The relationship between paediatric asthma severity, maternal illness beliefs and psychological adjustment in mother and child

by

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Volume I

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ACADEMIC DOSSIER
Compare and contrast the evidence base for two different theoretical models of Eating Disorders. What implications does this have for the delivery and provision of clinical services for people with Eating Disorders?"
Introduction

About 0.04% of the population are diagnosed with an eating disorder (ED) every year, although the actual incidence is probably higher (Bell, Clare & Thorn, 2001). Of these, 28.5% are diagnosed with bulimia nervosa (BN), 20% with anorexia nervosa (AN) and 50% with an eating disorder not otherwise specified (EDNOS).

This essay will compare and contrast the evidence base for cognitive-behavioural (CB) models and the interpersonal psychotherapy (IPT) model of anorexia nervosa (AN) and bulimia nervosa (BN). Although the incidence of EDNOS is higher than either AN or BN, this essay will focus only on AN and BN. This is because much of the research into EDs focuses on AN and BN, and because the diagnosis of EDNOS includes individuals with widely differing symptoms (DSM-IV, APA 1994; Walsh & Garner, 1997).

Bulimia nervosa is characterised by the undue influence of body shape and weight on self-evaluation and by recurrent episodes of binge eating involving a sense of lack of control, combined with compensatory behaviours including purging, laxatives, fasting or excessive exercise (DSM-IV, APA 1994). BN has an incidence rate of 0.0114 – 0.0135 per year (Hoek, Bartelds, Bosveld, van der Graf, Limpens, Maiwald & Spaaij, 1995; Turnbull, Ward, Treasure, Jick & Derby, 1996: both cited in Bell et al, 2001).

Anorexia nervosa is characterised by weight loss, an intense fear of gaining weight or of becoming fat, despite actually being underweight, and a disturbance in personal body image (DSM-IV, APA 1994). AN has an incidence rate of 0.004 – 0.01 per year (Hoek et al, 1995; Turnbull et al, 1996: both cited in Bell et al, 2001).

Cognitive-Behavioural Models of Eating Disorders

There are two main CB models for EDs, one for AN (Garner & Bemis, 1982, cited in Cooper, 1997) and one for BN (Fairburn, 1981, cited in Vitousek, 1996; Fairburn, 1985).
According to these models, the central feature of both AN and BN is an over-reliance on shape and weight, which is seen as more controllable than other aspects of life, for self-worth. This interacts with what is often a long-standing tendency for negative self-evaluation, resulting in perpetual dissatisfaction with personal weight and shape (Fairburn, 1997b). Consequently, extreme methods of intense and rigid dietary restriction (mediated by factors such as dichotomous thinking and perfectionism) are used in order to achieve an ‘ideal’ weight. In AN, psychological and physiological aspects of starvation, such as preoccupation with food, eating, weight and shape, the lowering of mood and social withdrawal, increase the focus on weight, shape and eating and maintain the ED. In BN, particularly at times of negative affect, extreme dietary restraint leads to physiological and psychological processes that cause loss of control and binge-eating. Binge-eating temporarily moderates the negative affect but this is short-lived, so purging occurs to expel the calories consumed and reduce post-binge anxiety and guilt. Binge-eating thus increases negative self-evaluation so the person becomes more determined to restrict their eating, resulting in a vicious circle. However, purging is seen as compensating for binge-eating, which means that binge-eating is more likely to occur, establishing another vicious circle. This loss of control also increases negative self-evaluation. (Anderson & Maloney, 2001; Cooper, 1997; Fairburn, 1997b)

In addition, Wilson (1999) and Fairburn, Shafran and Cooper (1999) have suggested a new CB account of the maintenance of AN, in which the key issue is one of self-control.

**Interpersonal Psychotherapy Model of Eating Disorders**

The basic premise of IPT, a brief, structured form of psychotherapy, is that eating disorders are caused by many things, but that interpersonal factors are important in both onset and maintenance. Treatment focuses not on beliefs or symptoms involving weight or eating but rather on interpersonal issues (Palmer, 2000).
IPT maintains that there are four key areas of possible interpersonal difficulties, and that by identifying and working on an individual’s own areas of interpersonal difficulty it is possible to treat the ED. The four key areas identified by IPT are interpersonal disputes (situations in which a significantly distressing conflict arises from the patient’s differing expectations of a situation from others’ expectations), role transitions (situations in which the patient has difficulty in adapting to changes in life circumstances), grief (which refers only to loss through death), and interpersonal deficits (in which patients have poor interpersonal relationships in terms of both number and quality) (http://www.interpersonalpsychotherapy.org).

