbers of people, including those who would not otherwise access this kind of help, for example, individuals who do not consult their GP. It therefore appears that it is able to redress the balance created by filters in the care pathway. However it still appears necessary to increase knowledge about the advice clinic and the role of the clinical psychologist amongst patients of the GP practice. This could be done through the use of a poster or handouts written in simple language, covering information about the service, such as confidentiality, how to make an appointment, and what will happen during the session. This should also include information about clinical psychologists, such as their training and the wide range of difficulties, both mental and physical that can benefit from psychological input. This could also be used to address the stigma associated with mental health problems and services, through reassurances that seeing a clinical psychologist does not mean that you are going “mad”. Previous research has found that similar handouts given to patients before they saw a clinical psychologist reduced the DNA rate by more than half. It is believed that this is because the handout demystified the role of the clinical psychologist and prepared patients for what might happen therefore making it easier for them to attend (Spector, 1988).

The advice clinic is currently run one morning a week, during usual surgery hours. An increase in the demand for the service has led to a six-week waiting list. It may therefore be necessary to extend the advice clinic allowing the clinical psychologist to see more clients per week thereby reducing the waiting list and the adverse effect that this can produce. It would be preferable for some of these sessions to be outside of office hours in order to ease clients’ access to the service.
References


Appendix Contents

Appendix A: Information letter

Appendix B: Questionnaire

Appendix C: Responses to open-ended questions
Appendix A
29\textsuperscript{th} May 2001

An audit of patient's understanding of the role of the clinical psychologist and of psychology service in a primary health care setting.

As you may know this is a very busy practice. It offers a wide range of services. One of the services offered is the opportunity to meet with a clinical psychologist for a consultation. We are currently looking at how patients of the Practice understand what a clinical psychologist does and whether they feel that the services currently available at Medical Centre meet their needs.

Attached is a short questionnaire that we would like you to complete and place in a box on the reception desk. If you do not wish to complete the questionnaire then please return it blank to the box on the reception desk.

\textbf{You do not have to take part if you do not wish to. All information will be completely confidential. It will not affect your treatment by the staff in this Practice.}

The results of the research will be used to inform service development within the Practice. It will also be used towards my thesis in Clinical Psychology. If you have any questions regarding the study or the content of the questionnaire then please feel free to contact either myself or , Clinical Psychologist at the Practice.

Thank you for your help.

Yours sincerely,

Trainee Clinical Psychologist
Appendix B
1) How often do you come to this GP practice?

2) Do you ever see anyone here apart from your GP? (If yes, please write who you see)

3a) If you had a personal problem e.g. worries, low mood, etc. where would you go for help/support? (please circle all responses that apply to you)

   - Clinical Psychologist
   - Counselling Psychologist
   - Self-help books
   - Family
   - Community Psychiatric Nurse
   - Other: (Please state who)

   - Practice nurse
   - GP
   - Psychiatrist
   - Friends
   - Social Worker
   - Occupational Therapist

   - Internet
   - Counsellor
   - Telephone helpline
   - Religious person e.g. priest
   - Social Worker
   - Occupational Therapist

b) Have you ever had professional help for a personal problem?  
   - Yes / No

   (please circle the response that applies to you)

c) Who did you see?

   ........................................................................................................................................

   ........................................................................................................................................

   ........................................................................................................................................

d) Why did you see them?

   ........................................................................................................................................

   ........................................................................................................................................

   ........................................................................................................................................
4a) Why do you think someone might see a Clinical Psychologist?

b) What kind of issues could someone talk to a Clinical Psychologist about?

c) Which of the following difficulties could a Clinical Psychologist help someone with? (please tick all appropriate responses)

- Depression
- Relationship difficulties
- Anxiety
- Bereavement
- Fears and phobias
- Physical health problems
- Sexual difficulties
- Response to trauma
- Suicidal ideas
- Schizophrenia
- Violence/ aggression
- Eating disorders
- Alcoholism
- Drug misuse
- Family problems
- Obsessive-compulsive disorder
- Self harm
- Problems of being a carer
- Sleep problems
- Worries about work
- Post natal depression
- Social skills
- Assertion
- Chronic pain
- Memory problems
- Sexual abuse
- Low self esteem
- Worries about children's behaviour
- Dementia
5a) Before you read the attached letter did you know that there was a psychology advice clinic in the practice?  
Yes / No  
*(please circle the response that applies to you)*  
If No, go to Question 7

b) How did you hear about the psychology advice clinic?  
*(please circle the response that applies to you)*  
GP / Practice nurse / Other member of staff (please state who..................) /  
Friend / Family / Other  
.............................................

c) Have you ever been to the psychology advice clinic?  
Yes / No  
*(please circle the response that applies to you)*  
If yes, please state why:  
........................................................................
........................................................................
........................................................................

d) Would you use the psychology advice clinic again?  
Yes / No  
*(please circle the response that applies to you)*  
Please give reasons for your answer.  
........................................................................
........................................................................
........................................................................

6a) Has anyone you know ever been to the psychology advice clinic?  
Yes / No  
*(please circle the response that applies to you)*  
If yes, please state who (e.g. friend / family member):  
........................................................................  
If yes, please state why:  
........................................................................  
........................................................................

b) Would they use the psychology advice clinic again?  
Yes / No / Not sure  
*(please circle the response that applies to you)*
7a) Now that you know about the psychology advice clinic do you think that you would ever use it?
Yes / No / Not sure  (please circle the response that applies to you)

b) What would stop you from using the psychology advice clinic?

........................................................................................................................................
........................................................................................................................................

c) What would make it easier for you to use the psychology advice clinic?

........................................................................................................................................
........................................................................................................................................

d) How would you feel if your GP suggested you make an appointment at the advice clinic?

........................................................................................................................................
........................................................................................................................................
8a) What do you think a Clinical Psychologist does?

______________________________

______________________________

______________________________

b) If you were to see a Clinical Psychologist where would you like to see them?

*(please circle the response that applies to you)*

<table>
<thead>
<tr>
<th>Health centre</th>
<th>General Hospital</th>
<th>Psychiatric Hospital</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP practice</td>
<td>At home</td>
<td></td>
</tr>
<tr>
<td>Other (please specify)</td>
<td>.....................</td>
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</tr>
</tbody>
</table>

c) Do you still feel there is a stigma attached to seeing a Clinical Psychologist?

Yes / No / Not sure  *(please circle the response that applies to you)*

Thank you for your co-operation.
It would be helpful to have some information about you. Please could you provide us with the following details.

**DATE OF BIRTH:** ............

**Are you:** Male / Female  
*(please circle the response that applies to you)*

**Are you:** White / Asian / Black / Other  
*(please circle the response that applies to you)*

**Are you:** Single / Married / Separated / Divorced / Widowed / Cohabiting  
*(please circle the response that applies to you)*

**Are you:** Unemployed / Employed / Home-maker / Sickness Benefit / Student / Other  
*(please circle the response that applies to you)*

**Do you have any children?** Yes / No  
*(please circle the response that applies to you)*

If yes, how many: ............

If yes do any of them still live at home?  
Yes / No  
*(please circle the response that applies to you)*

If yes, please list the ages of all the children that still live at home:

...........................................................................................................................................

Thank you for your help.

Trainee Clinical Psychologist
Please now place your questionnaire in the box on the reception desk.
3c) Which professional did you see for a personal problem?

- GP
- GP
- Clinical psychologist
- Psychologist
- Counsellor

3d) Why did you see them?

- depression
- depression
- depression
- depression
- Panic and anxiety attacks

4a) Why do you think someone might see a clinical psychologist?

- Depression, mood swings, children’s behaviour, grief, loss, anxieties
- Depression
- depression, anxiety
- eating disorders, trauma, people, schizophrenia
- emotional worries, depression, anxiety
- depression
- depression
- depression and psychological disorders
- depressed
- Depression
- need to talk about problems, particularly non-physical one
- Needing to speak to someone without them being judgemental
- person may have no-one to talk to so needs help
- to resolve any problems they may have, anxiety etc, or just to talk to someone professional
- if they feel they can’t deal with their problems themselves
- Personal problems
- personal help
- when feelings or emotions become acute
- Someone with serious problems not easily solved by a casual visit to a GP
- to change the way they look at life, to enable them to make constructive changes
- To find out why they feel the way they do i.e. depressed
4b) What kind of issues could someone talk to a clinical psychologist about?

- family problems
- depression, anxiety
- depression, low self esteem
- depression
- depression
- relationship problems, social problems
- personal e.g. sexual, depression, relationship, bereavement, anxiety
- personal problems, bereavement
- depression
- personal issues
- personal problems
- personal problems, family, friendship etc. or any others depending on the individuals situation
- personal problems i.e. depression
- anything that was causing distress
- whatever contributed to the difficulties being experienced
- anything that concerns them about life, health
- anything that could be affecting their inability to fulfil daily life on an emotional or psychological basis
- problems that are more related to the mind and not actual physical problems

5c) Why did you go to the advice clinic?

- family problems
- depression

d) Would you use it again?

- no – didn’t find it particularly helpful as the wait for initial appointment too long which meant problems had evolved by that time. Needed appointment quicker
- yes – I need my help

6a) Who do you know that has used the advice clinic?

- son
- mother
- friend

b) Why did they use it?

- family problems
- depression
- depression
7b) What would stop you from using the psychology advice clinic?

- Nothing if I needed it
- Nothing
- Nothing
- Nothing
- Nothing really
- If I wanted to use it I would, I wouldn’t let nothing stop me
- would use if I needed to so no reason to stop me
- confidentiality and having a record on my medical records
- not sure about the service and confidentiality
- not sure exactly what they do
- I’m not sure what issues they could help me with
- not being able to talk to an outside person i.e. stranger
- I like to talk to friends, I know them
- belief that it wouldn’t help

c) What would make it easier for you to use the advice clinic?

- More information and publicity about it
- more information
- more information on the problems they can help with
- information on the range of difficulties a clinical psychologist could help with
- More information about the service
- If you was informed more about it as I didn’t even know it existed
- A leaflet explaining what a psychologist does and why you would be likely to need their help
- leaflets, open surgery
- if we were told more about it e.g. sent information about it
- if I knew that people would never have access to any information that I had disclosed
- Complete privacy
- nothing now I know it is there
- Nothing in particular
- referral by GP
- knowing the clinical psychologist
- someone very caring and understanding and who has plenty of time to listen to your problem
- One to one help
- No waiting
d) How would you feel if your GP suggested you make an appointment?

- fine/relieved
- fine
- fine
- fine
- yes I would go
- Happy to go
- Ok
- probably slightly anxious initially but if it helped I would be happy to go
- Ok
- ok, but concerned if it was a long waiting time for appointment
- If it will help then fine
- Ok
- Ok
- probably relieved that any problem had been recognised
- I trust the GP’s opinion
- I would discuss other ways, but if he felt it would be the best course of treatment I would consent
- if he felt it was necessary I would trust him
- If he felt I may need to use this service I would have no problems
- if my GP felt it appropriate it wouldn’t be a problem
- I would accept the doctors advice
- Not happy/ worried
- worried
- I will not like it
- GPs avoiding the problem
- They don’t want to help, passing the buck
- Don’t feel need to attend
- I would turn it down because I can talk to family, friends, and pastor if I needed to
- Depends on the problem
- Would depend on my particular problem
8a) What do you think a clinical psychologist does?

- Don't know
- Not entirely sure
- Don't know
- Not sure
- Listen and talks about your problem helping you find a solution
- Aid people by listening to the specific problem or refer them to another agency that may be able to help with the problem
- Mainly listens
- Listens, advises, guides
- Talk your problems through and try to advise you
- Listens to problems and tries to deal with them by reasoned logic
- Listens
- Helps advises through any difficult emotional time
- Good advice
- Tries to talk about your problems what causes them etc.
- Talk to people, not sure
- Is a trained counsellor with medical knowledge who can assess client needs and help even by listening with sound non-biased advice
- Helps with people whose problems are mainly mind based
- Acts as a therapist for patients with depression, psychological problems etc.
- Supports those going through emotional/ mental/ personal difficulties to help find solutions/ lessen problems
- Help people with psychological problems
- Deals with all your personal problems
- Diagnose any psychological problems and help with treatment. Help people to come to terms with their problems and understand them
- Help with your problems
- Allows clients to discuss personal issues and guides them and enables clients to make own changes
- Assesses if further specialist help is needed if the clinical psychologist can not help
Major Research Project

An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

July 2003

Year 3
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ABSTRACT

Research with both adults and adolescents in the general population has established that dissatisfaction with one’s physical appearance is widespread in society. Body image dissatisfaction has also been shown to be a significant predictor of dietary restraint. This is particularly important in children and adolescents, where nutritional deficits due to restricted or altered food intake have the potential to cause considerable harm. However, in adolescents with Cystic Fibrosis (CF) this is thought to be an exceptionally significant problem, where low weight and poor nutritional status have deleterious effects on pulmonary function and overall health status. Many research studies carried out to date regarding the frequencies and types of psychosocial maladjustment associated with CF are characterised by methodological problems and inconsistent findings. As a result the level of psychological adjustment difficulties in adolescents with CF is unclear. This is particularly important since it has been shown that social and psychological factors can affect the prognosis in CF.

This study investigated the nature and prevalence of body image dissatisfaction in adolescents with CF, as well as the prevalence and types of psychological adjustment problems in CF adolescents. Forty-four adolescents with CF, aged between 12 and 16 years, were asked to identify their actual and desired body size using the Contour Drawing Rating Scale. Participants also completed the Body Image Questionnaire, The Role of CF in Body Satisfaction Questionnaire, the Children’s Depression Inventory, the State-Trait Anxiety Inventory and the Self-Perception Profile for Adolescents. Demographic information was collected for all participants, as was information regarding their weight and height.

Results revealed that over half the participants were dissatisfied with their body size and wished to gain weight and as a result were engaging in adaptive behaviours to help them to do this. However, a significant proportion of participants whose body mass index (BMI) was either in the normal or underweight ranges were dissatisfied with their body size and desired an even thinner figure. The results also indicated that the participants did not differ from their healthy peers in terms of psychological adjustment.

It was suggested that assessment of body image should be made part of the routine clinic visit, in order that CF teams will be able to identify and deliver appropriate interventions to those patients who are at risk of, or who have disturbances of body image. Strategies aimed at preventing the development of such negative attitudes also need to be routinely undertaken in an adolescent CF population, to counteract the impact of the continuous focus on feeding and
nutrition throughout the lives of patients with CF. Routinely asking about symptoms of depression and anxiety or administering simple screening procedures, such as those used in this study which are reasonably short and easy to complete, would help CF professionals to identify those patients at risk of, or experiencing psychological adjustment difficulties and intervene appropriately.
INTRODUCTION

Overview
This section will begin with a detailed account of Cystic Fibrosis (CF) including information relating to prevalence, genetics, diagnosis, symptomatology, treatment and prognosis. The nature and prevalence of body image dissatisfaction in the general adolescent population will then be reviewed and the link between body image dissatisfaction and dietary restraint will be discussed. Possible explanations for the high prevalence of body image dissatisfaction in adolescents in the general population will be given and the reasons why adolescents with CF might be at risk of developing a poor body image will be considered. A review of previous research examining body image dissatisfaction in individuals with CF to date will be given alongside a summary of body image assessment measures. This will be followed by a review of recent research examining psychosocial adjustment in individuals with CF and the need for further research will be examined. The research questions will then be presented.

Cystic Fibrosis
The prevalence of Cystic Fibrosis
Cystic Fibrosis (CF) is a complex autosomal recessive disease affecting the exocrine glands in several major organ systems, including respiratory, digestive, pancreas, kidney, liver and reproductive. It is the most common lethal hereditary disease of Caucasians, affecting 1 in 2,500 live births. The gene frequency shows wide ethnic variation, such that the prevalence of live CF births is 1 in 17,000 in African Americans and 1 in 90,000 in Oriental races. There are approximately 30,000 individuals affected with CF in the United States and an estimated 7 million carriers of the disease (Fitzsimmons, 1993). In the United Kingdom CF is the most common life-threatening disease affecting 7500 individuals. CF affects males and females in equal numbers (Green, 1996).

Genetics
There has been a significant amount of research into the genetics of CF. In 1985, the gene was localised to the long arm of chromosome 7 (Tsui, Buchwald, and Barker, 1985). Since then more than 800 mutations have been described. The commonest CF mutation is ΔF508, which accounts for up to 70 percent of all CF mutations. It was first thought that delineation of the genetic defect would allow for genotype-phenotype correlations, with genes for 'mild', 'moderate' and 'severe' CF being determined. However, although there are some exceptions, this is generally not the case.
As CF is a complex autosomal recessive gene disease, in order to have the disease, a child must inherit two copies of the defective gene, one from each parent. If an individual only inherits one CF gene, they will be a carrier of the CF gene, but will themselves be asymptomatic. It is estimated that one in every 25 people in the United Kingdom carries the CF gene (CF Trust, 2002). When both parents are carriers, they have a 25 percent chance with every pregnancy of passing two copies of the defective gene to their child, a 50 percent chance that their child will be a carrier and a 25 percent chance that their child will neither have CF, nor be a carrier of the faulty gene (CF Trust, 2002).

The diagnosis of CF

Patients are typically diagnosed within the first year of life, with 80 percent being diagnosed by age four years (Fitzsimmons, 1993). The earlier a diagnosis is made the better so that early treatment can slow the progression of lung damage caused by infection. Children with CF may display a variety of symptoms early in their lives that lead to referral for diagnostic testing, such as persistent or acute respiratory symptoms; failure to thrive or malnutrition, despite adequate intake; steatorrhea, or meconium ileus.

Prenatal tests are available to determine if a baby will be born with CF. However, currently antenatal testing is only offered early on in pregnancy in cases where there is a high chance of CF. About one-third of babies in the UK are routinely tested for CF at birth using a heel prick blood test. These tests indicate high levels of digestive enzymes suggestive of CF, but a certain diagnosis requires a sweat test. Sweat tests identify elevated chloride levels in sweat and are used to provide a valid diagnosis. Recently, the government has announced the intention to have all babies routinely tested at birth, enabling treatments to begin immediately.

Symptomatology

Cystic fibrosis is caused by a defect in the gene responsible for manufacturing cystic fibrosis transmembrane conductance regulator (CFTR), a protein that controls the flow of chloride ions into and out of certain cells. In healthy people, CFTR forms a channel in the plasma membrane through which chloride ions enter and leave the cells lining the lungs, pancreas, sweat glands, and small intestine. In people with CF, malfunctioning or absent CFTR prevents chloride from entering or leaving cells, resulting in the production of a thick, sticky mucus that clogs ducts or tubes in these organs. In the lungs, this mucus hinders the normal cleaning mechanism, resulting in the mucus accumulating in the bronchi and bronchioles, leading to obstruction and recurrent bronchitis and infection. This mucus also impedes natural infection-fighting mechanisms, eventually turning the body’s immune system against its own lung
tissue. Over time this process permanently damages the lungs resulting in bronchiectasis, respiratory insufficiency and ultimately respiratory and right heart failure and premature death (Bush, 2001). Most of the morbidity of CF and virtually all the mortality is related to chronic lower respiratory infection (Wood, Boat and Doershuk, 1976; cited in Bush, 2001).

Within the digestive system, mucus secretion results in the accumulation of mucus in the pancreatic ducts, which typically causes blockage of these ducts. This prevents crucial digestive enzymes produced in the pancreas from reaching the intestines, impairing the ability to break down certain foods. This causes tissue damage impairing the function of the acinar tissue, leading to inadequate secretion of digestive enzymes and resulting in inadequate absorption of nutrients from the intestinal tract. Such patients are termed pancreatic insufficient. Eighty-five percent of CF patients are pancreatic-insufficient at diagnosis and are therefore unable to digest fat, protein and fat-soluble vitamins without enzyme replacement supplements. However, even with enzyme supplements, CF patients continue to have some malabsorption of nutrients (Stark, Jelalian and Miller, 1999). Even in those individuals with sufficient pancreatic function for normal digestion and absorption, over time, malabsorption may supervene due to continual duct obstruction (Bush, 2001).

As a result of lung disease, chronic respiratory infections and suboptimal fat absorption, energy requirements are greater for people with CF than those without. There is also evidence that resting energy expenditure is higher than normal in CF. Both of these factors mitigate against normal growth and weight gain in CF (Bush, 2001). As a result, CF patients tend to be underweight and small for their age. In the early stages of the illness it is possible to achieve normal nutritional status and linear growth, although as the disease progresses, normal growth is difficult to maintain and stunting becomes more common (Pamukcu, Bush and Buchdahl, 1995). According to the CF patient registry in the United States, approximately 50 percent of patients are below the tenth percentile for weight, height or both (Fitzsimmons, 1993). Although the greatest mortality and morbidity in CF are attributable to lung disease, nutritional status has been found to correlate highly with lung disease and to affect recovery from illness (Kraemer, Rudeberg, Hadorn and Rossi, 1978).

As well as the above associated difficulties, approximately 30 percent of patients with CF develop abnormal glucose tolerance and four percent of patients develop diabetes mellitus (Fitzsimmons, 1993). CF may also cause liver disease, characterised by a focal biliary cirrhosis and portal hypertension, and impaired reproductive function. Delay in puberty and menarche is common in girls with CF. Secondary amenorrhoea may be a complication of
worsening lung disease and poor nutrition. Women with CF have decreased fertility and are more likely to experience complications during pregnancy and childbirth (Edenborough, Stableforth, Webb, Mackenzie and Smith, 1995). Delay in puberty is also common in boys with CF. About 98 percent of adult men who have CF are infertile due to the absence of a vas deferens (Bush, 2001). In healthy people most of the chloride in sweat is reabsorbed, but in people with CF, sweat glands cannot take up chloride ions, enabling excessive amounts of salt to escape in the sweat causing CF patients of all ages to be prone to dehydration (Online Encyclopedia, 2003). Clubbing of the digits is also seen in patients with CF. This is relatively common and is usually secondary to advanced pulmonary and hepatic disease (Bush, 2001).

The treatment of CF
Although there is currently no cure for CF, comprehensive therapy that is begun early and administered consistently can often delay the disease process. Treatment typically revolves around preventing and treating symptoms, in the lungs and pancreas (Stark, Jelalian and Miller, 1999), however, the precise treatment prescribed depends upon the stage of the disease and which organ systems are involved. Treatment is generally complex, time-consuming, and expensive (Geiss, Hobbs, Hammersley-Maercklein, Kramer and Henley, 1987).