At present IPT has only been considered as a treatment for BN, although a study is underway to look at its use in AN (http://www.interpersonalpsychotherapy.org).

Types of Evidence

There are two main types of evidence that are relevant when looking at theoretical models of eating disorders. The first is evidence that either supports or refutes various elements of the model itself, and the second it evidence for whether treatment based on the theoretical models is effective. By looking at both of these types of evidence it is possible to compare and contrast CB and IPT models. Both CBT and IPT have been researched, at least to some extent, for BN, but the evidence in AN is less prolific.

Evidence Looking At Elements of the Cognitive-Behavioural Model

If CB models of EDs are valid, then it can be assumed that evidence will support individual elements of the models. This section will outline the evidence currently available.

Many studies have supported the idea that patients with EDs are preoccupied with thoughts about food, eating, weight and shape, and have more negative weight-related cognitions and self-statements than controls (M.J. Cooper & Fairburn, 1992a; Phelan,
1987; Zotter & Crowther, 1991: all cited in Cooper, 1997). Patients with EDs have also been shown to place an over-reliance on extreme, rigid concepts of weight and shape to organise their world and when thinking about both themselves and others (Butow, Beumont & Touyz, 1993; Button, 1983; Fransella & Button, 1983; Mottram, 1985: all cited in Vitousek, 1996). Negative weight-related self-schema may also influence attention, perception and memory (Vitousek & Hollon, 1990; Vitousek & Orimoto, 1993: both cited in Porzelius, Berel & Howard, 1999).

Studies show that patients with EDs frequently have a negative self-schema, possibly predating the ED, that they have lower self-esteem than controls, and that self-esteem is a better predictor of the presence and severity of AN than family functioning (Cooper, Todd & Cohen-Tovée, 1996; Erol, Yazici, Erol & Kaptanoglu, 2000; Fairburn, Cooper, Doll & Welch, 1999; Teasdale & Barnard, 1993, cited in Garner, Vitousek & Pike, 1997). Negative body image may predict severity of the ED and play an important role in its development (Cash & Grant, 1996; Rosen, 1990; Thompson, 1992: all cited in Williamson, Muller, Reas & Thaw, 1999).

A causal relationship has been demonstrated between underlying assumptions, self-statements and eating behaviour, particularly dietary restraint (M.J. Cooper, D.M. Clark & Fairburn, 1993, cited in Cooper, 1997). It has also been shown that, in BN, 12-month post-treatment outcome is predicted by levels of attitudinal disturbance immediately post-treatment (Fairburn, Peveler, Jones, Hope & Doll, 1993, cited in Cooper, 1997), although P.J. Cooper & Steere (1995, cited in Cooper, 1997) failed to replicate these findings.

Studies have found that patients with EDs often have dysfunctional thinking styles such as dichotomous reasoning and perfectionism (Button, 1993, cited in Palmer, 2000; O'Connor & Dowrick, 1987, cited in Turk, 1993; Thompson, Berg & Shatford, 1987; Franko & Zuroff, 1992: Zotter & Crowther, 1991; all cited in Cooper, 1997) and that cognitions in AN tend to be self-defeating and extreme (O'Connor & Dowrick, 1987, cited in Turk, 1993). Personality features associated with restricting AN, such as perfectionism, obsessionality, rigidity & need for self-control (Smart, Beumont & George, 1976; Strober, 1981: both cited in Bulik, 1998), support these
ideas of dysfunctional thinking styles. However, personality characteristics related to
BN women are impulsivity, disorganisation, and affective lability (Bulik, Beidel,
Duchmann, Kaye & Weltzin, 1992; Casper, Hedeker & McClough, 1992: both cited in
Bulik 1998), which suggests that different factors may be relevant in BN.
Studies have supported the idea that affect is involved in binge-eating (Laberg,
BN, negative affect often precedes the binge-purge cycle (Hsu 1990; Kaye,
Gwirtsman, George, Weiss & Jimerson, 1986; Zotter & Crowther, 1991: all cited in
has also been shown to lead to reduction in negative mood states including depression,
anger, boredom, shame and anxiety (Lingswiler, Crowther & Stephens, 1989;
However, M.J. Cooper et al (1993, cited in Cooper, 1997) found that, in experimental
conditions, dietary restraint in BN patients did not result in binge-eating.