Respiratory therapies
Physiotherapy
From diagnosis, no matter how well the child, most physicians would advise a regular programme of chest physiotherapy (CPT). Most patients do physiotherapy twice a day when well, and more often at the time of exacerbations. (Bush, 2001). CPT takes approximately 20 minutes to complete and aims to aid the patient in moving the mucus out of the airways. During and after CPT, the patient coughs up and expectorates the mucus dislodged from the airways (Stark, Jelalian and Miller, 1999). Exercise is also encouraged as a valuable addition to CPT, as vigorous exercise may serve to loosen mucus from the lungs (Orenstein, Henke and Cherny, 1983, cited in Stark, Jelalian and Miller, 1999).

Prescribed medications to aid CPT
In addition to CPT, the patient may be prescribed inhalation therapies, such as Dnase. This is administered prior to CPT to wet and thin the mucus. Bronchodilators may also be prescribed in inhaled or nebulised form prior to CPT. These aim to aid sputum clearance by opening the airways. Inhaled corticosteroids are prescribed to decrease the airway hyperactivity that is common in CF.
Antibiotic treatments
The second mainstay of respiratory therapy is the liberal use of antibiotics. Some centres start all infants on continuous oral antibiotic prophylaxis, others use long courses of oral antibiotics at the first sign of respiratory deterioration. Antibiotics may be administered orally, through nebulizers or intravenous therapy.

Transplantation
Increasingly, CF patients with severe, irreparable lung damage turn to lung transplantation surgery. Although complications with transplantation surgery may pose problems for some patients, lung or combination heart and lung transplants provide nearly 80 percent of CF patients with severe lung damage an entirely new lease of life (Online Encyclopedia, 2003).

Pancreatic and digestive system therapies
Nutrition
Nutritional support is an integral part of the management of CF patients, as good nutritional status has been found to be directly associated with health status in patients with CF. Improvements in nutritional status in CF have been shown to result in better growth (Hanning, Blinkie, Bar-Or, Lands, Moss and Wilson, 1993) and improvement or stabilisation of pulmonary function (Levy, Durie, Pencharz and Corie, 1986). Patients with CF are recommended an increased caloric intake of 125-150 percent of the recommended daily allowance (RDA) of calories for healthy individuals, with a normal to high fat intake. If weight gain or growth is poor, then it is recommended that 35-45 percent of energy intake is fat and sugar. Fifteen percent of the total energy intake should be from protein to compensate for the excessive loss of nitrogen in the faeces and sputum (MacDonald, 1996). Dietary supplements, such as nutritionally fortified milkshakes and desserts, and glucose polymers are recommended for patients suffering from weight loss. CF patients are recommended to take vitamin supplements, in particular vitamins A,B,C,D and E (CF Trust, 2002). Routine salt supplements are advocated during hot weather and in all infants on normal infant formulas (MacDonald, 1996).

Pancreatic enzyme supplementation
Patients who are pancreatic insufficient must take pancreatic enzymes with meals. These facilitate the absorption of nutrients from the intestinal tract. This aids the digestion of food, which in turn enhances nutrition and consequently weight gain and growth.
Enteral feeding

Enteral feeding typically involves overnight feeding, through a nasogastric tube or gastrostomy. It tends to be initiated when oral methods of maintaining nutritional status have failed and substantial deviation from normal weight gain or growth occurs. MacDonald (1996) found that the majority of those needing enteral feeding were adolescents. It is believed that this reflects the deterioration in nutritional status which occurs in adolescents with CF, but it may also result from other issues observed during adolescence, such as weight and shape concerns.

Prognosis

Although no cure has yet been found, recent advances in the treatment of those with CF have resulted in marked increases in their life span (Kashani, Barbero, Wilfley, Morris and Shepperd, 1988). Three decades ago most babies born with CF died in early childhood, but advances in diagnosing and treating the disease have significantly improved its prognosis. Today more than 60 percent of babies born with CF reach adulthood (Online Encyclopedia, 2003). In 1999 the median survival rate was estimated to be approximately 34 years for males and 31 years for females (Cystic Fibrosis Foundation, 1999, cited in Bush 2001), whilst it is expected that babies born with CF in the 1990s will have a median survival rate of around 40 years (Elborn, Shale and Britton, 1991).

Scientists are currently investigating the use of gene therapy to introduce healthy copies of the CFTR gene into the cells of patients with CF. Scientists hope that once inside the cells, healthy copies of the gene will manufacture functional CFTR protein, permitting the flow of chloride into and out of cells in affected organs and restoring healthy function (Online Encyclopedia, 2003).

Body image dissatisfaction

Body image is a complex notion, referring both to "the picture of our body which we form in our minds" and to our affective response to our appearance (Wardle and Foley, 1989). The psychological construct of body image includes cognitive, attitudinal, and affective components as well as kinaesthetic and sensory input. The cognitive and affective components stem, in part, from comparisons of the physical self to others and to internalised representations of culturally determined standards of physical appearance and aesthetic appeal (Rosenblum and Lewis, 1999). In the past decade, research with both adults and adolescents...
in the general population has established that dissatisfaction with one’s physical appearance is widespread in society (Wood, Becker and Thompson, 1996).

**Body dissatisfaction in adolescents**

Body image dissatisfaction and weight loss attempts are increasingly common among adolescents (Graham, Eich, Kephart and Peterson, 2000). In fact, Cash, Winstead and Janda (1986, cited in Rosenblum and Lewis, 1999) in a national survey of body image found that adolescents place more importance on and feel more negatively about their bodies than older Americans. Brennan and Kevany (1985) investigated body image in 218 adolescent girls, aged 14 to 17 years, attending a non-fee paying day school in a predominantly middle class district of Dublin. Subjects were randomly selected from the school register. Participants were asked to complete questionnaires addressing attitudes towards their weight, both perceived and desired, and satisfaction with certain body dimensions. Six somatotype silhouettes were presented to assess body image satisfaction. Height and weight were noted, and triceps skinfold thickness was recorded and used to validate BMI as an indicator of adiposity. The results showed that the majority of subjects were clearly dissatisfied with their body size. Sixty-one percent of participants wanted to weigh less, including 68.8 percent of those categorised as normal in weight, and 15.6 percent of those classified as underweight. Subjects were also asked if they considered specific parts of their body to be “too large”, “just right” or “too small”. Approximately half of the respondents were dissatisfied with their thighs, buttocks, hips and waist, and 36 percent indicated a desire to be taller. These results provide evidence to support the theory that dissatisfaction with size and body image are common amongst adolescent girls.

**Gender differences in body image dissatisfaction**

Recent research has indicated that adolescent males are also dissatisfied with their body image, although this appears to operate in the direction of weight gain. Studies with high school and college students have indicated that the chief male desire at that age is to gain weight, size, and strength. Many studies report that adolescent males often describe themselves as being underweight or too thin. However, it has been hypothesised that boys who report wanting to gain weight are less interested in gaining weight per se and are actually more interested in becoming more muscular and equate muscularity with added weight (Drewnowski and Yee, 1987).

Further evidence for gender differences in body satisfaction comes from a study by Wardle and Beales (1986) who examined restraint, body image and food attitudes in 348 adolescents.
aged 12 to 18 years. Subjects were recruited from an independent, mixed sex, secondary school in London. Subjects’ weight and height were measured and a weight/height ratio was calculated. Body image was assessed by asking the children what their ideal weight was, and comparing this to their actual weight, as well as asking them to indicate which of the five categories: “thin”, “slightly underweight”, “just right”, “slightly overweight” and “fat”, they felt best described themselves. Dieting behaviour was assessed by asking the children whether they were dieting, and through administration of the Dutch Eating Behaviour Questionnaire (DEBQ), which provides a quantitative estimate of restrained eating behaviour. Food attitudes were assessed by asking the children to rate each of 12 food types on five sets of analogue ratings: “Like”, “Good for you”, “Bad for you”, “Makes you fat” and “Feel guilty about eating it”. Children were also given a form marked into hourly intervals and asked to record everything they had eaten on the previous day.

The results from this study reinforce the notion that girls as young as 12 are dissatisfied with their body image. Once again, even when their actual weight placed them in the normal or thin categories, a significant number of girls still expressed a preference for a lower weight. The researchers also found that there was a significant gender difference in desired weight. None of the girls had a preferred weight more than ten percent above their actual weight, whereas the maximum for the boys was 40 percent greater than actual weight. The results from the DEBQ also showed significant sex differences in restraint scores, with greater restraint in girls. The results from this study therefore provide support for the hypothesis that adolescent girls strive for an extremely thin body ideal, whereas boys desire a more masculine ideal of larger size and muscularity (Ferron, 1997).

**Relationship between body satisfaction and dietary restraint**

A number of studies examining body image in adolescents have found that body image dissatisfaction predicts subsequent eating behaviour. In the above study, Wardle and Beales (1986) found that in both sexes those participants who reported dissatisfaction with their body image also reported attempts to restrict food intake. However, in girls the whole process was triggered by body weights well below what might be considered a healthy weight. They reported that even the youngest girls had already embarked upon the task of trying to keep their body weight at an abnormally low level.

Wardle and Foley (1989) carried out a similar study examining body satisfaction and the feeling of fatness. The relationship of body image to dietary restraint was also investigated. Twenty female students aged between 18 and 20, and weighing within ten percent of their
ideal body weight took part. Body satisfaction was assessed using a 100mm visual analogue scale (VAS), labelled at the extremes “not at all satisfied” and “completely satisfied”. Feeling of fatness was also assessed using a VAS, but the scale was marked “very thin”, “fairly thin”, “slightly thin”, “neither thin nor fat”, “slightly fat”, “fairly fat” and “very fat”. Actual body size was measured using callipers, and dietary restraint was assessed with the Restrained Eating Scale of the DEBQ. The results of the study indicated that the majority of subjects did not feel satisfied with their appearance, and felt “fat”. Both of these factors were found to correlate significantly with dietary restraint, that is, women who felt fatter or were more dissatisfied with their appearance were more likely to report dieting to modify their weight. These relationships also remained significant after controlling for the contribution of actual body weight.

The results from these studies provide support for the hypothesis that body image dissatisfaction is clearly associated with attempts to restrict food intake. This is particularly important in children and adolescents, where nutritional deficits due to restricted or altered food intake have the potential to cause considerable harm. Dieting in young females has also been recognised as being associated with the onset of eating disorders (Hill, 1993) and a feeling of dissatisfaction with one’s body shape has been found to be the most reliable predictor of the outcome of eating disorders (Fairburn and Cooper, 1989). Hsu (1990) believes that dieting in adolescence due to body dissatisfaction can trigger the onset of an eating disorder as a result of poor self-esteem, poor body image and poor identity formation.

**Reasons for the high prevalence of body image dissatisfaction in adolescents**

**Puberty**

Early adolescence is marked by the onset of complex physiological changes. As well as notable increases in height and weight and the attainment of mature reproductive capacity, the individual also undergoes changes in the distribution of body fat, the development of a variety of secondary sexual characteristics, and alterations in body proportions. Individual differences in these characteristics and the timing of the pubertal process must be incorporated into one’s body image and personally evaluated in a diversity of settings (Blyth, Simmons and Zakin, 1985). Faust (1983, cited in Blyth, Simmons and Zakin, 1985) argued that adjustment to the physical changes of puberty and the timing of these changes, in early adolescence has a major impact on body image and self-image. Furthermore the relationship between body image and self-image is reported to be stronger for girls than boys. Smolak, Levine and Gralen (1993, cited in Striegel-Moore, Schreiber, Lo, Crawford, Obarzanek and Rodin, 2000) have shown that prepubertal girls report considerably less body dissatisfaction and dieting efforts than
For girls puberty is associated with a significant increase in adipose tissue and according to Striegel-Moore, et al. (2000) it is this increase in body fat that appears to contribute to the increase in body dissatisfaction. Striegel-Moore, et al. (2000) undertook a study examining age differences on each of the Eating Disorder Inventory (EDI) subscales in a sample of 2,379 early adolescent girls aged 11 to 16 years. The EDI is a self-report instrument for assessing the affective, cognitive and behavioural symptoms of eating disorders. It features three subscales measuring attitudes and behaviours related to the core symptoms of eating disorders: Body Dissatisfaction, Drive for Thinness, and Bulimia, and consists of 64 items that are rated on a six-point scale from “never” to “always”. The EDI data that was utilized for the study had been collected longitudinally as part of the National Heart, Lung and Blood Institute Growth and Health Study, designed to identify risk factors for the development of obesity and cardiovascular disease. The results showed that Body Dissatisfaction and Drive for Thinness scores increased with age. They attributed this positive association of age with weight concerns and dieting, mainly to the developmental changes of puberty, especially weight gain. They also found a strong association between BMI and all three core eating pathology scales on the EDI. This finding lends further support to the hypothesis that being overweight is a risk factor for girls' developing a poor self-image. In summary, the physiological changes that occur during puberty appear to heighten girls body image awareness, resulting in increased body dissatisfaction and drive for thinness as girls grow older.

Prepubertal changes typically begin around age nine and continue for several years, with the average age of menarche between 12 and 13 years of age. However, there is variability in the onset of prepubertal changes and there may be different psychological consequences to “early” versus “on time” versus “late” pubertal development (Rosenblum and Lewis, 1999). Recent research on the impact of pubertal timing or development relative to one’s peers on female body image and self-image has found that timing of puberty influences feelings about puberty, body satisfaction and overall psychological adjustment among children and adolescents. The general pattern is that early puberty has the most negative impact on girls, whereas being late is most distressing for boys (Siegel, Yancey, Aneshensel and Schuler, 1999). The increase in body mass, with a particular accumulation of fat around the hips and thighs, which is a normal consequence of puberty in females, results in a physique that is at odds with western culture’s standard of beauty. The loss of the prepubescent body and the increasing disparity between girls’ real and ideal bodies causes adolescent girls dissatisfaction and distress. Society’s current emphasis on thinness tends to favour late developing girls, who
are more likely to be longer legged and to have an overall thinner appearance than their early maturing counterparts, suggesting that early developing girls would be less satisfied with most aspects of their body image than late developing girls. In contrast it has been found that as boys progress through puberty, they tend to show an increase in satisfaction with their body image. This is because pubertal development generally serves to bring boys' bodies closer to the masculine ideal of larger size and masculinity. As a result delayed puberty in boys results in more dissatisfaction and distress (Rosenblum and Lewis, 1999).

**Developmental factors**

In adolescence several complex processes affect body image. Firstly, there is evidence of increasing cognitive and introspective abilities in adolescence. This allows individuals to construct and reinterpret their theories about themselves in new ways, but also equips them with the capacity for and proclivity towards self-evaluation and a heightened sense of being evaluated by others (Lapsley, Milstead, Quintana, Flannery and Buss, 1986). In addition, these changes occur at a time when early adolescents are becoming increasingly sensitive to issues of peer conformity (Bemdt, 1979). This egocentrism causes young adolescents to be very aware of the real and imagined evaluations of them made by others and to be highly sensitive to indications of acceptance and rejection (Rosenblum and Lewis, 1999).

**Sociocultural factors**

One of the most well-known attractiveness stereotypes is the thin, slim-hipped female beauty ideal prevalent among western, Caucasian cultures. Over the past 20 to 30 years the prevailing role model for women has been getting thinner (Silverstein, Peterson and Perdue, 1986). This sociocultural standard of thinness for women in western societies is portrayed as not only desirable, but attainable by all women. This image is consistently portrayed through the media and emphasizes a body form which is essentially prepubertal (Blyth, Simmons and Zakin, 1985). Internalisation of these stereotypes is reflected in significant discrepancies between women's perceived and ideal body shapes, as well as behavioural attempts to attain the ideal through dieting, exercise and disordered eating patterns (Rosenblum and Lewis, 1999), in order to attain an unrealistically thin body ideal. Such preoccupations are not only sustained but heightened by the anorexic-like bodies of fashion models, the plethora of diet manuals and weight loss therapies advertising quick "cures", as well as the fitness industry that expounds on the virtue of being slim and physically fit (Flannery-Schroeder and Chrisler, 1996).

Further evidence for the role of Western society's emphasis on thinness and dieting comes from research in non-western countries and non-Caucasian subcultures. Several studies have
indicated that in African, African American, and Caribbean men, women and girls, who value a larger body size, objectively normal-weight females are less likely to consider themselves overweight (Smith and Cogswell, 1994, cited in Rosenblum and Lewis, 1999). This view is supported by the findings that immigrants to Western societies do not develop eating disorders themselves, yet their children appear to be just as vulnerable to developing an eating disorder as those indigenous to Western society (Bryant-Waugh and Lask, 1991).

Why might adolescents with CF be at risk of poor body image?

Impact of CF on physical development

The physical development of patients with CF is affected in a number of different ways and these differences may be particularly highlighted during adolescence when there is a heightened sense of self-focus and a sense of being evaluated by others. Failure to thrive, short stature and malnutrition are relatively common in individuals with CF. Although in the early stages of the illness it is possible to achieve normal nutritional status and linear growth, as the disease progresses, normal growth is difficult to maintain and stunting becomes more common (Pamukcu, Bush and Buchdahl, 1995). Consistent with the poorer prognosis in females, nutrition tends to be worse in girls even before puberty. Even with the initiation of enteral feeding it may take up to six months before there is an increase in linear growth velocity, weight gain may be disappointing even two to three months after starting feeds, and the weight/height ratio is rarely returned to normal (MacDonald, 1996). Delay in menarche is common in girls with CF and delay in puberty is common in both males and females with CF. As a result adolescents with CF typically experience a delay in secondary sexual characteristics.

The respiratory problems in CF result in individuals having a constant cough and being chronically productive of sputum. Individuals may also have barrel chests due to over-inflation of the lungs. Clubbing of the digits is also common in CF, that is, a thickening of the fingertips and increased surface of the fingernails, and is usually secondary to advanced pulmonary or sometimes hepatic disease. All these factors are obvious external signs of difference when CF adolescents are compared to healthy peers, and are likely to negatively influence their body image.

Focus on feeding and high caloric intake

As noted above, malnutrition is a significant problem for many children with CF. Therefore, close monitoring of nutritional status and nutritional rehabilitation programs are considered important components of medical management. Nutritional recommendations for children
with CF include intake of 150 percent to 200 percent of calories recommended for healthy peers, with a normal to high fat intake, in order to maximize growth and minimize infection (Singer, Nofer, Benson-Szekely and Brooks, 1991). CF patients are also encouraged to have regular dietary supplements and consume a large number of digestive enzymes whenever they consume food. If weight gain or growth is poor, then enteral feeding, including nasogastric tubes and gastrostomies are initiated. In order to monitor their nutritional status, patients with CF are regularly weighed and measured at clinic visits, and doctors and other health professionals continuously emphasize the importance of weight gain within treatment. The continuous focus on feeding and nutrition experienced by patients with CF throughout their lives may trigger high levels of concern over body shape in CF adolescents.

Adolescents with CF are likely to subscribe to the same cultural values as their non-CF peers

Very little research has been undertaken examining the impact of the Westernized culturally determined standards for physical attractiveness on body image of adolescents with CF. However, there is no reason why adolescents with CF would not subscribe to the same cultural pressures as non-CF adolescents. The thin, slim-hipped female beauty ideal that female adolescents in Western societies frequently strive to achieve, is one which adolescent females with CF are also likely to desire. In contrast, adolescent boys tend to favor larger, more muscular bodies. The increase in height and muscle mass that boys experience during puberty has been shown to result in an improvement in body image satisfaction in adolescent boys. Based on this finding, it appears that adolescent boys with CF, who typically experience delayed puberty, shorter stature and are thinner than their peers, are likely to be dissatisfied with their body image.

Research into body image satisfaction in CF

Very little research has been carried out to date examining body image satisfaction in adolescents with CF. Sawyer, Rosier, Phelan and Bowes (1995) investigated psychological well-being and adjustment of adolescents with CF. Participants were male and female adolescents with CF between 14 and 18 years of age. The Offer Self-Image Questionnaire was used as a measure of adjustment. This contains 11 subscales recording the individual's self-perception of personal mastery of the problems of adolescence. Growth and pubertal development of all participants was recorded. The results showed that there was extensive growth delay in both males and females, although males' height and weight were more affected than those of females. Females with CF were found to be significantly less well-adjusted than controls in ten of the 11 subscales, with the greatest differences for the subscale addressing body and self-image. Males with CF were found to be as well adjusted as the
controls. Although male growth was more delayed than that of females, pubertal development was more delayed in the females in this study, and the authors concluded that it might be this that impacts on body image and self-esteem in adolescents with CF. They also offered an alternative explanation for these results, which was that males with CF use denial and optimism as an adaptive way to reduce the perceived impact of CF on their lives.

Strauss and Wellisch (1980) investigated psychosocial adaptation in 21 CF patients aged 18 or older, who attended the UCLA CF clinic. Participants were asked to complete a 79-item questionnaire addressing psychosocial functioning in certain key areas in their lives: 1) Aspects of their experience of CF, 2) Autonomy and relations with their parents, 3) Social relations, 4) Work, and 5) Emotions and feeling states. As part of the assessment of patients’ experiences of CF, participants were asked to list the symptoms of CF that bothered them the most. The results showed that participants found concerns regarding physical appearance, such as slim physique to be the most distressing symptom of CF other than having a chronic cough.

Abbott, Dodd, Gee and Webb (2001) undertook a study aimed at developing a patient derived self-report measure to evaluate the ways in which people with CF cope with CF concerns. They initially interviewed 60 patients with CF aged 16 to 44 years to identify CF related concerns. From this they derived a list of 23 specific concerns/worries, based upon the perceptions and beliefs of the patients themselves. They found that being too thin or small was the eighth most salient concern for this group. Interestingly, the group were less worried about death and dying, hospital admissions for treatment, coughing blood and undergoing a lung transplant.

Abbott, Conway, Etherington, Fitzjohn, Gee, Morton, Musson and Webb (2000) investigated perceived body image and eating behaviour in adolescents and young adults with CF. The study involved a cross-sectional questionnaire design, in which 221 English adults with CF and 148 English healthy controls participated. Perception of body image was evaluated using the Body Test. This measure comprises two sets of a series of seven silhouettes with corresponding BMIs, one male and one female, ranging from emaciated to obese. The silhouettes were presented to subjects on a single sheet with figures arranged in ascending size from left to right and participants were asked which silhouette looked most like them and which they would most like to be. Self-esteem was assessed using Rosenberg’s (1965) Self-Esteem Scale. This comprises ten items with a four-point response scale from strongly agree to strongly disagree. Eating attitudes and behaviours were assessed by the Eating Attitude
Test (EAT-26). The scale contains three subscales: dieting, bulimia and food preoccupation, and oral control. Body Satisfaction was measured by the Body Image Questionnaire (Hatfield and Sprecher, 1986). This scale asks respondents to rate how satisfied they are with a number of different body parts. The results from this study indicated that control males had an accurate perception of their body shape and were content with it, whereas CF males perceived their body shape as greater than it actually was and desired to be much heavier. Control females perceived their body shape to be less than it actually was and desired to be much slimmer, while CF females viewed their body shape as less than it actually was but were happy with this. In terms of self-esteem, both CF females and control females reported lower feelings of self-worth than CF and control males, respectively. A greater satisfaction with body physique was found to be associated with greater levels of self-esteem for all groups.

Although the findings from this study are informative, those regarding body satisfaction need to be interpreted with caution. Firstly, it is not possible to determine levels of body satisfaction and self-esteem in adolescents from these results since adolescents and adults were pooled together into a single group. Secondly the reliability of the results from the silhouettes is questionable because of the method of presentation. This method has been found to have spuriously high test-retest reliability because subjects have little difficulty remembering which silhouettes they previously chose. Presenting all the silhouettes on a single sheet of paper can also result in order effects, as subjects are able to determine which is the middle silhouette and choose their answer accordingly. As a result it has been recommended that silhouettes are put on separate cards and administered in a random order (Gardner, Friedman and Jackson, 1998).

Body Image Assessment Measures
The assessment of body image has generally focused on two aspects of body image: a perceptual component, commonly referred to as size perception accuracy, and a subjective component, which entails aspects such as satisfaction with body size, weight or overall physical appearance (Cash and Brown, 1987). A number of techniques have been developed to measure body size estimation, that is, whether individuals can accurately perceive their body size including Adjustable Light Beam Apparatus (Thompson and Spana, 1988, cited in Thompson, Penner and Altabe, 1990), Body Image Detection Device (Ruff and Barrios, 1989, cited in Thompson, Penner and Altabe, 1990), and Movable Calliper Technique (Slade and Russell, 1973, cited in Thompson, Penner and Altabe, 1990). These will not be discussed further because they are not relevant to this study which focuses on the subjective component of body image, rather than the perceptual component.
Attitudinal body image is commonly divided into four components: global subjective dissatisfaction, which refers to satisfaction or dissatisfaction with one's appearance; affective distress regarding appearance, which refers to an individual's emotions about their appearance, including anxiety, dysphoria, and discomfort; cognitive aspects of body image which refers to erroneous thoughts or beliefs about one's body and body schemas, and behavioural avoidance related to dissatisfaction with appearance, referring to avoidance of situations or objects due to their elicitation of body image concerns. Satisfaction may be further defined to reflect such components as weight satisfaction, shape satisfaction, and satisfaction with specific body sites and features (Thompson and Vanden Berg, 2002). A number of measures have been developed to assess each of the above dimensions, however only measures of global subjective dissatisfaction will be discussed further, as the others are not relevant to this study, which only addresses satisfaction with physical appearance.

The most widely used measure for the assessment of subjective components of body image disturbance are the schematic figures or silhouettes of different body sizes, which range from underweight to overweight (Thompson, et al., 1990). With this methodology, subjects are asked to choose the figures that they think reflect their current and ideal body sizes from a collection of between five and twelve silhouettes of the same gender. The discrepancy between these two measures is taken as an indication of level of dissatisfaction (Thompson, 1990). This form of assessment has been found to distinguish those with eating disturbance from normal controls, to have good test-retest reliability and to have good concurrent validity with other types of measures of eating disturbance (Dowdney, Woodward, Pickles and Skuse, 1995).

Many silhouettes and schematic figure scales have been developed, although many sets of figures have not yet been demonstrated to have good validity and reliability, and many figures have poorly defined bodily features (Thompson and Gray, 1995). Gardner, Friedman and Jackson (1988) recently criticized some of the figural scales because of the lack of consistent size gradations between adjacent figures. For instance, they evaluated the Figure Rating Scale (Stunkard, Sorenson and Schulsinger, 1983, cited in Gardner et al., 1988) which is a widely used scale consisting of a set of nine male and female schematic figures ranging from underweight to overweight and found that the size changes about the central figure occurred in non-equal intervals. In addition, they also found that the rates of changes differed for chest and waist and also between sexes. For this reason Thompson, Heinberg, Altabe and Tantleff-
Dunn (1995) suggest a consideration of the schematic figures by Thompson and Gray (1995), who constructed the adjacent figures to have similar differences in size.

Several questionnaire measures have also been constructed which provide a global, comprehensive evaluation of body dissatisfaction. For example, the Body Dissatisfaction subscale of the Eating Disorder Inventory 2 (Garner, Olmstead and Polivy, 1983, cited in Thompson et al., 1995), which is a nine-item measure assessing satisfaction with weight-related body sites (Thompson et al., 1995) or the Body Image Questionnaire (Hatfield and Sprecher, 1986) which lists 25 body parts that are rated on a scale ranging from extremely dissatisfied to extremely satisfied. Both of these scales ask subjects to rate their satisfaction with several different body sites, yielding a summary score of general body dissatisfaction. They also identify with which parts of the body a person is dissatisfied.

**Psychosocial adjustment in adolescents with CF**

Studies of psychosocial adjustment to serious illnesses have frequently identified the adolescent period as a sensitive time for the formation of identity, and a time during which psychosocial adjustment to illness is most difficult (Ben-Tovim and Walker, 1995). Population-based studies have shown that children with chronic illness have an increased risk of experiencing a significant psychological or social problem. This risk is estimated to be one and a half to three times as great as their healthy peers (Pless, 1984, cited in Thompson, Hodges and Hamlett, 1990). Possible reasons for such problems include physical limitations associated with illness, difficulties adhering to long-term medical regimens, high rates of school absence, limited opportunities for socialisation, feelings of helplessness, increased dependency and self-consciousness (Bennett, 1994).

A great deal of research has been carried out investigating the impact of CF on the adjustment of children and adolescents with CF. Thompson, Hodges and Hamlett (1990) compared psychological adjustment in children and adolescents with CF with psychiatrically referred and non-referred children. They used a structured clinical interview, the Child Assessment Schedule (CAS) to assess psychological adjustment. This is a semi-structured diagnostic interview, in which DSM-III items are embedded. The results showed that there was a significant difference across the groups in the percentage of subjects who met the criteria for a DSM-III diagnosis: 58 percent of the children with CF, 77 percent of the psychiatrically referred children and 23 percent of the non-referred children. The children with CF did not demonstrate more symptoms of behavioural disturbance than the non-referred children. However, in terms of the internalising problems of worries, self-image and anxiety, they
demonstrated symptom levels comparable to that of the psychiatrically referred children. The authors concluded that children with CF are at increased risk for internalising as opposed to externalising disorders, and that the risk for children with CF is primarily in terms of anxiety-based disorders and not depression. However, they did find a trend for the older children, aged 10 to 14 years, to demonstrate higher levels of depressive symptoms than the younger children, aged seven to nine years.

Thompson, Gustafson, Hamlett and Spock (1992) further investigated what types of psychological problems children with CF experience, according to mother and child report. The Missouri Children’s Behaviour Checklist (MCBC) was used to measure parent-reported problems. This consists of 77 items, which form seven scales: aggression, inhibition, activity level, sleep disturbance, somatisation, sociability and depression. The Child Assessment Schedule (CAS) was used to assess child-reported symptoms. The authors found that the most frequently reported difficulties included a combination of both internalising and externalising problems. The authors concluded that these findings suggest that children with CF may be at risk for a constellation of anxiety-based internalising problems and oppositional externalising problems. The research also compared children with good adjustment to those with poor adjustment. No significant differences were found on illness severity or on any demographic parameters, but they did find that children’s perception of self-worth was lower in children with poor adjustment.

DiGirolamo, Quittner, Ackerman and Stevens (1997) investigated the problematic situations experienced by adolescents with CF, in order to identify the most frequent and difficult problems encountered by this population, as well as emotional and social functioning. Forty-five adolescents aged 12 to 17 took part, recruited from two major medical centres. A 75-item structured interview was carried out in participants’ own homes in order to elicit a wide-range of problematic situations. Participants were asked to complete the Children’s Depression Inventory and the Self-Perception Profile for Adolescents (SPPA). The results indicated that adolescents with CF generally endorse a moderate number of depressive symptoms, with nine percent of the sample scoring above the clinical cut-off point, and with adolescent girls endorsing a greater number of depressive symptoms than boys. The results of the SPPA fell within the normal range. Behavioural analysis of the results from the interview indicated that the majority of problems faced by these adolescents were closely related to the demands of their illness. That is, the content of many so-called normal problems, for example, wanting to date, was influenced very specifically by the challenges of CF, such as feeling less attractive
because you are shorter and thinner than your peers (DiGirolamo, Quittner, Ackerman and Stevens, 1997).

In contrast, some studies have shown that adolescents with CF are as well adjusted as their normal peers. Moise, Drotar, Doershuk and Stern (1987) investigated psychosocial adjustment in a sample of 73 adolescents and young adults with CF. Psychosocial adjustment was measured using the Tennessee Self-Concept Scale (Fitts, 1965, cited in Moise et al., 1987), a 100-item, self-report instrument assessing self-concept, and the Psychological Screening Inventory (Lanyon, 1970, cited in Moise et al., 1987), a multiphasic instrument assessing psychopathological symptoms. The authors concluded that overall the results indicated that as a group, CF patients do not demonstrate greater psychological maladjustment than controls. However, the level of self-esteem in the CF group was found to be somewhat lower than for test norms, suggesting that CF may negatively affect self-esteem.

Similarly, Blair, Cull and Freeman (1994) investigated psychosocial functioning of adolescents and young adults with CF. Participants who were aged between 14 and 24 years, were recruited from three regional CF centres in Scotland. Two measures were employed to assess psychosocial functioning: a structured clinical interview able to identify DSM-IIIR diagnoses, and the General Health Questionnaire (GHQ-30, Goldberg, 1987). The authors found that the majority of the CF patients were in robust psychological health that was indistinguishable from their healthy peers.

Thus, the current available research presents with conflicting findings in relation to psychopathology in adolescents with CF. This may be due to a number of reasons. Firstly, the differing methods used to assess adjustment may contribute to the variable findings. Many of the studies involved small sample sizes that do not allow generalisation from the results. Secondly, in most studies there was little control for potentially significant variables within the population studied. For example, in many of the studies no distinction was drawn between children and adolescents. The differences in their childhood developmental tasks, and the developmentally determined differences in their adaptive capacities, make separation of these populations a necessity. Thirdly, outcome variables have been inconsistently defined and there have been wide variations in methods for measuring psychosocial adaptation, ranging from parent interviews alone, to standardised questionnaires or self-report measures (Mador and Smith, 1988).
A need for further research

Much of the research to date has indicated that body dissatisfaction is likely to be an area of difficulty for adolescents with CF. It is thought that disturbances of growth and pubertal development may have more immediate relevance and impact for adolescents with CF than the knowledge that CF is a lethal disease, which may be easier for adolescents to ignore or deny because of its future impact (Sawyer et al., 1995). However, despite this, body image and body dissatisfaction have never been directly investigated in adolescents with CF. Body image dissatisfaction is problematic in any population, since it has been shown to be a significant predictor of dietary restraint. However, it is felt to be an exceptionally significant problem in adolescents with CF, where low weight and poor nutritional status have deleterious affects on pulmonary function and overall health status. It is therefore important to clarify whether or not adolescents with CF are satisfied with their body image. At present patient satisfaction with weight and body appearance are not routinely assessed in CF clinics in the United Kingdom. However, if it is found that adolescents with CF do experience body image disturbances then this information can be used to direct future service provision, enabling CF teams to best meet the needs of their patients. By making assessment of body image part of a routine clinic visit, CF teams will be able to identify those patients who are potentially at risk of, or who have disturbances in their body image, and administer appropriate clinical interventions.

Many research studies carried out to date regarding the frequencies and types of psychosocial maladjustment associated with CF are characterised by methodological problems and inconsistent findings. As a result the level of psychological adjustment difficulties in adolescents with CF is unclear. This is particularly important since it has been shown that social and psychological factors can affect the outcome in CF. Poor psychological well-being can have a detrimental effect on physiological functioning, the onset and progression of disease, as well as morbidity and mortality (Abbott and Gee, 1998). It is therefore important to establish whether adolescents with CF do experience poor psychological adjustment and to what extent. Again, this information is necessary in order to guide efforts to derive intervention programmes to enhance adjustment to the stress associated with CF.

A number of studies have shown that poor body image in adolescents in the general population is associated with difficulties in psychosocial adjustment, in particular poor self-esteem, and internalising problems, such as depression and anxiety. However, the relationship between body image and psychological adjustment in adolescents with CF is currently unclear.
This study
This is an exploratory study aiming to investigate whether adolescents with CF are dissatisfied with their body image, as well as to determine the prevalence and types of psychological adjustment problems in CF adolescents and whether there is an association between body image dissatisfaction and psychological adjustment.
Research Questions:

**Question 1:** Are adolescents with Cystic Fibrosis satisfied with their perceived body size?

**Question 2:** Are adolescents with Cystic Fibrosis satisfied with their body appearance?

**Question 3:** What is the prevalence and nature of psychological adjustment problems in adolescents with Cystic Fibrosis?

**Question 4:** How does body satisfaction in adolescents with Cystic Fibrosis relate to the prevalence and nature of psychological adjustment difficulties?
METHOD

Study design
A cross-sectional interview and questionnaire design was used to assess body image and psychological adjustment in adolescents with CF.

Ethical considerations
The ethics committee at the hospital where the study was carried out, as well as the ethics Committee at the University of Surrey, reviewed the proposal for this study. A copy of the approval letters can be seen in Appendix 1. Informed consent will be discussed later in this section.

Participants
Participants were recruited from a CF centre in a national paediatric hospital, where the majority of patients are seen for three-monthly reviews. Forty-four participants were recruited after 69 potential participants had been approached. This is a participation rate of 64 percent. Participants were equally divided between males and females.

Inclusion and exclusion criteria
The criteria for inclusion were that patients had a diagnosis of CF and were aged between 12 and 16 years, and were well enough to take part. Although 17 and 18 year olds are still typically classed as adolescents, patients are only seen at the CF centre until they are 16 years and therefore this was used as the upper age limit for inclusion. All participants had a diagnosis of CF and were registered on the hospital’s database. No exclusion criteria were employed.

Demographic information
Demographic information such as the participant’s age, gender and ethnicity were obtained from their medical notes. Patients’ height and weight are routinely assessed at each hospital appointment and therefore this information was readily available from their review form. Demographic information including age, gender and ethnicity were also obtained for those patients who did not agree to participate to ensure that any potential bias in the sample of participants could be evaluated. However, no further information was collected, as the researcher did not have the patients’ consent to obtain this information.
Demographics

The participants' ages ranged from 12 years to 16 years 9 months (Mean = 14 years 2 months, S.D. = 1.3) (see Table 1) and included 22 female participants and 22 male participants. Forty-two participants (95.6%) were White British and two participants (4.4%) were Asian. Two of the participants did not go to school nor did they receive home schooling because of factors related to their CF.

Table 1: Age of participants

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Range</td>
<td>Mean (SD)</td>
<td>Range</td>
<td>Mean (SD)</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 yrs -</td>
<td>14 yrs 2 m</td>
<td>12 yrs -</td>
<td>14 yrs 1 m</td>
</tr>
<tr>
<td>16 yrs 9 m</td>
<td>(1.3)</td>
<td>16 yrs 3 m</td>
<td>(1.2)</td>
</tr>
</tbody>
</table>

Weight and Body Mass Index

Participants' weight ranged from 22.7 kg to 70.4 kg (mean = 45.6 kg, SD = 9.5), and their height ranged from 1.22 m to 1.80 m (mean = 1.56 m, SD = 0.1). Participants' height and weight were used to calculate their Body Mass Index (BMI) (kg/m²) (WHO, 1992), which is thought to be a better measure of weight status as height is also taken into consideration. The participants' BMI ranged from 13.8 kg/m² to 24.1 kg/m² (mean = 18.6 kg/m², SD = 2.3). The height, weight and BMI scores are shown in Table 2 for the total population and for male and female participants.
Table 2: Participants' weight height and BMI

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range (SD)</td>
<td>Range (SD)</td>
<td>Range (SD)</td>
</tr>
<tr>
<td>Height (m)</td>
<td>1.22 - 1.80</td>
<td>1.22-1.80</td>
<td>1.38 - 1.65</td>
</tr>
<tr>
<td></td>
<td>0.1</td>
<td>0.1</td>
<td>0.1</td>
</tr>
<tr>
<td>Weight (kg)</td>
<td>22.7 - 70.4</td>
<td>22.7 - 70.4</td>
<td>27.0 - 61.0</td>
</tr>
<tr>
<td></td>
<td>9.5</td>
<td>10.8</td>
<td>8.5</td>
</tr>
<tr>
<td>BMI (kg/m²)</td>
<td>13.8 - 24.1</td>
<td>14.2 - 24.1</td>
<td>13.8 - 23.2</td>
</tr>
<tr>
<td></td>
<td>2.3</td>
<td>2.4</td>
<td>2.3</td>
</tr>
</tbody>
</table>

According to classifications of weight status (Abraham and Llewellyn-Jones, 2001) 26 participants were either in the anorexic or underweight classifications (BMI = 18.9 and below), and 18 were in the normal weight range (BMI = 19.0 - 24.9). No participants were in the overweight or obese classifications (BMI = 25.0 or above) (see Table 3).

Table 3: Weight status classifications of BMI (Abraham and Llewellyn-Jones, 2001)

<table>
<thead>
<tr>
<th>BMI scores</th>
<th>Percentage of whole sample</th>
<th>Number of participants</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexic</td>
<td>16.9 or less</td>
<td>29.5</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Underweight</td>
<td>17.0-18.9</td>
<td>29.5</td>
<td>13</td>
<td>8</td>
</tr>
<tr>
<td>Desirable</td>
<td>19.0-24.9</td>
<td>41.0</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Overweight</td>
<td>25.0-29.9</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Obese</td>
<td>30 or more</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Demographics of retest sub-sample

Six participants were randomly selected from the larger sample and asked to complete the Contour Drawing Rating Scale again to assess test-retest reliability of the measure in this population. Five girls and one boy, were included in this sample. Their ages ranged from 12 years to 15 years 9 months (mean = 13 years 10 months, SD = 1.4). The sub-sample's weight ranged from 33.3 kg to 56.0 kg (mean = 42.4 kg, SD = 9.3). Their height ranged between 1.38 m and 1.65 m (mean = 1.50 m, SD = 0.1) and their BMI ranged from 16.3 kg/m² to 20.6 kg/m² (mean = 18.6 kg/m², SD = 2.1).
Demographics of Participants in comparison to Non-Participants
The non-participants' ages ranged from 12 years to 16 years 10 months (Mean = 14 years 1 month, S.D. = 1.6). Twelve non-participants were female and thirteen were male. All non-participants were White British.

Procedure
Recruitment of participants and informed consent
An information sheet from the senior consultant and a covering letter from the researcher, were sent to participants, who were on the hospital database and who met the inclusion criteria, three to four weeks before they were due to be seen in the review clinic (see Appendices 2 and 3). Similar letters were also sent to their parents or legal guardian (see Appendices 4 and 5). This was because all participants were below 18 years of age and therefore consent from their parent or legal guardian was also required. The information sheet described the aims of the study and what participating in the research entailed. It also provided contact details for the main researchers should participants or their parents/legal guardian wish to contact them. This method of recruitment allowed potential participants to consider and discuss participation prior to further contact by the researcher. Participants were then contacted by telephone two weeks before their clinic visit to discuss the study further, to address any questions and provide any further information required by the child or family, and to determine whether they would like to participate in the study. If they agreed to take part, it was decided whether they would prefer to meet with the researcher either directly before or after their clinic appointment, or for the researcher to visit them at home. The information sheet and covering letter were also sent to patients meeting the inclusion criteria but who were not due to be seen at the clinic during the time the research was carried out. Similar letters were also sent to their parent or legal guardian. The researcher contacted them by telephone two weeks later to further discuss the study and to arrange appointments to visit those patients who agreed to participate, at their homes.

Administration of the measures
When participants first met with the researcher they were asked if they had any further questions and if they still wished to participate. This provided them with another opportunity to discuss their involvement with the researcher before taking part. Once any questions had been satisfactorily answered potential participants were given further time to talk with their parents/legal guardian if they wished to. Once they had agreed to take part, both the participant and their parent/legal guardian were asked to sign the consent forms (see
Participants were then given the questionnaires and an envelope in which to return the completed questionnaires to the researcher. At the same time an appointment was made for them to meet with the researcher at a convenient time during the day so that the researcher could administer the Contour Drawing Rating Scale (CDRS). The researcher remained available throughout the day to answer any questions and to assist those participants who were unable to complete the questionnaires on their own.

Confidentiality of information

Participants were assured of total confidentiality of all information collected during the research. No member of the Cystic Fibrosis team was informed who was approached and who agreed to participate, neither were his or her GP. Questionnaires were coded, ensuring that no-one in the team would be able to identify individual participants’ scores and only the researcher was allowed access to the identity of the codes. Names and data were stored separately at all times.

Participant distress during the assessment

At the beginning of the assessment it was agreed that if the participant became distressed at any time, the assessment would be halted and they would be offered the opportunity to talk with either the researcher or a qualified clinical psychologist who was available throughout the research project to see participants and/or their families. Following the assessment, the researcher reminded both the participant and their parent/legal guardian that they had been given the contact details for the main researchers and that they may contact them in the future to ask any further questions or address any concerns. It was agreed that if any concerns became apparent following participation in the study, these would either be discussed with the participant before passing any information on to their Consultant or the researcher would seek consent from the participant to discuss the concerns with their parents/legal guardian and ask them if they would like their child to be referred to the clinical psychologist.

Measures

Body Image Satisfaction Measures

Contour Drawing Rating Scale (Thompson and Gray, 1995)

The Contour Drawing Rating Scale (Thompson and Gray, 1995) consists of a series of nine male and nine female front-view contour drawings of precisely graduated sizes ranging from...
underweight to overweight, with progressive and realistic waist-to-hip ratios (see Appendix 8). All the drawings are of equal height and have clearly defined facial and bodily features. For both sets of drawings, each of the nine six-inch figures were printed separately and evenly spaced on a card measuring 6 x 8.5 inches. Each card was labelled on the back from number 1, the most underweight figure to number 9, the most overweight figure.

The Contour Drawing Rating Scale has been demonstrated to have good test-retest reliability over a one-week period, in an adult population ($r=.78, p<.0005$). The scale has also been shown to have good validity. Thompson and Gray (1995) assessed the validity of the scale by asking 51 full-time, female undergraduate students to appropriately order the nine drawings. Participants correctly positioned 95.2 percent and 96.1 percent of the female set and male set respectively. Concurrent validity, examined by the degree of correspondence between an individual’s reported weight and current self-ratings, was also good ($r=.71, p,.0005$) (Thompson and Gray, 1995).