Overall, these studies show significant support for some, but certainly not all,
elements of the CB models. In addition, the validity and reliability of some of the
studies reported is questionable (Cooper, 1997; Vitousek, 1996). Therefore in order to
fully evaluate CB models, more work needs to be done to examine whether all of the
individual elements of the model are valid, and to look at whether differences in AN
and BN, such as personality type, has any impact on the validity of the models.

Evidence Looking At Elements of the IPT Model

Fairburn, Jones, Peveler, Carr, Solomon, O'Connor, Burton & Hope (1991) and
Fairburn, Jones, Peveler, Hope & O'Connor (1993) studied 99 patients with BN and
found that, of the four areas of potential interpersonal difficulties specified in IPT,
‘grief’ was present in 12%, ‘interpersonal disputes’ in 64%, difficulties with ‘role
transitions’ in 36%, and ‘interpersonal deficits’ in 16%.

Although at present there are not many studies directly researching individual
elements of the IPT model, evidence exists from work based on other theoretical
models of EDs that supports various elements of the model, although mainly in terms of BN and not AN.

Several studies support ‘interpersonal disputes’ as an important area of difficulty in EDs, although mainly relating to unexpressed rather than overt conflict, particularly in AN (Tiller, Sloane, Schmidt, Troop, Power & Treasure, 1997, cited in Porzelius et al, 1999; Banas, Januszkiewicz-Grabias & Radziwillowicz, 1998, cited in Gordon, 2000; Minuchin, Rosman & Baker, 1978, cited in Gordon, 2000). Feelings of ineffectiveness and poor interperceptive awareness (both of which may be related to interpersonal disputes) are also risk factors for adolescents with AN (Lyon, Chatoor, Atkins, Silber, Mosimann & Gray, 1997).

In terms of ‘role transitions’, studies have found that the onset of BN coincides with an excess of life events, (which may mean changes in life circumstances and role), in the previous year (Welch, Doll & Fairburn, 1997, cited in Palmer, 2000), that patients with BN report more stressful life events than controls (Raff, Rondini, Grandi & Fava, 2000) and that life events may play a part in AN (Gowers, North, Byram and Weaver, 1996, cited in Palmer, 2000).

The relative rarity of ‘grief’ as an important interpersonal factor (Fairburn, Jones et al, 1993) may explain why grief and its role has not received much investigation in AN and BN.

‘Interpersonal deficits’ is probably the area that has so far received the most empirical support. Studies have shown that patients with EDs have inadequate social support and elevated levels of interpersonal conflict (Grissett & Norvell, 1992; Herzog, Keller, Lavori & Ott, 1987; Tiller et al, 1997: all cited in Porzelius et al, 1999). BN patients have been show to have poorer social functioning, fewer emotionally supportive relationships, a lower quality of heterosexual relationships and to report more negative social interactions than controls and BN patients in remission (Chinnoy, 1996; Rorty, Yager, Buckwalter & Rossotto, 1999; Raff et al, 2000; Reiss & Johnson, 1995). Patients with AN that has not responded well to treatment have been shown to have
significant difficulties with family and social relationships (Steinhausen & Glanville, 1983)

In addition, there is a wide range of evidence relating to interpersonal factors in EDs that doesn’t fall neatly into any of the four categories, but that nevertheless provides support for the model in terms of the importance of interpersonal factors in ED onset and duration. For example, studies of ED patients have found a high incidence of family history of depression, alcoholism and EDs (Gershon, Schreiber, Hamovit et al, 1983; Kaye, Lilienfeld, Plotnikov et al, 1996; both cited in Bulik, 1998; Lyon et al, 1997) and a higher incidence of sexual abuse in women with BN compared to the overall population (24% to 50%: Bulik, Sullivan & Rorty, 1989; Pope & Hudson, 1992: both cited in Bulik, 1998), although this is similar to rates in the general psychiatric population (Bushnell et al, 1992, cited in Bulik, 1998).