Body Image Questionnaire (Hatfield and Sprecher, 1986)

The Body Image Questionnaire (BIQ; Hatfield and Sprecher, 1986) is a measure of satisfaction with various body parts. It consists of a list of 25 body parts, of which 10 involve the head, and 15 involve the body. Participants are asked to rate each body part on a six-point rating scale, from 1 (extremely dissatisfied) to 6 (extremely satisfied). The scale yields a summary score of overall body satisfaction and two subscale scores indicating satisfaction with head or facial attractiveness, and body physique satisfaction. See Appendix 9 for a copy of the measure.

Abbott et al. (2000) administered the BIQ on 221 adults with CF and 148 healthy controls. They performed principal-components analyses with varimax rotation on the data and found that a similar structure emerged for both the CF and the healthy populations and therefore undertook a combined analysis of the data. Items loading greater than 0.40 for a factor and communalities greater than 0.30 were considered meaningful indicators for that factor and were retained. The analyses produced a two-factor solution which accounted for 66.9 percent of the questionnaire’s variance. Factor 1 accounted for 51.5 percent of the variance and contained 12 items concerned with body physique satisfaction. Factor 2 comprised of 10 items concerned with head/facial attractiveness satisfaction and accounted for 15.4 percent of the variance. The cronbach alpha coefficients were 0.91 and 0.88 for factors 1 and 2, respectively.
Two items from this questionnaire: "size of sex organs" and "appearance of sex organs" were removed before administration, since they were not included in the above study which looked at validating the questionnaire on a CF population, due to ethical considerations. Height was also removed because it showed poor factor loading when the questionnaire was validated on a CF population. Scores for the questionnaire therefore range from 22 to 132 for the overall satisfaction scale, from 10 to 60 for the facial attractiveness scale and from 12 to 72 for the body physique scale, with higher scores indicating greater satisfaction.

The role of CF in body satisfaction questionnaire
A brief 19-item questionnaire was designed specifically for this study in order to determine how much participants thought that their CF influenced how satisfied they were with their body, since no standardised scale that measured this was available. The questionnaire was developed after careful consideration of the relevant literature, followed by consultation with experienced professionals working in this field. This was done in order to ensure that the questionnaire covered all the pertinent issues experienced by adolescents with CF. The initial item list was generated through expert sampling with a consultant clinical psychologist working with adolescents with CF to draw upon their clinical experience of this population. This also ensured content validity of the questionnaire (see Appendix 10).

The first part of the questionnaire consists of four questions assessing how satisfied participants are with various aspects of their body and how much they feel their CF contributes to their level of satisfaction. Assessment of satisfaction with physical appearance is measured using a six-point likert scale, ranging from "extremely dissatisfied" to "extremely satisfied". Assessment of how much participants think that their CF has affected how satisfied they are with their weight, height and overall physical appearance is measured using a five-point likert scale, ranging from "not at all" to "very much".

The second part of the questionnaire addresses specific treatments used in patients with CF that may affect their body appearance. Participants are asked to note if they have a gastrostomy, portocath, or any sores or scars resulting from their CF treatment and to rate how much they are bothered by these on a five-point likert scale ranging from "not at all" to "very much".

The third part of the questionnaire consists of five questions asking participants about how they feel their physical appearance affects them. These questions specifically address whether there is any part of their body they are unhappy with; whether they feel different from their
peers because of their physical appearance; if they avoid doing anything or if they engage in any specific behaviours because of their physical appearance, and whether they feel that their physical appearance affects relationships with their peers. Participants are asked to respond to these questions with either "yes" or "no"; however, if they responded yes to any of these questions, they are asked to provide further information to support this response, for example, which part of their body they are unhappy with, or in what way they feel different. These questions are included because they are specific to patients with CF and are therefore not included in existing body image measures developed for the general population. For example, the first question: "Is there any part of your body that you are not happy with?" was included as it provided the opportunity for participants to provide information about parts of their body that may have been affected by their CF that were not covered by the BIQ, such as, clubbed fingers or more rounded chests. This was felt important since the BIQ was developed on a healthy population and as a result may not be sensitive to body image issues evolving in patients with CF over the course of the disease.

Psychological Adjustment Measures

Children's Depression Inventory (Kovacs, 1981)

The Children's Depression Inventory (CDI) is a 27-item self-report inventory designed to measure affective, cognitive and behavioural symptoms of depression in children and adolescents, aged seven to seventeen (see Appendix 11). The CDI discriminates children and adolescents with a psychiatric diagnosis of major depressive or dysthymic disorder, from those with other psychiatric conditions or non-selected "normal" children and adolescents (Kovacs, 1992). Each item on the CDI consists of three choices, marked 0, 1, or 2, with higher scores indicating increasing severity. For each item, participants are asked to select which of the three statements best describes how he or she has been thinking or feeling during the preceding two weeks. Approximately half the items start with the choice that reflects the greatest severity, and the rest start with the choice that reflects the least severity. The results from the CDI provide a total score ranging from 0 to 54, and five factor scores relating to negative mood, interpersonal problems, ineffectiveness, anhedonia and negative self-esteem ranging from 0 to 12, 8, 8, 16 and 10 respectively. As a total score of 20+ is associated with major depressive disorder, this score is typically used as a cutoff point for the presence of depressive symptomatology (Kovacs, 1992).

The CDI can be completed in approximately 15 minutes. It has demonstrated high internal consistency (r=.84 for males and r=.87 for females) (Smucker, Craighead, Craighead and Green, 1986), and good test-retest reliability after two weeks (r=.82) (Finch, Saylor, Edwards
and McIntosh, 1987). The CDI has also been shown to have good convergent and discriminant validity (Hodges, 1990, cited in Kovacs, 1992).

**State-Trait Anxiety Inventory (Spielberger, 1983)**

The State-Trait Anxiety Inventory (STAI) is a 40-item self-report instrument designed to measure anxiety (See Appendix 12). Twenty of the items measure state anxiety and 20 measure trait anxiety. State anxiety indicates the presence of anxiety in an individual at the time of assessment. Trait anxiety indicates the overall level of anxiety that an individual experiences generally. For the State-Anxiety Scale participants are asked to rate each one of the 20 statements on a four-point scale, ranging from “not at all” to “very much so”, to indicate how they feel “right now, at this moment”. For the Trait-Anxiety Scale, participants are asked to rate each of the 20 statements on a four-point scale, ranging from “almost never” to “almost always”, to indicate how they feel “generally”. Scores on both scales range from 20 to 80 with higher scores indicating higher levels of anxiety.

Internal consistency of the STAI range from .86 to .95, with the stability estimates of the trait subscale ranging from .65 to .86 and the state subscale ranging from .16 to .62 (Chaplin, 1984, cited in Hains, Davies, Behrens and Biller, 1997). Validity scores have been estimated for the Trait-Anxiety Scale by correlating it with other measures. These range between .52 and .80 (Chaplin, 1984, cited in Hains, Davies, Behrens and Biller, 1997). Test-retest reliability for the Trait-Anxiety Scale has also been demonstrated to be high when administered on college students 20 days apart. The test-retest correlations were .86 and .76 for males and females respectively. However, test-retest correlations for the State-Anxiety Scale were relatively low when administered on the same population (.54 for males and .27 for females) (Spielberger, 1983).

**Self-Perception Profile for Adolescents (Harter, 1988)**

The Self-Perception Profile for Adolescents (SPPA) is a 45-item self-report questionnaire, which measures domain-specific judgements of competence or adequacy in eight separate domains, as well as global perceptions of self-worth (see Appendix 13). The eight specific domains are Scholastic Competence, Athletic Competence, Physical Appearance, Social Acceptance, Behavioural Conduct, Job Competence, Close Friendship, and Romantic Appeal (see Appendix 14 for a definition of each of these subscales). Each of the nine subscales contain five items. For each item, the participant is presented with a question in the following format:
The participant is first asked to decide which kind of teenager he or she is most like, and then asked whether this is only "sort of true" or "really true" for him or her, and then to place an "X" in the appropriate box. This type of question is thought to be very effective because it implies that half of the teenagers in the world view themselves in one way, whereas the other half view themselves in the other, that is, this type of question legitimises either choice (Harter, 1988). Each item is scored from one to four, where a score of one indicates low perceived competence or adequacy, and a score of four reflects high competence or adequacy. A score of 2.5 is the midpoint of the scale. Within each subscale, two or three of the items are worded so that the first part of the statement reflects low competence or adequacy and the other two or three are worded so that the first part of the statement reflects high competence or adequacy. Scores from each subscale are grouped together and the mean for each subscale is calculated, thus scoring results in a total of nine subscale means which define a given adolescent’s profile. The subscale “Job Competence” was not included in the analysis since the majority of participants were still at school and had never had a job.

Each of the subscales have been demonstrated to have good internal consistency, ranging from .74 to .91. A factor analysis was undertaken of the eight subscales excluding global self-worth. It was found that the factor loadings for each of the subscales were substantial and that there were no cross loadings greater than .30 indicating that each of the domains define distinct factors and therefore the questionnaire provides a differentiated and meaningful profile of self-esteem in adolescents (Harter, 1988).

Administration of the Contour Drawing Rating Scale

One participant refused to meet with the researcher directly but agreed to complete the questionnaires. The reason given for this was very poor body image. Therefore the Contour Drawing Rating Scale was administered to 43 participants. The nine cards, of the participant’s own gender, were placed in a random order on a table in front of them. Participants were told that the figures on the cards were all the same height, but were all different sizes. They were then asked to look at all the cards and to select the figure that they felt most accurately

<table>
<thead>
<tr>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Really True for Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>Some teenagers do very well at their class work</td>
<td>BUT</td>
<td>Other teenagers don’t do very well at their class work</td>
</tr>
</tbody>
</table>
depicted their current body size. They were then asked to select the figure that they felt most accurately depicted their ideal body size. Participants were informed that this could be the same card or a different card to their first response, so that it was not implied that there was something wrong with their current body size.

Body size dissatisfaction was calculated as the figure most like their current body size, minus their ideal figure, with possible dissatisfaction scores ranging from -8 to +8. Positive scores typically indicate that participants are dissatisfied with their body size and want to be thinner, a score of zero indicates body size satisfaction, and a negative score indicates that participants are dissatisfied with their body size and want to gain weight. However, since both ends of the scale indicate dissatisfaction, the CDRS can not be interpreted as a continuous variable. In order to interpret the CDRS as a continuous variable, it must be used as a measure of the extent to which participants are dissatisfied with their bodies and want to be thinner. Therefore positive scores indicate an increasing desire to be thinner and negative scores indicate the absence of this desire to differing degrees.

Test-retest reliability
Since the CDRS has not been standardised on an adolescent population, test-retest reliability of this measure in this population was assessed. This involved re-administering the scale on a subsample of six participants, randomly selected from the larger sample, 14 days after the initial administration of the measure.

Statistical analyses
The data was analysed using the Statistics Package for the Social Sciences (SPSS) version 9.0. The data was screened to identify whether the variables met the assumptions for parametric analysis. All the variables met the assumptions for parametric analysis except for two of the subscales on the CDI, the interpersonal problems and the ineffectiveness subscales, where the data was not normally distributed. Therefore nonparametric tests were employed for analysis involving these subscales. Parametric tests used were Paired Sample t-tests, Independent Sample t-tests, and a One-way Multivariate Analysis of Variance. Nonparametric tests used were Pearson's correlations, a Wilcoxon Matched-Pairs Signed Ranks Test, and a Mann-Whitney U Test. Demographic data collected in the study were used for descriptive analyses.
RESULTS

Demographic information of participants
An independent samples t-test was used to examine gender differences in age. No significant gender differences were found (t(42) = -0.18, p=0.86, 2-tailed test). Gender differences in height, weight and BMI were explored using an independent samples t-test. No significant gender differences were found for height (t(42) = 1.36, p=0.18, 2-tailed test); weight (t(42) = 0.75, p=0.46, 2-tailed test) or BMI (t(42) = -0.36, p=0.72, 2-tailed test).

Demographics of participants in comparison to non-participants
An independent samples t-test and chi-square were used to examine differences between participants and non-participants. No significant differences were found between participants and non-participants in terms of their age (t (67) = -0.03, p =0.97) or gender (χ² (1, n= 69) = 0.03, p=0.87).

Test-retest reliability of the Contour Drawing Rating Scale
Test-retest procedures were carried out on the Contour Drawing Rating Scale as there is no reliability and validity data on the use of this tool within an adolescent population. A sub-sample of six participants was randomly selected from the main group and the test was administered exactly two weeks after the initial assessment (see Table 9). A Wilcoxon Matched-Pairs Signed Ranks Test was chosen as an appropriate measure of test-retest reliability, due to the small sample size. No significant difference was found for either perceived body size (z(6) = .00, p=1.0, 2-tailed test) or desired body size (z(6) = -.27, p=0.79, 2-tailed test), at Time 1 and Time 2. This indicates that the Contour Drawing Rating Scale can be reliably used with an adolescent population.

Table 9: Figures chosen by the sub-sample at Time 1 and Time 2

<table>
<thead>
<tr>
<th>Participant</th>
<th>Time 1</th>
<th>Time 2</th>
<th>Time 1</th>
<th>Time 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Perceived</td>
<td>Perceived</td>
<td>Desired</td>
<td>Desired</td>
</tr>
<tr>
<td>Participant 1</td>
<td>5</td>
<td>6</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Participant 2</td>
<td>4</td>
<td>6</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Participant 3</td>
<td>6</td>
<td>5</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Participant 4</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Participant 5</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Participant 6</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Mean (SD): 3.50 (1.76) 3.50 (.84) 4.33 (1.63) 4.50 (.84)
Examination of the Research Questions

Question 1: Are adolescents with Cystic Fibrosis satisfied with their perceived body size?

Satisfaction As measured by the Contour Drawing Rating Scale
The level of body size dissatisfaction was calculated for each participant. Twenty-three (53.5%) participants wanted to be bigger, 11 (25.6%) wanted to stay the same size and nine (20.9%) wanted to be smaller (see Tables 4 and 5). Using a paired sample t-test a statistical difference was found between participants’ perceived and desired body size (t(42) = -3.33, p=0.002).

Table 4: Participants’ scores on the Contour Drawing Rating Scale

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Mean (SD)</td>
<td>Range</td>
</tr>
<tr>
<td>Perceived</td>
<td>1-7</td>
<td>4.33 (1.52)</td>
<td>2-6</td>
</tr>
<tr>
<td>Desired</td>
<td>2-7</td>
<td>5.05 (1.13)</td>
<td>3-6</td>
</tr>
</tbody>
</table>

An independent samples t-test was used to examine differences between male and female participants’ desired body size. Boys were found to desire a significantly larger body size (t (42) =2.62, p =0.013).
Table 5: Level of dissatisfaction with body size

<table>
<thead>
<tr>
<th>Level of dissatisfaction</th>
<th>Number of participants</th>
<th>Percentage</th>
<th>Number of girls</th>
<th>Percentage</th>
<th>Number of boys</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Want to gain weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-4</td>
<td>1</td>
<td>2.3</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>-3</td>
<td>2</td>
<td>4.7</td>
<td>2</td>
<td>9.1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>-2</td>
<td>12</td>
<td>27.9</td>
<td>6</td>
<td>27.3</td>
<td>6</td>
<td>28.6</td>
</tr>
<tr>
<td>-1</td>
<td>8</td>
<td>18.6</td>
<td>3</td>
<td>13.6</td>
<td>5</td>
<td>23.8</td>
</tr>
<tr>
<td>Total</td>
<td>23</td>
<td>53.4</td>
<td>11</td>
<td>50</td>
<td>12</td>
<td>57.2</td>
</tr>
<tr>
<td>Satisfied</td>
<td>0</td>
<td>25.6</td>
<td>5</td>
<td>22.7</td>
<td>6</td>
<td>28.6</td>
</tr>
<tr>
<td>Want to lose weight</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>18.6</td>
<td>6</td>
<td>27.3</td>
<td>2</td>
<td>9.5</td>
</tr>
<tr>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>3</td>
<td>1</td>
<td>2.3</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>4.8</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>9</td>
<td>20.9</td>
<td>6</td>
<td>27.3</td>
<td>3</td>
<td>14.3</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>100</td>
<td>22</td>
<td>100</td>
<td>21</td>
<td>100</td>
</tr>
</tbody>
</table>

Participants’ level of dissatisfaction with body size ranged from -4 to +3 (mean = -0.72, S.D. = 1.42). Female participants’ level of dissatisfaction with body size ranged from -3 to +1 (mean = -0.68, S.D. = 1.39). Male participants’ level of dissatisfaction with body size ranged from -4 to +3 (mean = -0.75, S.D. = 1.52).

Gender differences in body size dissatisfaction were explored using an independent samples t-test. No significant gender differences were found (t(43) = -1.83, p=0.856, 2-tailed test). A Pearson’s correlation was used to measure the relationship between body size dissatisfaction and each participant’s BMI. A significant positive correlation was found between these two variables (r(43) = .53, p=0.000, 2-tailed test). This indicates that the lower the participant’s BMI score, the more likely they were to choose an ideal figure bigger than their own. This provides supporting evidence for the construct validity of this test when used with adolescents with CF. Tables 6, 7 and 8 display the desire to increase in size, stay the same, or decrease in size dependent upon each participant’s BMI category.
### Table 6: BMI category and participants' desire to be bigger, smaller or stay the same size

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>Number of participants wanting to be bigger (%)</th>
<th>Number of participants wanting to stay the same size (%)</th>
<th>Number of participants wanting to be smaller (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexic (BMI 16.9 or less)</td>
<td>11 (25.5)</td>
<td>2 (4.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Underweight (BMI 17.0-18.9)</td>
<td>7 (16.3)</td>
<td>5 (11.6)</td>
<td>1 (2.3)</td>
</tr>
<tr>
<td>Desirable (BMI 19.0-24.9)</td>
<td>5 (11.6)</td>
<td>4 (9.3)</td>
<td>8 (18.6)</td>
</tr>
<tr>
<td>Overweight (BMI 25.0-29.9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Obese (BMI 30 or more)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

### Table 7: BMI category and girls' desire to be bigger, smaller or stay the same size

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>Number of participants wanting to be bigger (%)</th>
<th>Number of participants wanting to stay the same size (%)</th>
<th>Number of participants wanting to be smaller (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexic (BMI 16.9 or less)</td>
<td>6 (27.3)</td>
<td>1 (4.5)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Underweight (BMI 17.0-18.9)</td>
<td>3 (13.6)</td>
<td>2 (9.1)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Desirable (BMI 19.0-24.9)</td>
<td>2 (9.1)</td>
<td>2 (9.1)</td>
<td>6 (27.3)</td>
</tr>
<tr>
<td>Overweight (BMI 25.0-29.9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Obese (BMI 30 or more)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Table 8: BMI category and boys’ desire to be bigger, smaller or stay the same size

<table>
<thead>
<tr>
<th>BMI Category</th>
<th>Number of participants wanting to be bigger (%)</th>
<th>Number of participants wanting to stay the same size (%)</th>
<th>Number of participants wanting to be smaller (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anorexic (BMI 16.9 or less)</td>
<td>5 (23.8)</td>
<td>1 (4.8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Underweight (BMI 17.0-18.9)</td>
<td>4 (19.0)</td>
<td>3 (14.3)</td>
<td>1 (4.8)</td>
</tr>
<tr>
<td>Desirable (BMI 19.0-24.9)</td>
<td>3 (14.3)</td>
<td>2 (9.5)</td>
<td>2 (9.5)</td>
</tr>
<tr>
<td>Overweight (BMI 25.0-29.9)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Obese (BMI 30 or more)</td>
<td>0 (0)</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>
Question 2: Are adolescents with Cystic Fibrosis satisfied with their body appearance?

Satisfaction As measured by the Body Image Questionnaire
Reliability analysis was undertaken for the overall score on the Body Image Questionnaire and scores on the head/ facial attractiveness and body physique subscales. The Cronbach Alpha reliability coefficients were 0.94, 0.86 and 0.93 respectively. Participants’ overall scores on the Body Image Questionnaire ranged from 67 to 132, their scores on the head/ facial attractiveness subscale ranged from 30 to 60 and their scores on the body physique subscale ranged from 26 to 72 (see Table 10). Independent sample t-tests were used to examine gender differences on participants’ overall body satisfaction scores and their scores on the head/facial attractiveness subscale and the body physique subscale. No significant gender differences were found for any of these scores (see Table 11).

Table 10: Participants’ scores on the Body Image Questionnaire

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range  Mean (SD)</td>
<td>Range  Mean (SD)</td>
<td>Range  Mean (SD)</td>
</tr>
<tr>
<td>Overall body satisfaction</td>
<td>67-132  105.7 (16.5)</td>
<td>69-132  109.2 (16.5)</td>
<td>67-130  102.1 (16.2)</td>
</tr>
<tr>
<td>Head/ facial attractiveness</td>
<td>30-60  48.9 (7.1)</td>
<td>36-60  50.0 (7.1)</td>
<td>30-59  47.8 (7.1)</td>
</tr>
<tr>
<td>Body physique</td>
<td>26-72  56.8 (10.6)</td>
<td>26-72  59.2 (11.2)</td>
<td>37-72  54.4 (9.7)</td>
</tr>
</tbody>
</table>

Table 11: T-tests to examine gender differences on the Body Image Questionnaire

<table>
<thead>
<tr>
<th></th>
<th>Statistic</th>
<th>df</th>
<th>p-value (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall body satisfaction</td>
<td>t = 1.43</td>
<td>42</td>
<td>0.16</td>
</tr>
<tr>
<td>Head/ facial attractiveness</td>
<td>t = 1.02</td>
<td>42</td>
<td>0.31</td>
</tr>
<tr>
<td>Body physique</td>
<td>t = 1.54</td>
<td>42</td>
<td>0.13</td>
</tr>
</tbody>
</table>
Comparison of body satisfaction with a non-CF population

The means and standard deviations for both 22 male and 22 female participants were compared with the means and standard deviations of 74 adult male controls and 74 adult female controls respectively for both subscales of the Body Image Questionnaire, using a one-sample t-test. This information was derived from the study undertaken by Abbott et al. (2000).

It was not possible to compare the means and standard deviations from the participants in the current study with means and standard deviations from an adolescent sample because no research study has used this questionnaire on an adolescent population. The mean scores for both male and female adolescent participants were found to be significantly higher than the mean scores for male and female adult controls respectively, for both the head/facial attractiveness and the body physique subscales (see Tables 12 and 13).

Table 12: Means and standard deviations for CF males and control males

<table>
<thead>
<tr>
<th></th>
<th>CF Males Mean (SD)</th>
<th>Control Males Mean (SD)</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head/face</td>
<td>49.95 (7.07)</td>
<td>44.12 (8.46)</td>
<td>t=2.94</td>
<td>94</td>
<td>P&lt;.05</td>
</tr>
<tr>
<td>Body physique</td>
<td>59.23 (11.19)</td>
<td>51.88 (12.10)</td>
<td>t=2.54</td>
<td>94</td>
<td>P&lt;.05</td>
</tr>
</tbody>
</table>

Table 13: Means and standard deviations for CF females and control females

<table>
<thead>
<tr>
<th></th>
<th>CF Females Mean (SD)</th>
<th>Control Females Mean (SD)</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head/face</td>
<td>47.77 (7.10)</td>
<td>43.36 (7.21)</td>
<td>t=2.47</td>
<td>94</td>
<td>P&lt;.05</td>
</tr>
<tr>
<td>Body physique</td>
<td>54.36 (9.67)</td>
<td>45.75 (10.50)</td>
<td>t=3.44</td>
<td>94</td>
<td>P&lt;.05</td>
</tr>
</tbody>
</table>
Comparison of body satisfaction in CF adolescents with CF adults

The means and standard deviations for both 22 male and 22 female participants were compared with the means and standard deviations of 104 adult males with CF and 117 adult females with CF respectively for both subscales of the Body Image Questionnaire, using a one-sample t-test. This information was derived from the study undertaken by Abbott et al. (2000). The mean scores for both male and female adolescent participants were found to be significantly higher than the mean scores for adult males with CF and adult females with CF respectively, for the body physique subscale (see Tables 14 and 15). However, no significant differences were found between mean scores for male and female participants and adult males with CF and adult females with CF respectively for the head/ facial attractiveness subscale (see Tables 14 and 15).

Table 14: Means and standard deviations for CF male participants and adult males with CF

<table>
<thead>
<tr>
<th></th>
<th>CF male participants</th>
<th>Adult males with CF</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head/ face</td>
<td>49.95 (7.07)</td>
<td>48.40 (7.15)</td>
<td>t=-0.68</td>
<td>124</td>
<td>P&gt;.05</td>
</tr>
<tr>
<td>Body physique</td>
<td>59.23 (11.19)</td>
<td>44.12 (8.46)</td>
<td>t=3.72</td>
<td>124</td>
<td>P&lt;.05</td>
</tr>
</tbody>
</table>

Table 15: Means and standard deviations for CF female participants and adult females with CF

<table>
<thead>
<tr>
<th></th>
<th>CF female participants</th>
<th>Adult females with CF</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Head/ face</td>
<td>47.77 (7.10)</td>
<td>46.0 (7.43)</td>
<td>t=1.03</td>
<td>137</td>
<td>P&gt;.05</td>
</tr>
<tr>
<td>Body physique</td>
<td>54.36 (9.67)</td>
<td>47.52 (10.50)</td>
<td>t=2.84</td>
<td>137</td>
<td>P&lt;.05</td>
</tr>
</tbody>
</table>
Parts of the body that participants were dissatisfied with

A score of 1-3 on each of the items on the Body Image Questionnaire was taken as indicating dissatisfaction with that particular part of the body. A score of 4-6 on each of the items on the Body Image Questionnaire was taken as indicating satisfaction with that particular part of the body. Table 16 indicates the number of parts of the body that participants were dissatisfied with. The number of parts of the body that female participants reported being dissatisfied with ranged from 0 to 14 (mean = 3.18, SD = 3.75). The number of parts of the body that male participants reported being dissatisfied with ranged from 0 to 14 (mean = 2.27, SD = 3.83). An independent samples t-test indicated that there was no significant gender difference in the number of parts of the body that participants were dissatisfied with (t(43) = -.80, p=0.43, 2-tailed test).

Table 16: The number of parts of the body that participants were dissatisfied with

<table>
<thead>
<tr>
<th>Number of body parts</th>
<th>Number of participants</th>
<th>Percentage</th>
<th>Number of girls</th>
<th>Number of boys</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>16</td>
<td>35.6</td>
<td>6</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>9</td>
<td>20.05</td>
<td>5</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>3</td>
<td>6.7</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>4</td>
<td>8.9</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>6.7</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5</td>
<td>2</td>
<td>4.4</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>6</td>
<td>1</td>
<td>2.2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>2.2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>8</td>
<td>1</td>
<td>2.2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>9</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>10</td>
<td>1</td>
<td>2.2</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>12</td>
<td>1</td>
<td>2.2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>13</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>14</td>
<td>2</td>
<td>4.4</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44</strong></td>
<td><strong>100</strong></td>
<td><strong>22</strong></td>
<td><strong>22</strong></td>
</tr>
</tbody>
</table>
Satisfaction as measured by the Role of CF in Body Satisfaction Questionnaire

Participants were asked how satisfied they were with their overall physical appearance. Thirty-four participants (77.3%) reported being either somewhat satisfied, quite satisfied or extremely satisfied and nine participants (22.7%) reported being either somewhat dissatisfied, quite dissatisfied or extremely dissatisfied with their overall physical appearance. Participants were also asked how much they thought that their CF affected how satisfied they were with their weight, height and physical appearance. Table 17 shows the frequencies of participants' responses.

Table 17: How much participants thought their CF affected how satisfied they were with their 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>14 (31.7)</td>
<td>19 (43.2)</td>
<td>15 (34.1)</td>
</tr>
<tr>
<td>Very little</td>
<td>9 (20.5)</td>
<td>7 (15.9)</td>
<td>16 (36.4)</td>
</tr>
<tr>
<td>A little</td>
<td>9 (20.5)</td>
<td>10 (22.7)</td>
<td>7 (15.9)</td>
</tr>
<tr>
<td>Quite a lot</td>
<td>9 (20.5)</td>
<td>4 (9.1)</td>
<td>3 (6.8)</td>
</tr>
<tr>
<td>Very much</td>
<td>3 (6.8)</td>
<td>4 (9.1)</td>
<td>3 (6.8)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>44 (100)</strong></td>
<td><strong>44 (100)</strong></td>
<td><strong>44 (100)</strong></td>
</tr>
</tbody>
</table>

Impact of CF treatments

Participants were asked about specific CF treatments and how much they were bothered by these. Seven participants (15.9%) had a gastrostomy at the time the research was undertaken. Out of these, four (57.1%) reported that their gastrostomy affected them either "very little" or "a little", and three (42.9%) reported that it affected them either "quite a lot" or "very much". Fourteen participants (31.8%) reported that they had a portocath. Six of these participants (42.9%) reported that their portocath bothered them "not at all", seven participants (50%) reported that their portocath bothered them "very little" or "a little" and one participant (7.1%) reported that their portocath bothered them "quite a lot". Seven participants (15.9%) reported that they had sores. Three of these participants (42.8%) stated that these bothered them "not at all", two (28.6%) reported that these bothered them "a little" and two (28.6%) reported that these bothered them "quite a lot". Twenty-five participants (56.8%) reported that they had...
Major Research Project

scars. Fifteen of these participants (60%) reported that these bothered them “not at all” and 10 (40%) reported that these bothered them either “very little” or “a little”.

Participants were asked if there was any part of their body that they were not happy with. Eighteen participants (40.9%) replied “yes” to this question. See Table 18 for a list of participants’ responses.

Table 18: Parts of the body that participants reported that they were not happy with

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related responses (4 participants)</td>
<td>CF-related responses (9 participants)</td>
</tr>
<tr>
<td>Chest (2 participants)</td>
<td>Having a gastrostomy</td>
</tr>
<tr>
<td>Hands</td>
<td>Shoulders (2 participants)</td>
</tr>
<tr>
<td>Fingers</td>
<td>Hands (2 participants)</td>
</tr>
<tr>
<td>The bit of my rib cage that sticks out</td>
<td>Height</td>
</tr>
<tr>
<td></td>
<td>Weight</td>
</tr>
<tr>
<td></td>
<td>Bottom</td>
</tr>
<tr>
<td></td>
<td>Chest (2 participants)</td>
</tr>
<tr>
<td></td>
<td>Breasts</td>
</tr>
<tr>
<td></td>
<td>Thighs (2 participants)</td>
</tr>
<tr>
<td></td>
<td>Hips (2 participants)</td>
</tr>
<tr>
<td></td>
<td>Stomach (3 participants)</td>
</tr>
<tr>
<td></td>
<td>Not enough muscles</td>
</tr>
<tr>
<td>Non-CF-related responses (1 participant)</td>
<td>Non-CF-related responses (9 participants)</td>
</tr>
<tr>
<td>Ears</td>
<td>Ears (3 participants)</td>
</tr>
<tr>
<td></td>
<td>Spots</td>
</tr>
<tr>
<td></td>
<td>Hair</td>
</tr>
<tr>
<td></td>
<td>Teeth</td>
</tr>
<tr>
<td></td>
<td>Bags under eyes</td>
</tr>
<tr>
<td></td>
<td>Dark body hair</td>
</tr>
<tr>
<td></td>
<td>No cheekbones</td>
</tr>
<tr>
<td></td>
<td>Face</td>
</tr>
<tr>
<td></td>
<td>Wrists</td>
</tr>
<tr>
<td></td>
<td>Feet (2 participants)</td>
</tr>
<tr>
<td></td>
<td>Nose</td>
</tr>
<tr>
<td></td>
<td>Back</td>
</tr>
</tbody>
</table>
Participants were asked if they felt they looked different from other young people the same age as them. Ten participants (22.7%) responded “yes” to this question. See Table 19 for a list of their reasons why.

Table 19: Reasons participants gave as to why they feel different to others the same age

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related (5 participants)</td>
<td>CF-related (3 participants)</td>
</tr>
<tr>
<td>Muscles</td>
<td>Looking thinner</td>
</tr>
<tr>
<td>Looking younger</td>
<td>Being shorter</td>
</tr>
<tr>
<td>Looking smaller</td>
<td>Height and weight</td>
</tr>
<tr>
<td>Being shorter</td>
<td></td>
</tr>
<tr>
<td>Look less healthy</td>
<td></td>
</tr>
<tr>
<td>Having nails that are a different shape</td>
<td></td>
</tr>
<tr>
<td>Having a back which is sloped</td>
<td></td>
</tr>
<tr>
<td>Non-CF-related (1 participant)</td>
<td>Non-CF-related (2 participants)</td>
</tr>
<tr>
<td>Feeling fatter</td>
<td>Feeling less pretty</td>
</tr>
<tr>
<td></td>
<td>Having a different shaped face</td>
</tr>
<tr>
<td></td>
<td>Eye colour</td>
</tr>
<tr>
<td></td>
<td>Hair colour</td>
</tr>
</tbody>
</table>
Participants were asked if there was anything that they avoid doing because of their physical appearance. Six participants (13.7%) replied “yes” to this question. See Table 20 for a list of what participants reported they avoided doing.

**Table 20: Things participants reported they avoided doing because of their physical appearance**

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related (2 participants)</td>
<td>CF-related (4 participants)</td>
</tr>
<tr>
<td>Avoiding sports activities (2 participants)</td>
<td>Avoiding wearing certain clothes (3 participants)</td>
</tr>
<tr>
<td></td>
<td>Avoiding sports activities (2 participants)</td>
</tr>
<tr>
<td>Non-CF-related</td>
<td>Non-CF-related</td>
</tr>
<tr>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>
Participants were asked if there was anything that they did because of their physical appearance. Twelve participants\(^1\) (27.3%) responded “yes” to this question. See Table 21 for a list of participants’ responses.

**Table 21: Things participants reported they did because of their physical appearance**

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related (5 participants)</td>
<td>CF-related (7 participants)</td>
</tr>
<tr>
<td>Sports and exercise (3 participants)</td>
<td>Sports and exercise (4 participants)</td>
</tr>
<tr>
<td>Eat more (2 participants)</td>
<td>Eat more (4 participants)</td>
</tr>
<tr>
<td>Avoid wearing certain clothes (2 participants)</td>
<td>Avoid wearing certain clothes (2 participants)</td>
</tr>
<tr>
<td>Non-CF-related</td>
<td>Non-CF-related</td>
</tr>
<tr>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

\(^1\) The six participants that answered the previous question also responded to this question.
Participants were asked if they think the way they look affects their relationships with other people the same age as themselves. Eight participants (18.2%) responded “yes” to this question. See Table 22 for a list of participants’ responses.

Table 22: Ways in which participants reported they thought the way they looked affected their relationships with others the same age as themselves

<table>
<thead>
<tr>
<th>Male responses</th>
<th>Female responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>CF-related responses (2 participants)</td>
<td>CF-related responses (3 participants)</td>
</tr>
<tr>
<td>Weighing less</td>
<td>Looking younger</td>
</tr>
<tr>
<td>Being shorter</td>
<td>Being shorter</td>
</tr>
<tr>
<td>Being less well built</td>
<td>Looking ill</td>
</tr>
<tr>
<td>Non-CF-related responses (2 participants)</td>
<td>Non-CF-related responses (1 participant)</td>
</tr>
<tr>
<td>Hair</td>
<td>Having spots</td>
</tr>
<tr>
<td>Feet</td>
<td></td>
</tr>
<tr>
<td>Having big ears</td>
<td></td>
</tr>
</tbody>
</table>
Question 3: What is the prevalence and nature of psychological adjustment problems in adolescents with Cystic Fibrosis?

Children’s Depression Inventory

Participants’ scores on the Children’s Depression Inventory (CDI) ranged between 0 and 23. Three participants (7.1%) scored at or above 20, the clinical cut-off point for depression. Table 23 shows the means, standard deviations and range of scores on the CDI and the five subscales.

Table 23: Means, standard deviations and range of scores on the CDI

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range Mean (SD)</td>
<td>Range Mean (SD)</td>
<td>Range Mean (SD)</td>
</tr>
<tr>
<td>CDI Total</td>
<td>0-23 7.0 (6.3)</td>
<td>0-18 6.3 (5.7)</td>
<td>0-23 7.7 (6.9)</td>
</tr>
<tr>
<td>Negative mood</td>
<td>0-6 1.5 (1.6)</td>
<td>0-6 1.2 (1.6)</td>
<td>0-6 1.8 (1.6)</td>
</tr>
<tr>
<td>Interpersonal problems</td>
<td>0-3 0.4 (0.7)</td>
<td>0-3 0.5 (0.9)</td>
<td>0-2 0.3 (0.6)</td>
</tr>
<tr>
<td>Ineffectiveness</td>
<td>0-6 1.3 (1.6)</td>
<td>0-6 1.3 (1.8)</td>
<td>0-6 1.3 (1.5)</td>
</tr>
<tr>
<td>Anhedonia</td>
<td>0-10 2.4 (2.4)</td>
<td>0-6 2.0 (2.0)</td>
<td>0-10 2.7 (2.8)</td>
</tr>
<tr>
<td>Negative self-esteem</td>
<td>0-6 1.4 (1.6)</td>
<td>0-5 1.3 (1.5)</td>
<td>0-6 1.6 (1.7)</td>
</tr>
</tbody>
</table>
State-Trait Anxiety Inventory
Participants’ scores on the State-Trait Anxiety Inventory (STAI) ranged from 20 to 47 on the State-Anxiety subscale and 22 to 59 on the Trait-Anxiety subscale. Table 24 shows the means, standard deviations and range of scores on the two subscales of the STAI.

Table 24: Means, standard deviations and range of scores on the two subscales of the STAI

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range</td>
<td>Mean (SD)</td>
<td>Range</td>
</tr>
<tr>
<td>State-Anxiety Scale 1</td>
<td>20-47</td>
<td>30.5 (7.3)</td>
<td>20-47</td>
</tr>
<tr>
<td>Trait-Anxiety Scale 2</td>
<td>22-59</td>
<td>36.4 (10.1)</td>
<td>22-58</td>
</tr>
</tbody>
</table>

Comparison of state and trait anxiety with a normative sample
The means and standard deviations for both 22 male and 22 female participants were compared with the means and standard deviations of 202 male and 222 female American high school students respectively, for both subscales of the State-Trait Anxiety Inventory, using a one-sample t-test. This information was derived from the manual for the State-Trait Anxiety Inventory (Spielberger, 1983). The mean scores for both male and female participants were found to be significantly lower than the mean scores for male and female high school students respectively, for the State-Anxiety subscale (see Tables 25 and 26). The mean scores for male participants were found to be significantly lower than the mean scores for the male high school students on the Trait-Anxiety subscale, whereas there was no significant difference between the mean scores for female participants and female high school students on the Trait-Anxiety subscale (see Tables 25 and 26).

Table 25: Means and standard deviations for CF males and male high school students

<table>
<thead>
<tr>
<th></th>
<th>CF Males</th>
<th>High school males</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (SD)</td>
<td>Mean (SD)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>State-Anxiety</td>
<td>28.82 (6.72)</td>
<td>39.45 (9.74)</td>
<td>t = -4.99</td>
<td>222</td>
<td>P&lt;.05</td>
</tr>
<tr>
<td>Trait-Anxiety</td>
<td>34.45 (10.61)</td>
<td>40.17 (10.53)</td>
<td>t = -2.43</td>
<td>222</td>
<td>P&lt;.05</td>
</tr>
</tbody>
</table>
Table 26: Means and standard deviations for CF females and female high school students

<table>
<thead>
<tr>
<th></th>
<th>CF Females</th>
<th>High school females</th>
<th>Statistic</th>
<th>df</th>
<th>Significance level (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>State-Anxiety</td>
<td>32.18 (7.53)</td>
<td>40.54 (12.86)</td>
<td>t = -3.00</td>
<td>242</td>
<td>P &lt; .05</td>
</tr>
<tr>
<td>Trait-Anxiety</td>
<td>38.36 (9.48)</td>
<td>40.97 (10.63)</td>
<td>t = -1.11</td>
<td>242</td>
<td>p &gt; .05</td>
</tr>
</tbody>
</table>
Self-Perception Profile for Adolescents

Table 27 shows the mean self-esteem scores obtained by all participants and compares the means, standard deviations and range of scores obtained by male and female participants on the Self-Perception Profile for Adolescents. Based on Harter's normative sample of eight, ninth and tenth grade students (Harter, 1988) participants' mean scores on the Scholastic Competence, Social Acceptance, Romantic Appeal, Physical Appearance and Global Self-Worth subscales fell within the normal range, whereas their mean scores on the Close Friendship and Behavioural Conduct subscales fell above the normal range, and their mean scores on the Athletic Competence subscales fell below the normal range.
Table 27: Scores obtained on the Self-Perception Profile for Adolescents

<table>
<thead>
<tr>
<th></th>
<th>Total sample</th>
<th>Male participants</th>
<th>Female participants</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Range Mean (SD)</td>
<td>Range Mean (SD)</td>
<td>Range Mean (SD)</td>
</tr>
<tr>
<td>Global Self-Worth</td>
<td>1.4-3 3.1 (0.6)</td>
<td>1.8-4.0 3.2 (0.6)</td>
<td>1.2-3.8 2.9 (0.7)</td>
</tr>
<tr>
<td>Scholastic Competence</td>
<td>1.0-4.0 2.9 (0.7)</td>
<td>1.0-4.0 2.8 (0.9)</td>
<td>2.0-3.8 2.9 (0.5)</td>
</tr>
<tr>
<td>Athletic Competence</td>
<td>1.0-4.0 2.4 (0.9)</td>
<td>1.0-4.0 2.6 (0.8)</td>
<td>1.0-3.6 2.1 (0.8)</td>
</tr>
<tr>
<td>Physical Appearance</td>
<td>1.0-4.0 2.7 (0.8)</td>
<td>1.0-4.0 2.8 (0.9)</td>
<td>1.0-3.6 2.6 (0.7)</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>1.6-4.0 3.2 (0.6)</td>
<td>2.0-4.0 3.3 (0.5)</td>
<td>1.6-4.0 3.2 (0.6)</td>
</tr>
<tr>
<td>Behavioural Conduct</td>
<td>1.6-4.0 3.1 (0.6)</td>
<td>2.0-4.0 3.1 (0.6)</td>
<td>1.6-3.8 3.0 (0.6)</td>
</tr>
<tr>
<td>Close Friendship</td>
<td>2.0-4.0 3.4 (0.6)</td>
<td>2.0-4.0 3.3 (0.6)</td>
<td>1.4-3 3.6 (0.6)</td>
</tr>
<tr>
<td>Romantic Appeal</td>
<td>1.4-3.6 2.5 (0.5)</td>
<td>1.4-3.2 2.7 (0.5)</td>
<td>1.4-3.2 2.4 (0.5)</td>
</tr>
</tbody>
</table>
Gender differences in psychological adjustment
An independent samples t-test was used to examine gender differences for total CDI scores. No significant gender differences were found (t(41) = -0.71, p=0.49, 2-tailed test). A Mann-Whitney U test was used to examine gender differences on two subscales of the CDI: interpersonal problems and ineffectiveness. No significant gender differences were found on the Interpersonal problems subscale (z(22,22) = -1.1, p=0.28, 2-tailed test) or the ineffectiveness subscale (z(22,22) = -0.20, p= 0.84, 2-tailed test). A one-way multivariate analysis of variance was used to examine gender differences for three subscales of the CDI: negative mood, anhedonia and negative self-esteem, both the State-Anxiety and the Trait-Anxiety subscales of the STAI and the eight subscales of the Self-Perception Profile for Adolescents. No significant gender differences were found on any of these subscales (F(14,26) = 1.20, p=0.34).
Question 4: How does body satisfaction in adolescents with Cystic Fibrosis relate to the prevalence and nature of psychological adjustment difficulties?

Children's Depression Inventory

Pearson's correlations were used to investigate whether participants' overall scores on the BIQ, their scores on the head/facial attractiveness and body physique subscales correlated with their total CDI score. Significant negative correlations were found between participants' total score on the CDI and their overall scores on the BIQ ($r (42) = -0.59, p = 0.00, 2$-tailed test); their scores on the head/facial attractiveness subscale ($r (42) = -0.53, p = 0.00, 2$-tailed test), and their scores on the body physique subscale ($r(42) = -0.56, p = 0.00, 2$-tailed test). These results indicate that higher scores on the CDI were associated with less satisfaction on the BIQ.

A Pearson's correlation was also used to investigate whether participants' level of dissatisfaction with their body size, as measured by the Contour Drawing Rating Scale, correlated with their total CDI score. No significant correlation was found between these two variables ($r (42) = -0.11, p = 0.50, 2$-tailed test).