Fairburn (1997a) postulated that IPT works for BN in four ways including: increasing self-actualisation beliefs; improving mood and self-esteem, leading to reductions in the reliance on shape and weight for self-worth; by social activity increasing and interpersonal stressors decreasing, leading to less opportunities and reasons to binge eat. Therefore, studies showing deficits in these areas in BN patients may also provide support for the IPT model of BN. For example, Keller (1998) found that BN patients had a weaker sense of coherence, (possibly related to self-efficacy and locus of control) than controls, and low self-esteem has been found to be a risk factor for developing an ED (Button, Sonuga-Barke, Davies & Thompson, 1996; Fairburn et al, 1999: both cited in Palmer, 2000).

Overall, although various studies show some support for interpersonal difficulties in EDs and for individual elements of the IPT model, the evidence for these is, as yet, still unclear, with some studies seeming to contradict elements of the model (e.g. ‘interpersonal disputes’ in AN). It may also be the case that the IPT provides a good model for BN but not for AN. For example, it has been suggested that families of BN patients may be more overtly dysfunctional than families of AN patients (Bulik, 1998), and studies have shown that women with BN perceive their families as more hostile, conflictual, isolative, depriving and disorganised and less nurturing and
empathic than AN patients (Humphrey, 1986; Johnson & Flach, 1985; Strober, 1981: all cited in Bulik, 1998). Therefore, in order to fully evaluate the IPT model, more work needs to be done in examining whether the individual elements of the model are valid.

**Treatment Based On Cognitive-Behavioural Models**

There is a broad evidence base supporting cognitive-behavioural therapy (CBT) as an effective treatment for BN, although the evidence for its effectiveness in AN is less conclusive.

Studies have shown that, for BN, CBT is superior to no treatment or waiting list controls (Wolf & Crowther, 1992, cited in Wilson, 1996; Freeman, Barry, Dunkeld-Turnbull & Henderson, 1988, cited in Cooper, 1997) and to other psychotherapies, such as supportive psychotherapy (Agras, Schneider, Arnow, Telch, Raeburn, Bruce & Koran, 1989, cited in Wilson, Fairburn & Agras, 1997), supportive-expressive therapy (Garner, Rockert, Davis, Garner, Olmsted & Eagle, 1993, cited in Wilson et al, 1997), and exposure plus response prevention (Cooper and Steere, 1995, cited in Ricca, Manucci, Zucchi, Rotella & Faravelli, 2000). CBT either with or without antidepressant drug treatment is superior to medication alone, and combining CBT and medication produces no, or only small, improvements to CBT alone (Agras, Rossiter, Arnow, Schneider, Telch, Raeburn, Bruce, Perl & Koran, 1992; Leitenberg, Rosen, Wolf, Var, Detzer & Srebnik, 1994; Walsh, Wilson, Loeb, Devlin, Pike, Roose, Fleiss & Wateraux, 1997: all cited in Ricca et al, 2000). CBT has also been shown to be more acceptable to patients than medication and has a lower drop-out rate (Wilson & Fairburn, in press, cited in Wilson et al, 1997).

Other studies have shown that as well as overall outcome, CBT has positive effects on most specific aspects of BN. For example, Anderson & Maloney (2001) carried out a review of sixteen studies to determine the effect of CBT on the five core symptoms of BN. They found that, on average, CBT reduced binge-eating by 75%, compensatory behaviour by 78%, and restrictive eating by 57% (although only seven of the studies
provided acceptable measures of restraint). They also found some evidence that CBT reduced body dissatisfaction in terms of concern with body shape and weight (although there was also evidence from some studies for a continued raised level of body dissatisfaction compared to controls), and three out of five studies that measured self-esteem reported a significant increase in self-esteem. Overall they found that the evidence generally supported the efficacy of CBT for BN, although the strength of this evidence varied depending on the assessment measures used.