State-Trait Anxiety Inventory

Pearson's correlations were used to investigate whether participants' overall scores on the BIQ, their scores on the head/facial attractiveness and body physique subscales correlated with their scores on both subscales of the STAI. Significant negative correlations were found between participants' scores on the State-Anxiety subscale and their overall scores on the BIQ ($r (44) = -0.68, p = 0.00, 2$-tailed test); their scores on the head/facial attractiveness subscale ($r (44) = -0.53, p = 0.00, 2$-tailed test), and their scores on the body physique subscale ($r (44) = -0.70, p = 0.00, 2$-tailed test). Significant negative correlations were also found between participants' scores on the Trait-Anxiety subscale and their overall scores on the BIQ ($r (44) = -0.63, p = 0.00, 2$-tailed test); their scores on the head/facial attractiveness subscale ($r (44) = -0.51, p = 0.00, 2$-tailed test), and their scores on the body physique subscale ($r (44) = -0.64, p = 0.00, 2$-tailed test). These results indicate that higher scores on the STAI were associated with less reported satisfaction on the BIQ.

Pearson's correlations were also used to investigate whether participants' level of dissatisfaction with their body size, as measured by the Contour Drawing Rating Scale, correlated with their scores on the two subscales of the STAI. No significant correlations were found between body size dissatisfaction and participants' scores on either the State-Anxiety
subscale ($r (43) = -0.01, p = 0.95, 2$-tailed test) or their scores on the Trait-Anxiety subscale ($r (43) = -0.06, p = 0.69, 2$-tailed test).

**Self-Perception Profile for Adolescents**

Pearson's correlations were used to investigate whether participants' overall scores on the BIQ, their scores on the head/ facial attractiveness and body physique subscales correlated with their score on the Global Self-Worth subscale of the Self-Perception Profile for Adolescents. Significant positive correlations were found between participants' scores on the Global Self-Worth subscale and their overall scores on the BIQ ($r (44) = 0.61, p = 0.00, 2$-tailed test); their scores on the head/ facial attractiveness subscale ($r (44) = 0.52, p = 0.00, 2$-tailed test), and their scores on the body physique subscale ($r (44) = 0.60, p = 0.00, 2$-tailed test). These results indicate that higher scores on the Global Self-Worth subscale were associated with higher levels of reported satisfaction on the BIQ.

A Pearson's correlation was also used to investigate whether participants' level of dissatisfaction with their body size, as measured by the Contour Drawing Rating Scale, correlated with their score on the Global Self-Worth subscale. No significant correlation was found between these two variables ($r (42) = -0.01, p = 0.95, 2$-tailed test).
DISCUSSION

The aims of this study were to survey whether adolescents with CF are satisfied with their perceived body size and body appearance, to examine the nature and prevalence of psychological adjustment problems in adolescents with CF, and to assess whether these two factors are related. In the following section, each of the research questions will be discussed in turn. The results will be summarised and possible explanations for both similarities and differences in the findings in relation to previous research will be discussed. Methodological limitations of the study will then be addressed along with clinical implications of the findings and the need for future research.

Satisfaction with body size

Overall a significant difference was found between participants’ perceived and desired body size, with the majority of participants wanting to gain weight. Interestingly, no significant gender differences were found for body size dissatisfaction, as is typically found in the general population. For male participants, this dissatisfaction with body size is likely to reflect concerns about their physiques, which due to their shorter stature, delayed puberty and typically being thinner than their peers, are far removed from the larger size and more muscular physique commonly portrayed as the masculine ideal within Western society (Pope, Olivardia, Gruber and Borowiecki, 1999). These findings are comparable with those from previous research into body image dissatisfaction in adolescents, which has found that the majority of adolescent males are dissatisfied with their body image, and wish to gain weight, size and strength (Drewnowski and Yee, 1987). Similar results have also been found in research addressing body size dissatisfaction in adult males with CF. Abbott et al. (2000) found that CF males were dissatisfied with their body weight and desired to be much heavier than they were. For female participants, this dissatisfaction with body size and a desire to be bigger indicates that the majority of CF females in this sample are protected from societies “beauty myth” for young women that equates being beautiful with being thin. However, these findings are inconsistent with the results from previous research which found adult CF females to be happy with their perceived weight and did not wish this to differ (Abbott et al., 2000).

Good nutritional status and adequate weight gain are important targets in the treatment of CF. The participants in this study routinely visit their CF centre at least every three months, where their height and weight are routinely measured and any concerns regarding either of these are addressed. They are also constantly encouraged by their healthcare professionals to gain
weight. Consequently patients with CF are focused upon their weight throughout their lives. It is likely that these factors account for the high percentage of participants who were dissatisfied with their perceived size and wished to gain weight. These results are particularly important since good nutritional status has been found to be directly associated with health status in patients with CF and improvements in nutritional status in CF have been shown to result in better growth (Hanning, Blimkie, Bar-Or, Lands, Moss and Wilson, 1993) and improvement or stabilisation of pulmonary function (Levy, Durie, Pencharz and Corie, 1986). This desire to gain weight therefore appears to be adaptive and may even aid compliance to treatment regimens resulting in better health outcomes.

However, despite the above findings 41 percent of female participants and 33 percent of male participants had a BMI that was in the desirable range and wished to lose weight or a BMI that was either in the Anorexic or Underweight ranges and wished to remain the same size. The findings for female participants are comparable to those from previous research into body image dissatisfaction in adolescents in the general population, whereas the findings for male participants are not. It is likely that this is because the influences on male and female participants are different. CF females appear to be under pressure from two different sources in terms of their body image: CF professionals who constantly encourage weight gain, and sociocultural pressures which encourage a drive for thinness in adolescent girls. This suggests that the attitudes of this subgroup of participants are more influenced by the cultural ideal of thinness for females in Western society, than the recommendations given by CF professionals. This may be because they are unaware of the impact that their nutritional status may have upon their health. Or, they may disregard this information as they feel it more important to attain the anorexic-like body portrayed by society as desirable. As noted earlier, such attitudes are common amongst adolescent girls in the general population and it is therefore possible that the attitudes held by CF females are influenced by the attitudes and beliefs held by their peers, resulting in them subscribing to the same cultural pressures as their peers.

Although in general CF males are also under pressure to gain weight from CF professionals, the age of the participants in the current study may have resulted in less sociocultural pressures to gain weight. Forty percent of the male participants were aged 12 or 13 and it is therefore possible that many of their peers had not yet completed puberty. As a result, at the time the research was carried out a significant number of male participants may not have felt that their physical development differed from that of their peers despite the impact their CF had on their physical appearance. Thus resulting in them being content with their current body size and not favouring the larger more muscular body, portrayed by society as the masculine
ideal. This suggests that a higher prevalence of body dissatisfaction and a desire to be bigger may have been found if a greater number of older adolescents had participated in the study.

The close monitoring of nutritional status and nutritional rehabilitation programmes are considered important components of the management of patients with CF. The constant focus on feeding and nutrition experienced by patients with CF throughout their lives, may result in negative attitudes with regards to eating and a preoccupation with food, which in turn may result in higher levels of dissatisfaction with body size. This may partly account for the high numbers of participants who reported dissatisfaction with their body size and a desire for a BMI below the desirable range, in this study.

Participants in this study were aware that any concerns raised during the research would be addressed with them and that any particular concerns may be discussed with their doctor. Participants were also aware of the treatments for poor weight and growth, such as increasing their daily food intake and enteral feeding, including nasogastric tubes and gastrostomies. Both of these factors may have prevented participants from admitting that they were dissatisfied with their body weight and wished to gain weight, and instead reported that they were either satisfied with their current weight or would like to weigh less than they did.

The finding that such a large proportion of both male and female participants had a BMI in the underweight range and were satisfied with this, or had a BMI in the desirable weight and reported a desire to lose weight, is particularly concerning. Previous research examining body image in adolescents has found that dissatisfaction with one’s shape predicts subsequent eating behaviour. A number of studies have also shown evidence of a strong association between body size dissatisfaction and dietary restraint and eating disorders (Wardle and Beales, 1986; Wardle and Foley, 1989). This is particularly problematic in children and adolescents where nutritional deficits, resulting from restricted or altered food intake could cause considerable harm. However, it is thought to be an especially significant problem in adolescents with CF, where low weight and poor nutritional status have deleterious effects on pulmonary function and overall health status.

**Satisfaction with body appearance**

No significant gender differences were found on the Body Image Questionnaire (BIQ) for participants’ overall scores, or their scores on the head/facial attractiveness and the body physique subscales. The lack of significant gender differences on the body physique subscale is comparable with previous research (Abbott et al., 2000). However, unlike the present study,
Abbott et al. (2000) found CF females to be less satisfied with their facial appearance than CF males. These differences may be due to the age of the participants in the present study. The timing of puberty has been found to influence feelings about body satisfaction, with early puberty having the most negative impact on girls (Siegel et al., 1999). Since adolescents with CF typically experience delayed puberty, the female participants in this study may be more satisfied with their body image, including their facial appearance, than the participants in the study by Abbott et al. (2000) who were mainly adults.

This study also found that adolescents with CF were more satisfied with their physique and facial features than both adult controls and adults with CF. Again both of these findings may have been due to the age of the participants in this study. Although body image dissatisfaction has been found in girls as young as five years old (Davison, Markey and Birch, 2000), Smolak, Levine and Gralen (1993) reported considerably more body image dissatisfaction in girls who have completed pubertal development. Individuals with CF typically experience a delay in puberty and it is therefore possible that the greater satisfaction with both physique and facial appearance, reported by females is a consequence of delayed pubertal development in the population studied. As noted earlier, 40 percent of male participants were aged 12 or 13 and it is therefore possible that many of their peers had not completed pubertal development. Therefore, even though a number of male participants may have experienced delayed puberty, their CF may not necessarily result in obvious signs of difference from their peers at this stage. Thus resulting in greater reported levels of satisfaction. A higher prevalence of body image dissatisfaction in both male and female participants may have been found if a greater number of older adolescents had participated in the study.

Another reason for the high levels of reported body image satisfaction is that all participants in the study have regular contact with their CF centre, with routine hospital appointments at least every three months, as well as further telephone contact and hospital admissions in between appointments, if necessary. Patients are seen annually for a review by all members of the CF team, including a clinical psychologist. They also have access to a clinical psychologist when they attend routine hospital appointments and may, if necessary, be seen by a psychologist on an outpatient basis. It may be that this system provides a forum in which any particular concerns regarding body image may be raised and addressed.
Impact of CF on body image

When participants were asked to assess the impact of CF on their satisfaction with their weight, height and physical appearance, the majority thought that it had little impact. That is, only 13 percent felt their CF significantly affected their satisfaction with their physical appearance and just under one-fifth thought their CF significantly affected their satisfaction with their height. However, a more substantial minority of 27 percent (nearly one in four participants) reported that their CF significantly affected their satisfaction with their weight. These findings suggest that overall the participants in this study did not feel that having CF impacts too much on body image satisfaction in these areas.

Participants were also asked about specific CF treatments they had had, and how much they were bothered by these. The CF treatments participants reported included gastrostomies and portocaths. Just under one-third of participants reported having a portocath, but did not appear to be overly bothered by them. Whereas only 16 percent of participants reported having a gastrostomy, and just under half of these reported being significantly bothered by it. In terms of the impact on body image, it is likely that participants expressed such different views regarding these two treatments since portocaths are not easily visible to others, whereas gastrostomies are.

Although participants reported high levels of satisfaction with their physique and facial appearance, 30 percent of participants reported an area of their body that they were unhappy with as a result of their CF. A number of different areas were reported. Both male and female participants reported being unhappy with their chests and their hands. However, female participants reported a number of additional areas including their shoulders, height, weight, bottom, thighs, hips, stomach, not having enough muscles and having a podgy face due to steroids. Male participants also reported they were unhappy with the shape of their fingers, and having a swollen spleen. Thus these findings indicate that although there were certain body parts that both male and female participants reported being dissatisfied with, overall having CF appeared to impact upon body satisfaction differently in male and female participants.

Approximately one-fifth of participants felt that they looked different from their peers. Male and female participants generally reported similar responses, which included looking younger, smaller, less healthy, skinnier and having less muscle. Thirteen percent of participants reported there were things they avoided doing because of their physical appearance and just over one-quarter of participants reported that there were things they did because of the way
they looked as a result of having CF. Again male and female participants gave similar responses on both of these questions. Things participants reported that they tended to avoid included sports and swimming, as well avoiding wearing certain clothes, such as small tops or short skirts for female participants and short shorts for male participants. Things participants did because of their physical appearance included trying to do more exercise and eat more. Just under 20 percent of participants stated that they thought the way they look affects their relationships with their peers. Again male and female participants gave similar responses, including being shorter than their peers and not looking as attractive as others because of their CF or their weight. The findings from this questionnaire are very informative and have a number of clinical implications, which will be discussed later in this section.

**Psychological adjustment problems**

The results from this study were consistent with those from previous research which has shown that, as a group, adolescents with CF do not demonstrate increased psychological adjustment problems. Overall the participants in this study did not endorse a large number of depressive symptoms, with only seven percent of participants scoring at or above the clinical cut-off point for depression. Although, some authors have reported that adolescents with CF do experience moderate levels of depressive symptomatology (DiGirolamo et al., 1997), others have reported low prevalence rates of psychopathology in children and adolescents with CF. Thompson et al. (1990) found significantly less depressive symptoms, depressive diagnoses and diagnoses of dysthymia than psychiatrically referred children. Similarly, Breslau (1985) utilizing the Psychiatric Screening Inventory with mothers of 65 children with CF reported a lack of evidence of elevated depression scores.

Overall both male and female participants in this study reported levels of both state and trait anxiety scores that were similar to or below those of male and female high school students from an American normative sample, respectively. These findings differ from a number of research studies which have found that children and adolescents with CF are at risk of anxiety-based disorders (Thompson et al., 1990; Thompson et al., 1992).

The finding from this study that participants did not report low self-esteem is not consistent with previous research. Moise et al. (1987) found the level of self-esteem in the CF group to be somewhat lower than for test norms, suggesting that self-esteem may be negatively affected in CF.
The difference in levels of self-esteem between the two studies may be due to differences in the age range of participants. Moise et al. (1987) included both adolescents and adults with CF between the ages of 18 and 40, whereas the mean age of participants in this study was 14.2, with 73 percent being aged 14 or under. Health status is known to deteriorate with increasing age in CF, and typically brings with it deteriorating physical functioning and confrontations with the inevitability of a shortened life-span (Thompson et al. 1990). It is possible that the higher self-esteem scores found in the current study may reflect the fact that it is easier for adolescents to ignore or deny the knowledge that CF is a lethal disease because of its future impact. This may also be a factor in the low rates of psychopathology found in the current study, since previous research comparing psychiatric symptomatology in younger and older patients with CF, has indicated a greater rate of symptoms of anxiety and depression in older adolescents and adults (Pearson, Pumariega and Seilheimer, 1991). Therefore a higher level of psychopathology may have been found had the study included a greater number of older adolescents.

The lower levels of psychological maladjustment reported in this study may also reflect the recent improvements in the treatment of those with CF which have resulted in marked increases in their life span. Knowledge regarding these may result in adolescents with CF experiencing less psychological disturbance than was previously reported.

**Relationship between psychological adjustment and body satisfaction**

A significant relationship was found between body image satisfaction and depression, anxiety and self-esteem. That is, the more satisfied participants were with their body image, the lower their reported levels of depression and anxiety, and the higher their reported levels of self-esteem. These findings are consistent with previous research in the general population, which has found that satisfaction with one’s body is positively correlated with self-esteem and negatively correlated with depression. Siegel et al. (1999) found negative feelings about their bodies were related to higher levels of depressive symptomatology and lower self-esteem in girls. Befort, Kurpiaus, Hull-Blanks, Nicpon, Huser and Sollenberger (2001) reported a significant relationship between body image and self-esteem. They found that on average, women who reported lower self-esteem also reported feeling shame about their bodies, watching their bodies as an onlooker, having a greater discrepancy between their current and ideal body figures, and having greater overall physical dissatisfaction. Gross and Rosen (1988) found that in addition to body dissatisfaction, both depression and high social anxiety were significant predictors of eating disturbance in adolescent females.
Methodological limitations

One limitation of the current study is that the upper age limit was 16. The physiological changes that occur during puberty, such as changes in the distribution of body fat, the development of a variety of secondary sexual characteristics, and alterations in body proportions, have a major impact on body image. Since adolescents with CF typically experience delayed puberty a greater prevalence of body image dissatisfaction may have been found had the upper age range for the sample been 18, thus including a greater number of older adolescents. The prevalence of psychopathology may have also been found to be higher had the study included more older adolescents, since higher rates of psychiatric symptomatology have been found in older patients with CF compared to younger patients (Pearson et al., 1991).

Generalisation of the results from this study may be limited by the relatively small sample size, specific geographical area and the fact participants were predominantly Caucasian. Small sample sizes typically result in decreased statistical power and therefore the reduced likelihood of detecting an accurate prevalence rate of body image dissatisfaction and psychological adjustment difficulties. However, despite these factors, the study sample was found to be representative of the clinic population from which it was drawn in terms of demographic parameters including age, gender and ethnicity.

Since participation was voluntary, it is possible that there was selective participation based on levels of body image dissatisfaction or psychological distress. However, the significant association between body image satisfaction and depression, anxiety and self-esteem scores, suggests some important variation on these measures.

The correlational and cross-sectional nature of the present study does not allow precise determination of the direction of influence of the obtained relationship between body image satisfaction and psychological adjustment. Although it is possible that participants’ body image influenced their psychological adjustment, it is equally possible that their general level of psychological adjustment affected their body image. Prospective studies are therefore needed to determine whether body image dissatisfaction is an antecedent of psychological maladjustment or vice versa.
Future research

This study found that half of the female participants and over half of the male participants were dissatisfied with their body size and wished to gain weight. However, the study also found evidence that a large number of participants were either underweight and wished to stay the same size, or were a desirable weight and wished to lose weight. At present it is unclear why participants’ responses regarding satisfaction with their body size differ to such an extent. It would therefore be beneficial for research to be undertaken, which examines the risk factors for the development of body size dissatisfaction and the desire to have a BMI that is below the desirable range, in adolescents with CF. By determining the factors that precipitate body image dissatisfaction in adolescents with CF this information could be incorporated into future service provision, enabling healthcare professionals to identify those individuals at risk of developing a poor body image, and intervene appropriately.

A number of participants in the current study reported that they were either dissatisfied with their current weight and wished to lose weight or were content with their current low weight. As noted earlier, previous research investigating body image dissatisfaction in adolescents has found that body image dissatisfaction predicts subsequent eating behaviour. However, it is unclear from these results whether participants are reducing their dietary intake in order to modify their body weight. In addition, research in adolescents with insulin dependent diabetes mellitus has found that adolescent girls report omitting or reducing their dose of insulin in order to control their weight and shape. It would therefore be valuable for research to be carried out investigating whether adolescents with CF engage in dietary restraint and whether they exploit their treatment regimens in order to reduce or maintain a low weight, for example, not taking the prescribed amount of enzymes or not consuming nutritional supplements.

Previous research has shown that both body image dissatisfaction and psychological adjustment difficulties are not stable factors and change over time. There is therefore a need for longitudinal research to be carried out to further explore these issues and how they are influenced at different ages and by different developmental stages. This would also provide an opportunity to identify the specific risk factors that influence the development of body image dissatisfaction and emotional adjustment difficulties in adolescents with CF, and explore the changes in the interrelationship between these factors over time. This information would allow CF professionals to guide efforts to derive intervention programmes which aim to prevent adolescents with CF developing a poor body image and enhance psychological adjustment.
Clinical implications

Previous research has shown that body image dissatisfaction has been found to be a significant predictor of dietary restraint. Given the fact that low weight and poor nutritional status have been found to have potentially fatal consequences in individuals with CF the findings from the current study that a large proportion of male and female participants reported body size dissatisfaction and a desire to either lose weight or maintain a low body weight is particularly concerning. A heightened awareness by the CF team of the prevalence of body size dissatisfaction in adolescents with CF is therefore required. Professionals working with CF adolescents need to routinely enquire about satisfaction with weight, body size, dieting and compliance to CF treatments. This will enable the CF team to identify those patients who are potentially at risk and provide early preventive interventions. This is particularly importance for those patients going through puberty, when individuals are at greatest risk of body size dissatisfaction. In addition, by providing information about the health consequences of these behaviours to adolescents with CF the CF team may be able to prevent individuals from developing poor body images and maladaptive weight-loss behaviours from developing. The findings from this study that male and female adolescents may respond differently to the impact of CF on their body image highlights the need for gender differences to be taken into consideration in the assessment and subsequent treatment of body image dissatisfaction.

As noted earlier close monitoring of nutritional status and nutritional rehabilitation programmes are considered important components of the medical management of individuals with CF. This results in a continuous focus on feeding and nutrition throughout the lives of patients with CF. This may be a contributing factor in the high levels of concern over body shape and desire to be thinner observed in many of the participants in this study, as it may lead to disturbed eating attitudes and behaviour. In such cases the mental health professionals working within the CF team could carry out individual therapy to facilitate more adaptive attitudes and behaviour. Another approach would be for the mental health professionals to work with other members of the CF team helping them to think about alternative ways to manage nutrition without the continual focus on food, weight and body size.

Over 40 percent of participants who had a gastrostomy reported that they were significantly bothered by it. Issues regarding how the individual’s body image may be affected by such treatments needs to be taken into account before the treatment is prescribed, and regularly reviewed once the gastrostomy has been fitted.
A number of participants in the current study reported that they avoided exercise, including physical education and swimming because of the impact their CF had on their physical appearance. This finding is concerning since exercise is seen as a valuable addition to chest physiotherapy in the treatment of respiratory symptoms in CF. This suggests that it would be valuable for CF teams to address this issue with patients and help individuals find ways of exercising which they feel comfortable with.

This study also found that although the majority of adolescents with CF did not experience psychological adjustment problems, there was a small minority of participants who did report increased levels of depression and anxiety. Routinely asking about symptoms of depression and anxiety or administering simple screening procedures, such as those used in this study which are reasonably short and easy to complete, would help CF professionals to identify those patients at risk of, or experiencing psychological adjustment difficulties and intervene appropriately. This is important considering social and psychological factors have been found to have a detrimental effect on physiological functioning, the onset and progression of disease, as well as morbidity and mortality (Abbott and Gee, 1998).

Conclusion

The results from this study showed that over half of the participants were dissatisfied with their body size and wished to gain weight. Consequently, these participants reported engaging in adaptive behaviours to help them to gain weight. However, a significant proportion of participants were dissatisfied with their body size and desired an even thinner figure. Coupled with the fact that body size dissatisfaction has been found to be a significant predictor of dietary restraint, these results are particularly concerning. These findings highlight the need for assessment of body image to be made part of the routine clinic visit. Strategies aimed at preventing the development of such negative attitudes also need to be routinely undertaken, to counteract the impact of the continuous focus on feeding and nutrition throughout the lives of patients with CF.