Another review, by Fairburn, Agras & Wilson (1992, cited in Wilson et al, 1997), concluded that of the best controlled studies of CBT treatment of BN to date then, there was a mean reduction in binge eating from 73% - 93%, a mean reduction in purging from 77% - 94%, a mean remission in binge eating of 51% - 71%, and a mean remission in purging from 36% - 56% (Agras et al, 1989; Agras et al, 1992; Fairburn et al, 1991; Garner et al, 1993: all cited in Wilson et al, 1997).

CBT also has been shown to have wider effects on the associated psychopathology of BN – for example, leading to improvements on measures of depression, self-esteem, social functioning and personality disorder (Fairburn, Kirk, O' Connor & Cooper, 1986; Fairburn et al, 1992; Garner et al, 1993: all cited in Wilson et al, 1997)

However, it has been suggested that for both BN and AN, manual based CBT is less effective in affecting the key issue of shape and weight concern than in eliminating behavioural symptoms such as binge-eating, purging and restrictive dieting, which is how treatment effectiveness is usually measured (Walsh et al, 1997, cited in Wilson 1999; Wilson, 1999). Therefore it may be that CBT treatment studies of EDs do not offer as much support to the CB model as they might initially seem to.

Looking at AN, various researchers have suggested that there are strong theoretical reasons for using CBT (Pike et al, 1996, cited in Wilson, 1999). However, there is a dearth of controlled treatment studies for AN – by 1996 there were only five controlled studies of psychotherapy for AN (Vitousek 1996). Of those studies that exist, the results are generally poor – Channon, de Silva, Hemsley & Perkins (1989, cited in Wilson, 1999) found no difference between CBT, BT and an eclectic control
treatment in terms of weight gain and psychosocial functioning at six- and twelve-month follow-up, and Ball (1998, cited in Wilson, 1999) found no difference between CBT and behavioural family therapy (BFT) at six-month follow-up. However, the fact that sample sizes were small means that only limited conclusions can be drawn (Wilson, 1999).

Overall, the evidence supports CBT as beneficial in EDs, and, certainly in BN, as superior to other treatments. However, even with CBT, only an average of 50% of BN patients 'recover' (Wilson, 1996), leaving much scope for improvements.

**Treatment Based On the Interpersonal Psychotherapy Model**

All of the studies looking at IPT treatment for EDs have compared it with CBT, which will be covered later in this essay. However, the fact that CBT for BN often focuses on interpersonal factors (O'Leary & Wilson, 1987, cited in Wilson et al, 1997), that interpersonal themes are explicitly integrated into descriptions of CBT for AN (Garner, 1988; Garner & Bemis, 1982, 1985; both cited in Garner et al, 1997), and that the resolution of family and interpersonal problems has often been seen by ED patients as vital in their recovery (Hsu, Crisp & Challender, 1992, Rorty, Yager & Rossotto, 1993: both cited in Garner et al, 1997; Morgan, 1988, cited in Jarman & Walsh, 1999), supports the notion that IPT may have some role to play in the treatment of EDs.

**Studies Comparing Treatment using CBT and IPT**

There are three relevant studies directly comparing CBT and IPT treatments for BN, but at present there are no results from similar studies of AN.

Fairburn et al's (1986) study compared CBT with short-term focal psychotherapy, which was similar to IPT in mainly focusing on interpersonal difficulties. Both
treatments resulted in significant improvements, but overall CBT was superior to short-term focal psychotherapy.

Fairburn et al (1991) and Fairburn et al (1993) replicated and extended Fairburn et al’s (1986) study, treating seventy-five BN patients with either CBT, behavioural therapy (BT) or IPT and comparing them immediately post-treatment and at twelve-months follow-up. All three treatment modalities involved nineteen fifty-minute outpatient sessions over eighteen weeks.

Immediately post-treatment, all three groups had significantly reduced the frequency of objective and subjective bulimic episodes (mean = 93%) with no differences between the groups in percent abstaining. CBT was more effective than IPT in terms of reducing dietary restraint, reducing vomiting, and improving eating attitudes, but they resulted in similar percentages ceasing vomiting. All three treatments resulted in similar improvements in the level of general psychiatric symptoms and social adjustment.

At one-year follow-up, the CBT and IPT groups had maintained the reduction in frequency of objective and subjective bulimic episodes and purging, and the IPT group percentage had improved non-significantly. Levels of reduction in dietary restriction, decrease in the levels of general psychiatric symptoms and increase in self-esteem were also maintained in the CBT and IPT groups. There were no significant differences between the CBT and IPT groups. On most measures, CBT was also superior to BT immediately post-treatment and at follow-up both CBT and IPT were significantly better than BT.

The patients from these trials (Fairburn et al, 1986; Fairburn, Jones et al, 1991; Fairburn, Jones et al, 1993) were followed up by Fairburn, Norman, Welch, O’Connor, Doll & Peveler (1995). They compared the long-term (mean of 5.8 years) outcome of CBT, BT and Focal Interpersonal Psychotherapy (FIT – the name given for focal psychotherapy and IPT in the two trials). At follow-up, there was no significant difference between CBT and FIT in terms of percent with an ED (CBT 37%, FIT 28%) and percent who were abstinent from binge-eating and purging (CBT...
50%, FIT 52%). However, patients treated using CBT did have a lower level of symptoms on the Eating Disorder Examination than patients treated using FIT. The outcome of the BT group was significantly worse than either the CBT or the FIT groups.

Agras, Walsh, Fairburn, Wilson & Kraemer (2000) treated 220 BN patients with nineteen fifty-minute sessions of either CBT or IPT over twenty weeks, evaluating them immediately post-treatment and at one-year follow-up. They found that, immediately post-treatment, CBT was significantly superior to IPT in terms of percent recovered (CBT 29%, IPT 6%), percent remitted (CBT 48%, IPT 28%) and percent who met community norms for eating attitudes and behaviours (CBT 41%, IPT 27%), as well as percent of treatment-completers who had reduced binge-eating (CBT 86%, IPT 51%), purging (CBT 84%, IPT 50%) and dietary restraint. There was no difference between CBT and IPT in terms of weight and shape concerns, self-esteem and interpersonal functioning. However, at one-year follow-up, no significant differences were found between CBT and IPT on any measures, with 40% of CBT and 27% of IPT having recovered. Overall between post-treatment and follow-up, the CBT group had a tendency towards maintenance of recovery or slight relapse, whereas the IPT group had a tendency to continued improvement.

Overall, these studies show that, for BN, CBT is quicker than IPT at reducing primary behavioural symptoms. However, in the long-term, CBT and IPT are equally effective, in terms of reducing behavioural symptoms and in improving psychiatric symptoms, self-esteem and interpersonal functioning.

IPT is also being extended for use with patients with AN, and a trial is currently being carried out to compare the efficacy of CBT, IPT and specialist supportive care for outpatients with AN (www.interpersonalpsychotherapy.org/eating_disorders.htm). At present there is no data on the results of this study.
Summary

Overall, the evidence supports both the CB and the IPT theoretical models of EDs in terms of BN, although the evidence for these as models of AN is more patchy. At present the evidence base for CB models is better than that for the IPT model, but this can be explained by the fact that IPT is a relatively recent development in terms of treatments for EDs. Since both models are primarily models of maintenance, it is possible AN and BN are maintained by factors as described in both CB and IPT models. While CB models focus on attitudes to weight and shape and behavioural symptoms and IPT models focus on interpersonal difficulties, the long-term outcomes of treatments using the models is similar. It is thus postulated that CBT works by improving eating habits and attitudes, which leads to improved interpersonal functioning, whereas IPT works by improving interpersonal functioning, which leads to improvements in eating habits and attitudes (Fairburn, 1993). However, although the models are postulated to work in opposite ways, the suggested treatment structure is similar for both, relying on approximately nineteen outpatient sessions over eighteen to twenty weeks. However, to fully evaluate these models, and thus to be able to effectively compare and contrast them, more research needs to be done, particularly in terms of IPT treatment and model elements in general and for CB model elements and treatment for AN.

Implications for the delivery and provision of clinical services for people with eating disorders

The results of the aforementioned studies have several implications in terms of delivery and provision of clinical services for people with AN and BN.