The findings from the current study regarding psychopathology suggest that adolescents with CF, between the ages of twelve and sixteen, do not differ from their healthy peers in terms of psychological adjustment. It is plausible that these findings result from the fact that adolescents with CF are receiving sufficient care and attention from health professionals, and/or family to offset any increases in psychopathology which might be associated with the illness (Kashani et al., 1988).
Future research could build upon the results of the present study by assessing the implications of weight concerns in adolescents with CF on dietary practices and adherence to treatment regimens. Comprehensive longitudinal assessment of the frequencies and types of psychological problems demonstrated by adolescents with CF alongside a thorough assessment of body image disturbances may also help to identify which children are susceptible to such difficulties. These studies will provide the necessary information for the understanding of the relationships between body image dissatisfaction and psychological adjustment difficulties, throughout the course of the illness, enabling health professionals to devise intervention programmes that best meet the needs of individuals with CF.
References:


Cystic Fibrosis Trust (2002). 11 London Road, Bromley, Kent, BR1 1BY.


Appendices

Appendix 1: Ethics approval letters
Appendix 2: Child information sheet
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Appendix 1
Ethics approval letters
Institute of Child Health
and Great Ormond Street Hospital for Children NHS Trust
UNIVERSITY COLLEGE LONDON

30 Guilford Street, London, WC1N 1EH. Telephone: 020 7242 9789 Fax: 020 7813 8234

6 September 2002

Dr M Bryon
Department of Psychological Medicine
GOS

Dear Dr Bryon,

Title: An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

R&D registration number: 02BS14
Protocol number/version: N/A

Notification of ethical approval

The above research has been given ethical approval after review by the Great Ormond Street Hospital for Children NHS Trust / Institute of Child Health Research Ethics Committee subject to the following conditions.

1. Your research must commence within twelve months of the date of this letter and ethical approval is given for a period of 8 months from the commencement of the project. If you wish to start the research more than twelve months from the date of this letter or extend the duration of your approval you should seek Chairman's approval.

2. You must seek Chairman's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature, eg. using the same procedure(s) or medicinal product(s). Each research project is reviewed separately and if there are significant changes to the research protocol, for example in response to a grant giving body's requirements you should seek confirmation of continued ethical approval.

3. Researchers are reminded that REC approval does not imply approval by the GOS Trust. Researchers should confirm with the R&D office that all necessary permissions have been obtained before proceeding.
4. It is your responsibility to notify the Committee immediately of any information which would raise questions about the safety and continued conduct of the research.

5. On completion of the research, you must submit a report of your findings to the Research Ethics Committee.

6. Specific conditions pertaining to the approval of this project are:
   • The use of the enclosed standard consent forms for the research. A copy of the signed consent form must be placed in the patient's clinical records and a copy must be kept by you with the research records.

Yours sincerely

Orlagh Sheils
Administrator to the Research Ethics Committee

Cc: Miss S Dickson, Trainee Clinical Psychologist
Dear Ms Dickson

An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis (ACE/2001/78/Psych) – FAST TRACK

I am writing to inform you that the University Advisory Committee on Ethics has considered the above protocol under its ‘Fast Track’ procedure and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, these Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (ACE/2002/78/Psych) - Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

Date of approval by the Advisory Committee on Ethics: 07 October 2002
Date of expiry of approval by the Advisory Committee on Ethics: 06 October 2007

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Advisory Committee on Ethics

cc: Chairman, ACE
    Dr L Dowdney, Supervisor, Dept of Psychology
    Dr
Appendix 2
Child information sheet
An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

Dear

We are inviting you to take part in a research study. The research forms part of my Doctoral Degree in Clinical Psychology. The information that follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely up to you and one of your parents or your legal guardian. Please ask any questions you want to about the research and we will try our best to answer them.

- Why have you been chosen to take part in the research?

You have been asked to take part in this study because you are aged between 12 and 17 years old and have Cystic Fibrosis.

- What is the aim of the research?

The aim of the research is to see how people your age with Cystic Fibrosis feel about the way they look, what kind of difficulties they might experience and how this may affect them emotionally. This will help us to think about ways that we could provide for such difficulties in the future. The research also aims to learn from people your age who are not experiencing any difficulties and find out how they have managed.

- What will be expected of me?

You will be asked to complete some questionnaires and will then be asked to take part in a very short interview.

- How long will it take?

You will need to be seen alone for approximately 10-15 minutes by a female Trainee Clinical Psychologist. You will be able to fill out the questionnaires at your leisure throughout the day. Altogether it should take no longer than 45 minutes.

- What will I get out of taking part?

By taking part in this study, you will be helping us to learn more about how people with Cystic Fibrosis feel about themselves, what they think of their appearance, especially their weight and how they look. If you wanted to talk about any of these issues afterwards, we would be able to sort that out for you.

- Will I have to come back to hospital more often than I normally do in order to take part in the study?

No. If you agree to take part, you could be seen before or after your review at Clinic.
• Could taking part in this study upset me in any way?

The questionnaires and interview are not known to upset people, but you can stop at any time if you do become upset and a qualified Clinical Psychologist will be available if you want to talk to someone about it.

• Are there any reasons why I should not take part in the study?

We are looking for people between the ages of 12 and 17 who have been diagnosed with Cystic Fibrosis and can speak English well enough to understand the questions.

• How will confidentiality be protected?

All information gathered will remain totally confidential. This is one of the agreements of the Consent form that you and your Parent/Legal Guardian will be asked to sign before the assessment takes place. No-one in the Cystic Fibrosis team will be informed of your decision to take part or not. No-one other than myself will have access to any information you give during the assessment. Your name will be coded and therefore no-one in the team will know your scores. Only I will be allowed access to the identity of the codes on your questionnaires. If I have any concerns after the interview, I will discuss it with you before talking to your Consultant.

• You do not have to join the study. You can decide not to be in the study or to drop out at any time. If you do decide now or at a later stage, that you do not wish to participate in this study, this is entirely your right and will not in any way prejudice any present or future treatment.

• If you are worried about anything then you can either call Dr Dinwiddie or Sara Dickson.

• A brief summary of the findings will be available at the end of the study.

• If you would like to talk to someone about the study before making a decision, please contact:

   Dr Or, Sara Dickson
   Senior Consultant  Trainee Clinical Psychologist
   lospital  Department of Psychology
   University of Surrey
   Guildford GU2 7XH
   Tel: 01483 259441
This project has been approved by an independent research ethics committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital.

Yours Sincerely,

Sara Dickson
Trainee Clinical Psychologist
Appendix 3

Child covering letter
Dear

RE: A study examining Body Image and Emotional Adjustment in Adolescents with Cystic Fibrosis

Please find enclosed an invitation for you to participate in a research study by Sara Dickson who is a Trainee Clinical Psychologist.

The main aim of the study is to identify how people between the ages of 12 and 17 who have Cystic Fibrosis feel about the way they look. This would help us to think about ways that we could provide help for such difficulties in the future as part of our service.

The invitation describes the study in detail, but please do not hesitate to contact either myself or Sara Dickson if you have any queries. You will find our contact addresses and telephone numbers on page 2 of the invitation.

Yours Sincerely,

Senior Consultant
Appendix 4

Adult information letter
(Son and daughter)
Invitation to Participate in a Research Project

An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

Dear

We invite your son to take part in a research study. The research forms part of my Doctoral Degree in Clinical Psychology. The information that follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if your son takes part and what the risks might be. Try to make sure you know what will happen to , if you decide to give consent that he can take part. Whether or not he does take part is entirely up to you and . Please ask any questions you want to about the research and we will try our best to answer them.

• Why has your son been identified as suitable to take part in the research?

has been asked to take part in this study because he is aged between 12 and 17 years and has been diagnosed with Cystic Fibrosis.

• What is the aim of the research?

The aim of the research is to identify how adolescents with Cystic Fibrosis feel about the way they look, what kind of difficulties they might experience and how this may affect them emotionally. This will help us to think about ways that we could provide for such difficulties in the future. The research also aims to learn from those who are not experiencing difficulties and find out how they have managed.

• What will be expected of

will be asked to complete some questionnaires and will then be asked to take part in a very short interview, where he will be asked about what he thinks about the way he looks.

• How long will be expected to participate?

will need to be seen for approximately 10-15 minutes. He will be interviewed alone by a female Trainee Clinical Psychologist. will be able to fill out the questionnaires at his leisure throughout the day. Altogether it should take no longer than 45 minutes to participate.

• What will gain by participating?

By taking part in the study, your son will be helping us to learn more about how people with Cystic Fibrosis feel about themselves and what they think of their appearance, particularly their weight. He might find it interesting to discuss these issues. This will also help us to provide future help for others of the same age who experience similar difficulties. If necessary further support could be arranged following his participation in the study.
• Will he have to come back to hospital more often than he normally does in order to take part in the study?

No. If you and your son agree to take part, a researcher will contact both of you to arrange a convenient time when he could be seen. Perhaps he could attend before or after his review at Clinic.

• Could participating in this study upset him in any way?

The questionnaires and interview are not known to upset people. However, you can stop at any time. Also, you can talk to a qualified Clinical Psychologist who will be available throughout if he wants to talk to someone about any issues raised.

• Are there any reasons why he should not take part in the study?

We are looking for young people between the ages of 12 and 17 who have been diagnosed with Cystic Fibrosis and can speak English well enough to understand the questions.

• How will confidentiality be protected?

All information gathered will remain totally confidential. This is one of the agreements of the Consent form that you and your son will be asked to sign before the assessment takes place. No-one in the Cystic Fibrosis team will be informed of their decision whether to take part or not. No-one other than myself will have access to any information given by your son during the assessment. Names of participants will be coded and therefore no-one in the team will know individual participants’ scores. Only I will be allowed access to the identity of the codes on the questionnaires. Names and data will be stored separately at all times. If any concerns become apparent following your son participating in the study, this will be discussed with your son before any information is passed on to your son’s Consultant.

• Your son does not have to join the study. He is free to decide not to be in the study or to drop out at any time once the study has begun. If he decides now or at a later stage, that he does not wish to participate in this study, this is entirely his right and will not in any way prejudice any present or future treatment.

• You will always be able to contact an investigator to discuss your concerns and/or to get help in an emergency from either Dr Dinwiddie or Sara Dickson.

• A brief summary of the findings will be available at the end of the study.
If you have any queries or concerns that you would like to talk to someone about, before making a decision, please contact:

Dr
Senior Consultant

Or,

Sara Dickson
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford GU2 7XH

Tel: 01483 259441

This project has been approved by an independent research ethics committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital.

Yours Sincerely,

Sara Dickson
Trainee Clinical Psychologist
Invitation to Participate in a Research Project

An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

Dear

We invite your daughter, to take part in a research study. The research forms part of my Doctoral Degree in Clinical Psychology. The information that follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if your daughter takes part and what the risks might be. Try to make sure you know what will happen to if you decide to give consent that she can take part. Whether or not she does take part is entirely up to you and Please ask any questions you want to about the research and we will try our best to answer them.

- Why has your daughter been identified as suitable to take part in the research?

has been asked to take part in this study because she is aged between 12 and 17 years and has been diagnosed with Cystic Fibrosis.

- What is the aim of the research?

The aim of the research is to identify how adolescents with Cystic Fibrosis feel about the way they look, what kind of difficulties they might experience and how this may affect them emotionally. This will help us to think about ways that we could provide for such difficulties in the future. The research also aims to learn from those who are not experiencing difficulties and find out how they have managed.

- What will be expected of

will be asked to complete some questionnaires and will then be asked to take part in a very short interview, where she will be asked about what she thinks about the way she looks.

- How long will be expected to participate?

will need to be seen for approximately 10-15 minutes. She will be interviewed alone by a female Trainee Clinical Psychologist. will be able to fill out the questionnaires at her leisure throughout the day. Altogether it should take no longer than 45 minutes to participate.

- What will gain by participating?

By taking part in the study, your daughter will be helping us to learn more about how people with Cystic Fibrosis feel about themselves and what they think of their appearance, particularly their weight. She might find it interesting to discuss these issues. This will also help us to provide future help for others of the same age who experience similar difficulties. If necessary further support could be arranged following her participation in the study.
• Will she have to come back to hospital more often than she normally does in order to take part in the study?

No. If you and your daughter agree to take part, a researcher will contact both of you to arrange a convenient time when she could be seen. Perhaps she could attend before or after her review at Clinic.

• Could participating in this study upset her in any way?

The questionnaires and interview are not known to upset people. However, she can stop at any time. Also she can talk to a qualified Clinical Psychologist who will be available throughout if she wants to talk to someone about any issues raised.

• Are there any reasons why she should not take part in the study?

We are looking for young people between the ages of 12 and 17 who have been diagnosed with Cystic Fibrosis and can speak English well enough to understand the questions.

• How will confidentiality be protected?

All information gathered will remain totally confidential. This is one of the agreements of the Consent form that you and your daughter will be asked to sign before the assessment takes place. No-one in the Cystic Fibrosis team will be informed of their decision whether to take part or not. No-one other than myself will have access to any information given by your daughter during the assessment. Names of participants will be coded and therefore no-one in the team will know individual participants’ scores. Only I will be allowed access to the identity of the codes on the questionnaires. Names and data will be stored separately at all times. If any concerns become apparent following your daughter participating in the study, this will be discussed with your daughter before any information is passed on to your daughter’s Consultant.

• Your daughter does not have to join the study. She is free to decide not to be in the study or to drop out at any time once the study has begun. If she decides now or at a later stage, that she does not wish to participate in this study, this is entirely her right and will not in any way prejudice any present or future treatment.

• You will always be able to contact an investigator to discuss your concerns and/or to get help in an emergency from either Dr Dinwiddie or Sara Dickson.

• A brief summary of the findings will be available at the end of the study.
• If you have any queries or concerns that you would like to talk to someone about, before making a decision, please contact:

Dr
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Sara Dickson
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Tel: 01483 259441

This project has been approved by an independent research ethics committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study.

No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital.

Yours Sincerely,

Sara Dickson
Trainee Clinical Psychologist
Appendix 5

Adult covering letter
(Son and daughter)
Dear

RE: A study examining Body Image and Emotional Adjustment in Adolescents with Cystic Fibrosis

Please find enclosed an invitation for your son to participate in a research study by Sara Dickson who is a Trainee Clinical Psychologist at the University of Surrey. The research forms part of her Doctoral Degree in Clinical Psychology.

The main aim of the study is to identify how adolescents with Cystic Fibrosis feel about the way they look, what kind of difficulties they might experience and how this may affect them emotionally. This would help us to think about ways that we could provide help for such difficulties in the future, as part of our service.

The invitation describes the study in detail, but please do not hesitate to contact either myself or Sara Dickson if you have any queries. You will find our contact addresses and telephone numbers on page 3 of the invitation.

Yours Sincerely,

Senior Consultant
Dear

RE: A study examining Body Image and Emotional Adjustment in Adolescents with Cystic Fibrosis

Please find enclosed an invitation for your daughter to participate in a research study by Sara Dickson who is a Trainee Clinical Psychologist at the University of Surrey. The research forms part of her Doctoral Degree in Clinical Psychology.

The main aim of the study is to identify how adolescents with Cystic Fibrosis feel about the way they look, what kind of difficulties they might experience and how this may affect them emotionally. This would help us to think about ways that we could provide help for such difficulties in the future, as part of our service.

The invitation describes the study in detail, but please do not hesitate to contact either myself or Sara Dickson if you have any queries. You will find our contact addresses and telephone numbers on page 3 of the invitation.

Yours Sincerely,

Senior Consultant
Appendix 6
Child assent form
Research Ethics Committee

Assent Form for CHILDREN Participating in Research Studies

Title: An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

NOTES FOR CHILDREN

1. You have been asked to take part in some research. The person organising that study must explain the project to you before you agree to take part.

2. Please ask the researcher any questions you like about this project, before you decide whether to join in.

3. If you decide, now or at any other time, that you do not wish to be involved in the research project, just tell us and we will stop the research. If you are a patient your treatment will carry on as it would normally.

4. You will be given an information sheet which describes the research. This information is for you to keep and refer to at any time. Please read it carefully.

5. If you have any complaints about the research project, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via The Research and Development Office, or if urgent, by telephone on and the committee administration will put you in contact with him.

ASSENT

I __________________________ agree that the Research Project named above has been explained to me to my satisfaction, and I agree to take part in this study. I have read both the notes written above and the Information Sheet about the project, and understand what the research study involves.

SIGNED __________________________ PRINTED __________________________ DATE __________________________

SIGNED (Researcher) __________________________ PRINTED __________________________ DATE __________________________
Appendix 7
Adult consent form
**Consent Form for PARENTS OR GUARDIANS**

of Children Participating in Research Studies

**Title:** An exploratory study of body image and emotional adjustment in adolescents with Cystic Fibrosis

**NOTES FOR PARENTS OR GUARDIANS**

1. Your child has been asked to take part in a research study. The person organising that study is responsible for explaining the project to you before you give consent.

2. Please ask the researcher any questions you may have about this project, before you decide whether you wish to participate.

3. If you decide, now or at any other stage, that you do not wish your child to participate in the research project, that is entirely your right, and if your child is a patient it will not in any way prejudice any present or future treatment.

4. You will be given an information sheet which describes the research project. This information sheet is for you to keep and refer to. Please read it carefully.

5. If you have any complaints about the way in which this research project has been or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via The Research and Development Office, or if urgent, by telephone on , and the committee administration will put you in contact with him.

**CONSENT**

I/We ________________, being the parent(s)/guardian(s) of ________________, agree that the Research Project named above has been explained to me to my/our satisfaction, and I/We give permission for our child to take part in this study. I/We have read both the notes written above and the Information Sheet provided, and understand what the research study involves.

SIGNED (Parent(s)/Guardian(s)) PRINTED DATE

SIGNED (Researcher) PRINTED DATE
Appendix 8
Contour Drawing Rating Scale
THE CONTOUR DRAWING RATING SCALE

(Thompson & Gray, 1995)
Appendix 9

Body Image Questionnaire
Body Satisfaction Scale (Hatfield and 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>Item</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>
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<td>Eyes</td>
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<td>Ears</td>
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<td>Mouth</td>
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<td>Teeth</td>
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<td>Voice</td>
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<td>Chin</td>
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<td>Complexion</td>
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<tr>
<td>Overall facial attractiveness</td>
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<td>Shoulders</td>
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<td>Chest or breast</td>
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<td>Hands</td>
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<tr>
<td>Size of abdomen</td>
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<tr>
<td>Buttocks</td>
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<tr>
<td>Hips (upper thighs)</td>
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<tr>
<td>Legs and ankles</td>
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<tr>
<td>Feet</td>
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<tr>
<td>General muscle tone or development</td>
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<tr>
<td>Overall body appearance</td>
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</tbody>
</table>
Appendix 10
The role of CF in body satisfaction questionnaire
Here are some questions asking you about how you see the way you look.

- **How satisfied are you with your physical appearance?**

  Extremely    Quite    Somewhat    Somewhat    Quite    Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied

  *(Please circle the response that best applies to you)*

- **How much do you think your cystic fibrosis has affected how satisfied you are with your weight?**

  Not at all / Very little / A little / Quite a lot / Very much

  *(Please circle the response that best applies to you)*

- **How much do you think your cystic fibrosis has affected how satisfied you are with your height?**

  Not at all / Very little / A little / Quite a lot / Very much

  *(Please circle the response that best applies to you)*

- **How much do you think your cystic fibrosis has affected how satisfied you are with your physical appearance?**

  Not at all / Very little / A little / Quite a lot / Very much

  *(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.

- How satisfied do you think your mother is with your weight?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)

- How satisfied do you think your mother is with your height?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)

- How satisfied do you think your mother is with your physical appearance?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)

- How satisfied do you think your father is with your weight?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)

- How satisfied do you think your father is with your height?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)

- How satisfied do you think your father is with your physical appearance?
  
  Extremely Dissatisfied Quite Somewhat Somewhat Quite Extremely
  Dissatisfied dissatisfied dissatisfied satisfied satisfied satisfied

(Please circle the response that best applies to you)
• How satisfied do you think your doctor is with your weight?

Extremely  Quite  Somewhat  Somewhat  Quite  Extremely
Dissatisfied  dissatisfied  dissatisfied  satisfied  satisfied  satisfied

(Please circle the response that best applies to you)

• How satisfied do you think your doctor is with your height?

Extremely  Quite  Somewhat  Somewhat  Quite  Extremely
Dissatisfied  dissatisfied  dissatisfied  satisfied  satisfied  satisfied

(Please circle the response that best applies to you)

• How satisfied do you think your doctor is with your physical appearance?

Extremely  Quite  Somewhat  Somewhat  Quite  Extremely
Dissatisfied  dissatisfied  dissatisfied  satisfied  satisfied  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.

- Do you have any of the following?

  Gastrostomy / Portocath / Sores / Scars / Other

  (Please circle any response that applies to you)

  If other, please write down any other physical difficulties you have

  • If you are bothered by any of these, please state how much:

    Please tick the appropriate box:

    |                      | Not at all | Very Little | A little | Quite a lot | Very much |
    |----------------------|-----------|-------------|---------|-------------|-----------|
    | Gastrostomy          |           |             |         |             |           |
    | Portocath            |           |             |         |             |           |
    | Sores                |           |             |         |             |           |
    | Scars                |           |             |         |             |           |
    | Other                |           |             |         |             |           |

    Please state:..............................................................................................................................

    |                      | Not at all | Very Little | A little | Quite a lot | Very much |
    |----------------------|-----------|-------------|---------|-------------|-----------|
    | Gastrostomy          |           |             |         |             |           |
    | Portocath            |           |             |         |             |           |
    | Sores                |           |             |         |             |           |
    | Scars                |           |             |         |             |           |
    | Other                |           |             |         |             |           |

    Please state:..............................................................................................................................

    |                      | Not at all | Very Little | A little | Quite a lot | Very much |
    |----------------------|-----------|-------------|---------|-------------|-----------|
    | Gastrostomy          |           |             |         |             |           |
    | Portocath            |           |             |         |             |           |
    | Sores                |           |             |         |             |           |
    | Scars                |           |             |         |             |           |
    | Other                |           |             |         |             |           |

    Please state:..............................................................................................................................

    |                      | Not at all | Very Little | A little | Quite a lot | Very much |
    |----------------------|-----------|-------------|---------|-------------|-----------|
    | Gastrostomy          |           |             |         |             |           |
    | Portocath            |           |             |         |             |           |
    | Sores                |           |             |         |             |           |
    | Scars                |           |             |         |             |           |
    | Other                |           |             |         |             |           |

    Please state:..............................................................................................................................
• 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:

• 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:

• Is there anything you avoid doing because of your physical appearance?

YES / NO

If yes, please list all the things you avoid doing:

• Is there anything you do because of your physical appearance? (For example, some people tell me that they avoid wearing certain clothes, or alter the amount they eat)

YES / NO

If yes, please list everything you do:
• 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 11
Children’s Depression Inventory
Kids sometimes have different feelings and ideas.

This form lists the feelings and ideas in groups. From each group of three sentences, pick one sentence that describes you *best* for the past two weeks. After you pick a sentence from the first group, go on to the next group.

There is no right answer or wrong answer. Just pick the sentence that best describes the way you have been recently. Put a mark like this □ next to your answer. Put the mark in the box next to the sentence that you pick.

Here is an example of how this form works. Try it. Put a mark next to the sentence that describes you *best*.

**Example:**

- □ I read books all the time.
- □ I read books once in a while.
- □ I never read books.

When you are told to do so, tear off this top page. Then, pick the sentences that describe you best on the first page. After you finish the first page, turn to the back. Then, answer the items on that page.

**Remember, pick out the sentences that describe you best in the PAST TWO WEEKS.**
<table>
<thead>
<tr>
<th>Item 1</th>
<th>Item 8</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I am sad once in a while.</td>
<td>☐ All bad things are my fault.</td>
</tr>
<tr>
<td>☐ I am sad many times.</td>
<td>☐ Many bad things are my fault.</td>
</tr>
<tr>
<td>☐ I am sad all the time.</td>
<td>☐ Bad things are not usually my fault.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 2</th>
<th>Item 9</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Nothing will ever work out for me.</td>
<td>☐ I do not think about killing myself.</td>
</tr>
<tr>
<td>☐ I am not sure if things will work out for me.</td>
<td>☐ I think about killing myself but I would not do it.</td>
</tr>
<tr>
<td>☐ Things will work out for me O.K.</td>
<td>☐ I want to kill myself.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 3</th>
<th>Item 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I do most things O.K.</td>
<td>☐ I feel like crying every day.</td>
</tr>
<tr>
<td>☐ I do many things wrong.</td>
<td>☐ I am not sure if things will work out for me.</td>
</tr>
<tr>
<td>☐ I do everything wrong.</td>
<td>☐ Things will work out for me O.K.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 4</th>
<th>Item 11</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I have fun in many things.</td>
<td>☐ Things bother me all the time.</td>
</tr>
<tr>
<td>☐ I have fun in some things.</td>
<td>☐ Things bother me many times.</td>
</tr>
<tr>
<td>☐ Nothing is fun at all.</td>
<td>☐ Things bother me once in a while.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 5</th>
<th>Item 12</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I am bad all the time.</td>
<td>☐ I like being with people.</td>
</tr>
<tr>
<td>☐ I am bad many times.</td>
<td>☐ I do not like being with people many times.</td>
</tr>
<tr>
<td>☐ I am bad once in a while.</td>
<td>☐ I do not want to be with people at all.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 6</th>
<th>Item 13</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I think about bad things happening to me once in a while.</td>
<td>☐ I cannot make up my mind about things.</td>
</tr>
<tr>
<td>☐ I worry that bad things will happen to me.</td>
<td>☐ It is hard to make up my mind about things.</td>
</tr>
<tr>
<td>☐ I am sure that terrible things will happen to me.</td>
<td>☐ I make up my mind about things easily.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Item 7</th>
<th>Item 14</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ I hate myself.</td>
<td>☐ I do not like myself.</td>
</tr>
<tr>
<td>☐ I do not like myself.</td>
<td>☐ I like myself.</td>
</tr>
<tr>
<td>☐ I look O.K.</td>
<td>☐ There are some bad things about my looks.</td>
</tr>
<tr>
<td>☐ I look ugly.</td>
<td>☐ I look ugly.</td>
</tr>
</tbody>
</table>

Remember to fill out the other side.
Remember, describe how you have been in the past two weeks.....

**Item 15**
- □ I have to push myself all the time to do my schoolwork.
- □ I have to push myself many times to do my schoolwork.
- □ Doing schoolwork is not a big problem.

**Item 16**
- □ I have trouble sleeping every night.
- □ I have trouble sleeping many nights.
- □ I sleep pretty well.

**Item 17**
- □ I am tired once in a while.
- □ I am tired many days.
- □ I am tired all the time.

**Item 18**
- □ Most days I do not feel like eating.
- □ Many days I do not feel like eating.
- □ I eat pretty well.

**Item 19**
- □ I do not worry about aches and pains.
- □ I worry about aches and pains many times.
- □ I worry about aches and pains all the time.

**Item 20**
- □ I do not feel alone.
- □ I feel alone many times.
- □ I feel alone all the time.

**Remember to fill out the other side**
Appendix 12
State-Trait Anxiety Inventory
**STAI Form Y-1**

Name: _______________________________ Date: __________ S __________

Age: _____________________ Sex: M _____ F ______ T _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel right now, that is, at this moment. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Circle Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel calm</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>2. I feel secure</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>3. I am tense</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>4. I feel strained</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>5. I feel at ease</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>6. I feel upset</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>7. I am presently worrying over possible misfortunes</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>8. I feel satisfied</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>9. I feel frightened</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>10. I feel comfortable</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>11. I feel self-confident</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>12. I feel nervous</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>13. I am jittery</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>14. I feel indecisive</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>15. I am relaxed</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>16. I feel content</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>17. I am worried</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>18. I feel confused</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>19. I feel steady</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>20. I feel pleasant</td>
<td>1 2 3 4</td>
</tr>
</tbody>
</table>

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Published by Consulting Psychologists Press, Inc.
# SELF-EVALUATION QUESTIONNAIRE

**STAI Form Y-2**

Name: ___________________________ Date: _______________

**DIRECTIONS:** A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Almost Never</th>
<th>Sometimes</th>
<th>Almost Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>21. I feel pleasant</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>22. I feel nervous and restless</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>23. I feel satisfied with myself</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>24. I wish I could be as happy as others seem to be</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>25. I feel like a failure</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>26. I feel rested</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>27. I am &quot;calm, cool, and collected&quot;</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>28. I feel that difficulties are piling up so that I cannot overcome them</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>29. I worry too much over something that really doesn't matter</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>30. I am happy</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>31. I have disturbing thoughts</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>32. I lack self-confidence</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>33. I feel secure</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>34. I make decisions easily</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>35. I feel inadequate</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>36. I am content</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>37. Some unimportant thought runs through my mind and bothers me</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>38. I take disappointments so keenly that I can't put them out of my mind</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>39. I am a steady person</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>40. I get in a state of tension or turmoil as I think over my recent concerns and interests</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

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Appendix 13
Self-Perception Profile for Adolescents
INSTRUCTIONS

On the next sheet are some sentences. As you can see from the top of the sheet where it says, “What I am like,” we are interested in what you are like, what kind of a person you are like. This is a survey not a test, so there are no right or wrong answers.

At the top of the first page there is a sample question, marked (a). This question talks about two kinds of teenagers, and we want to know which kind of teenager is most like you.

First, read this sentence and then decide whether you are more like the teenager on the left side, who would rather go to the movies or whether you are like the teenager on the right side, who would rather go to a sports event. Don’t mark anything yet, but decide which kind of teenager is most like you, and go to that side of the sentence.

Now that you have decided which teenager is most like you, decide whether that is only sort of true for you, or really true for you. If it’s only sort of true, then put an X in the box under sort of true, if it’s really true for you, then put an X in the box under really true.

For each sentence, you only mark one box. Sometimes it will be on one side of the page, another time it will be on the other side of the page, but you can only mark one box for each sentence.

Continue with each of the sentences, marking the box that is most true for you.
<table>
<thead>
<tr>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
<th>Sample Sentence</th>
<th>Really True for Me</th>
<th>Sort of True for Me</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>Some teenagers like to go to movies in their spare time BUT other teenagers would rather go to sports events.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers feel that they are just as smart as others, their age BUT other teenagers aren’t so sure and wonder if they are as smart.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers find it hard to make friends BUT for other teenagers it’s pretty easy.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers do very well at all kinds of sports BUT other teenagers don’t feel that they are very good when it comes to sports.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers are not happy with the way they look BUT other teenagers are happy with the way they look.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers feel that they are ready to do well at a part-time job BUT other teenagers are not quite ready to handle a part-time job.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers feel that if they are romantically interested in someone, that person will like them back BUT other teenagers worry that when they like someone romantically, that person won’t like them back.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers usually do the right thing BUT other teenagers often don’t do what they know is right.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers are able to make really close friends BUT other teenagers find it hard to make really close friends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers are often disappointed with themselves BUT other teenagers are pretty pleased with themselves.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers are pretty slow in finishing their school work BUT other teenagers can do their school work more quickly.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers have a lot of friends BUT other teenagers don’t have very many friends.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Some teenagers think they could do well at just about any new athletic activity BUT other teenagers are afraid they might not do well at a new athletic activity.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Really True for Me</td>
<td>Sort of True for Me</td>
<td>Really True for Me</td>
<td>Sort of True for Me</td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------</td>
<td>-------------------</td>
<td>---------------------</td>
<td></td>
</tr>
<tr>
<td>Some teenagers wish their body was different</td>
<td>BUT Other teenagers like their body the way it is.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers feel that they don't have enough skills to do well at a job</td>
<td>BUT Other teenagers feel that they do have enough skills to do a job well.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers are not dating the people they are really attracted to</td>
<td>BUT Other teenagers are dating those people they are attracted to.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers often get in trouble for the things they do</td>
<td>BUT Other teenagers usually don't do things that get them in trouble.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers do have a close friend they can share secrets with</td>
<td>BUT Other teenagers do not have a really close friend they can share secrets with.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers don't like the way they are leading their life</td>
<td>BUT Other teenagers do like the way they are leading their life.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers do very well at their classwork</td>
<td>BUT Other teenagers don't do very well at their classwork.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers are very hard to like</td>
<td>BUT Other teenagers are really easy to like.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers feel that they are better than others their age at sports</td>
<td>BUT Other teenagers don't feel they can play as well.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers wish their physical appearance was different</td>
<td>BUT Other teenagers like their physical appearance the way it is.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers feel they are old enough to get and keep a paying job</td>
<td>BUT Other teenagers do not feel they are old enough, yet, to really handle a job well.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers feel that people their age will be romantically attracted to them</td>
<td>BUT Other teenagers worry about whether people their age will be attracted to them.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers feel really good about the way they act</td>
<td>BUT Other teenagers don't feel that good about the way they often act.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers wish they had a really close friend to share things with</td>
<td>BUT Other teenagers do have a close friend to share things with.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers are happy with themselves most of the time</td>
<td>BUT Other teenagers are often not happy with themselves.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some teenagers have trouble figuring out the answers in school</td>
<td>BUT Other teenagers almost always can figure out the answers.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Really True for Me</td>
<td>Sort of True for Me</td>
<td></td>
<td>Really True for Me</td>
</tr>
<tr>
<td>---</td>
<td>--------------------</td>
<td>---------------------</td>
<td>---</td>
<td>--------------------</td>
</tr>
<tr>
<td>29.</td>
<td>Some teenagers are popular with others their age</td>
<td>BUT</td>
<td>Other teenagers are not very popular.</td>
<td></td>
</tr>
<tr>
<td>30.</td>
<td>Some teenagers don't do well at new outdoor games</td>
<td>BUT</td>
<td>Other teenagers are good at new games right away.</td>
<td></td>
</tr>
<tr>
<td>31.</td>
<td>Some teenagers think that they are good looking</td>
<td>BUT</td>
<td>Other teenagers think that they are not very good looking.</td>
<td></td>
</tr>
<tr>
<td>32.</td>
<td>Some teenagers feel like they could do better at work they do for pay</td>
<td>BUT</td>
<td>Other teenagers feel that they are doing really well at work they do for pay.</td>
<td></td>
</tr>
<tr>
<td>33.</td>
<td>Some teenagers feel that they are fun and interesting on a date</td>
<td>BUT</td>
<td>Other teenagers wonder about how fun and interesting they are on a date.</td>
<td></td>
</tr>
<tr>
<td>34.</td>
<td>Some teenagers do things they know they shouldn't do</td>
<td>BUT</td>
<td>Other teenagers hardly ever do things they know they shouldn't do.</td>
<td></td>
</tr>
<tr>
<td>35.</td>
<td>Some teenagers find it hard to make friends they can really trust</td>
<td>BUT</td>
<td>Other teenagers are able to make close friends they can really trust.</td>
<td></td>
</tr>
<tr>
<td>36.</td>
<td>Some teenagers like the kind of person they are</td>
<td>BUT</td>
<td>Other teenagers often wish they were someone else.</td>
<td></td>
</tr>
<tr>
<td>37.</td>
<td>Some teenagers feel that they are pretty intelligent</td>
<td>BUT</td>
<td>Other teenagers question whether they are intelligent.</td>
<td></td>
</tr>
<tr>
<td>38.</td>
<td>Some teenagers feel that they are socially accepted</td>
<td>BUT</td>
<td>Other teenagers wished that more people their age accepted them.</td>
<td></td>
</tr>
<tr>
<td>39.</td>
<td>Some teenagers do not feel that they are very athletic</td>
<td>BUT</td>
<td>Other teenagers feel that they are very athletic.</td>
<td></td>
</tr>
<tr>
<td>40.</td>
<td>Some teenagers really like their looks</td>
<td>BUT</td>
<td>Other teenagers wish they looked different.</td>
<td></td>
</tr>
<tr>
<td>41.</td>
<td>Some teenagers feel that they are really able to handle the work on a paying job</td>
<td>BUT</td>
<td>Other teenagers wonder if they are really doing as good a job at work as they should be doing.</td>
<td></td>
</tr>
<tr>
<td>42.</td>
<td>Some teenagers usually don't go out with the people they would really like to date</td>
<td>BUT</td>
<td>Other teenagers do go out with the people they really want to date.</td>
<td></td>
</tr>
<tr>
<td>43.</td>
<td>Some teenagers usually act the way they know they are supposed to</td>
<td>BUT</td>
<td>Other teenagers often don't act the way they are supposed to.</td>
<td></td>
</tr>
<tr>
<td>44.</td>
<td>Some teenagers don't have a friend that is close enough to share really personal thoughts with</td>
<td>BUT</td>
<td>Other teenagers do have a close friend that they can share personal thoughts and feelings with.</td>
<td></td>
</tr>
<tr>
<td>45.</td>
<td>Some teenagers are very happy being the way they are</td>
<td>BUT</td>
<td>Other teenagers wish they were different.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 14

Definition of Self-Perception Profile for Adolescents subscales
Adolescent Self-Perception Profile: content of each domain

**Scholastic Competence:** This subscale taps the adolescent’s perception of his/her competence or ability within the realm of scholastic performance e.g. how well he/she is doing at classwork, and how smart or intelligent one feels one is.

**Social Acceptance:** This subscale taps the degree to which the adolescent is accepted by peers, feels popular, has a lot of friends, and feels that he/she is easy to like.

**Athletic Competence:** This subscale taps the adolescent’s perception of his/her athletic ability, and competence at sports e.g. feelings that one is good at sports and athletic activities.

**Physical Appearance:** This subscale taps the degree to which the adolescent is happy with the way he/she looks, likes one’s body, and feels that he/she is good looking.

**Romantic Appeal:** This subscale tape teenagers perceptions that they are romantically attractive to those in whom they are interested, are dating the people they would like to be dating, and feel that they are fun and interesting on a date.

**Behavioural Conduct:** This subscale taps the degree to which one likes the way one behaves, does the right thing, acts the way one is supposed to, and avoids getting into trouble.

**Close Friendship:** This subscale taps one’s ability to make close friends they can share personal thoughts and secrets with.

**Global Self-Worth:** These items tap the extent to which the adolescent likes oneself as a person, is happy the way one is leading one’s life, and is generally happy with the way one is. Thus it constitutes a global judgement of one’s worth as a person, rather than domain-specific competence or adequacy.
Log of Research Experience

September 2000 – July 2003
## LOG OF RESEARCH EXPERIENCE

<p>| Research skill/ experience          | Description of how research skill/experience acquired                                                                                                                                                                                                                                                                                                                                                       | Date research skill/experience acquired                  |
|-------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <strong>Conduct a literature search</strong>    | I conducted a number of literature searches relevant to essays, case reports and research studies, as well as clinical cases I was working with, using PsychLit, PsychInfo and Medline. From these experiences I learnt how to select the most relevant articles from the list of references obtained. I also learnt the best way to use keywords in order to obtain a list of the most relevant references.                                                                                                                                       | During years one, two and three of the course             |
| <strong>Critically review the literature</strong>| Each piece of work submitted (essays, case reports and research projects) contained a component involving critical analysis of the relevant literature. Through these experiences I learnt to critically evaluate the usefulness of different literature in relation to a specific question. With regard to research studies I learnt to evaluate different research methodologies in relation to examining specific research questions.                                                                 | During years one, two and three of the course             |
| <strong>Formulate a specific research question</strong> | I formulated specific research questions for my Major Research Project through examining the existing literature relevant to the population which I wanted to study, in order to identify gaps in the existing literature. As well as looking at similar literature in a different population, and consultation with experienced professionals working in the field in which I wanted to carry out the research project. Through this I learnt the importance of developing research questions that had not been answered through previous research, as well as developing focused and clear research questions that could be easily addressed. | During year one and year two                             |
| <strong>Write a brief research proposal</strong> | I did this for both my Service Related Research Project and my Major Research Project, based on the university guidelines. This helped me to focus my initial ideas and develop a broad framework for the research projects, which could be expanded upon later.                                                                                                                                                                                                 | During year one and year two                             |
| <strong>Write a detailed proposal/protocol</strong> | Again I did this for both my Service Related Research Project and my Major Research Project. This taught me the importance of a thorough understanding of the topic and the necessary methods to apply.                                                                                                                                                                                                                                                  | During year one and year two                             |</p>
<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
<th>Time Period</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>I obtained supervision for my Major Research Project from a member of the course team who had interests in child psychology and from a field supervisor who had worked for a long time with the population I intended to research. Both these supervisors were therefore in a position to offer good supervision to the project. I found that I received very different types of supervision from both of them, however, their contributions were both equally important to the project. I also learnt the importance of good collaboration with other members of the medical team working with the research population.</td>
<td>During years one, two and three of the course</td>
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<tr>
<td>Write a participant information sheet and consent form</td>
<td>I did this through supervision with both my research supervisors, who advised what should and should not be included, as well as by looking at information sheets and consent forms from previous trainees and research projects carried out in the hospital where I intended to carry out the research project.</td>
<td>During year one and year two</td>
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<tr>
<td>Judge ethical issues in research and amend plans accordingly</td>
<td>Whilst developing my research project protocol I discussed with both my supervisors what should happen should a research participant indicate levels of psychopathology that were of clinical concern and amended the protocol accordingly.</td>
<td>During year two</td>
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<tr>
<td>Obtain approval from a research ethics committee</td>
<td>Filling out the ethics approval form at the hospital where I planned to carry out my Major Research Project, as well as discussion with my supervisors, gave me a thorough understanding of the types of ethical issues that need to be taken into consideration when planning a research project and how best to address these.</td>
<td>During year one and two</td>
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<tr>
<td>Collect data from research participants</td>
<td>I identified potential research participants for my Major Research Project by looking at the hospital database, which also allowed me to determine when they would be attending clinic. I was therefore able to write to them in advance, so they understood what was involved in the research project and could give informed consent. I was therefore able to collect most of the data by attending weekly clinics. However, for those individuals who were not due to attend clinic during the time the project was being carried out, I arranged to carry out home visits. This taught me the importance of planning ahead and being extremely organized throughout data collection.</td>
<td>During year two and three</td>
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<tr>
<td>Log of Research Experience</td>
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<td><strong>Set up a data file</strong></td>
<td>I did this before I began data collection, whilst I waited for ethics approval. From this experience I further developed my understanding of SPPS and learnt the benefits of being organized early on in the research process.</td>
<td>During year two</td>
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<tr>
<td><strong>Analyse quantitative data</strong></td>
<td>I used qualitative research methods in both my Service Related Project and Major Research Project. I feel that this process furthered my knowledge and understanding of qualitative research methods.</td>
<td>During years one, two and three of the course</td>
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<tr>
<td><strong>Analyse qualitative data</strong></td>
<td>I used this for a group qualitative research project. I had not carried out a qualitative research project before, so this was useful in helping me to appreciate the strengths and drawbacks of qualitative versus quantitative research methods.</td>
<td>During year two</td>
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<tr>
<td><strong>Summarise results in figures/graphs</strong></td>
<td>I did this when writing up my Major Research Project. It taught me how large amounts of information can be presented in a way that is clear and understandable to the reader.</td>
<td>During years one, two and three of the course</td>
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<tr>
<td><strong>Interpret results from data analysis</strong></td>
<td>This was done for all three research projects I carried out during the three years. It taught me the importance of analyzing my results within a framework of existing literature in order to make them meaningful.</td>
<td>During years one, two and three of the course</td>
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<tr>
<td><strong>Present research findings/plans to an audience</strong></td>
<td>This was done with the Service Related Research Project and is planned for the Major Research project. This has highlighted the importance of feeding back the results to the relevant people in order that the findings can be taken into consideration in future service provision.</td>
<td>During year one (Planned for during year three)</td>
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<tr>
<td><strong>Produce a written report on a research project</strong></td>
<td>This was done for all three research projects carried out throughout the course. This process has taught me the importance of writing a report that is clear and concise, yet providing sufficient information that the reader will be able to understand why the research project was carried out, how it was carried out and understand the findings within a framework of existing literature.</td>
<td>During years one, two and three of the course</td>
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<tr>
<td><strong>Defend Research project at an oral examination</strong></td>
<td>This is planned for the viva examination on 12/9/03.</td>
<td>During year three</td>
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<tr>
<td><strong>Submit research report for publication in a book/journal</strong></td>
<td>I plan to rewrite the Major research project for submission to an appropriate journal.</td>
<td>Planned for during year three</td>
</tr>
<tr>
<td><strong>Apply research findings to clinical practice (give examples of 3 papers published during your training which influenced your</strong></td>
<td>I feel that it is important to carry out evidence-based practice and therefore throughout training I would frequently carry out literature searches whenever I took on a new case to find information regarding treatment of their specific</td>
<td>During years one, two and three of the course</td>
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<td>difficulties.</td>
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