The main implication is related to the fact that, although CBT and IPT had similar long-term outcomes for BN, CBT was much faster-acting than IPT. This means that in, terms of service provision, CBT should probably still be seen as the treatment of choice for BN (Fairburn, 1997a), as faster-acting in general equates to more cost-
effective. In addition, the fact CBT and IPT have similar long-term outcomes means that, although IPT may offer an alternative treatment strategy to CBT, it is unlikely to lead to a reduction in chronic cases and hence unlikely to be any more cost-effective than CBT. Since CBT and IPT have similar efficacy rates, the introduction of IPT to ED services is unlikely to reduce the number of inpatient admissions and tertiary services required (e.g. 5-10% needing tertiary care: Saleh 1999).

Another implication is related to the differences between AN and BN. In BN, weight gain is not a major aim of treatment, but in AN it is, and delaying weight restoration in AN may detrimentally affect long-term outcome (Nozoe, Soejima, Yoshioka et al, 1995; Zipfel, Lowe, Reas, Deter & Herzog, 2000: both cited in Bell et al, 2001). This means that IPT, which in BN takes longer to act on behavioural factors, may not be suitable for AN where immediate weight gain is of primary importance. However, conversely, IPT, in which the focus is not on weight and shape but rather on interpersonal issues, may be more acceptable to patients with AN, who are often reluctant to engage in treatment that focuses on weight gain. Therefore, in patients with AN in which immediate weight gain is not such a pressing priority, or in patients who are particularly difficult to engage in CBT, IPT could be seen as another treatment option.

IPT may also be useful in treating other difficult-to-engage groups, such as patients with BN and insulin-dependent diabetes mellitus (Peveler & Fairburn, 1992, cited in Fairburn, 1997a).

A third implication is that, since the two treatments are postulated to work in diametrically opposite ways but result in similar long-term outcomes, it may be quicker and more cost-effective to work on elements of both treatments at once. Although it is not possible to directly combine the two styles of treatment, as CBT works directly on the eating disordered behaviour and attitudes and IPT directs the focus away from this, it may be possible to combine the treatments in other ways, such as by expanding CBT to include more of an interpersonal focus (Wilson et al 1997) or combining IPT with self-help CBT manuals (Fairburn, 1997a; Treasure, Troop & Ward, 1996).
It may also be useful to attempt to ‘match’ patients to treatments, in order to improve treatment efficacy (Fairburn, 1997). For example, offering CBT when BN symptoms are maintained mainly by behavioural symptoms (i.e. the restriction-purge-binge cycle), and offering IPT when emotional and interpersonal factors seem strongly related to eating behaviour (Meyer, Waller & Waters, 1998, cited in Ricca et al, 2000).

Another implication may be related to the different populations that present with EDs, such as adolescents. Robin, Gilroy & Dennis (1998) report good results in using adolescent-modified IPT for BN, stating that the “here and now” focus of IPT may appeal to adolescents “whose lives revolve around their interpersonal relationships with peers, perhaps giving IPT an edge with this hard to engage population”. Family therapy (FT) is recommended for adolescents with AN (Eisler, Dare, Russell, Szmukler, le Grange & Dodge, 1997; Robin, Siegel, Moye, Gilroy, Dennis & Sikand, 1999; both cited in Bell et al, 2001) and may be useful for adolescents with BN (Dodge, Hodes, Eisler & Dare, 1995, cited in Dare & Eisler, 1997). IPT may be seen as compatible with this, where the FT emphasis is on interpersonal issues within the family and when the family is not seen as a whole, enabling the patient with the ED to be treated individually with IPT.

A final implication is related to the possibility of group therapy. Various studies have demonstrated that group therapy can be effective for BN, with improvements being maintained at one-year follow-up (Fettes & Peters, 1992), group therapy for AN has been seen as useful in improving interpersonal relationships (Hall, 1985; Polivy, 1981: both cited in Pyle, 1999), and group IPT and group CBT have been shown to have similar long-term outcomes for binge-eating disorder (50% and 55% reduction in number of days binged at one year) (Wilfley, Agras, Telch, Rossiter, Schneider, Cole, Sifford & Raeburn, 1993). Since group therapy is likely to be more cost-effective than individual therapy in terms of numbers of clinicians required, investigating group CBT and IPT may be important in terms of service provision.
REFERENCES


www.interpersonalpsychotherapy.org/eating_disorders.htm
Should people with autism and a learning disability go on holiday? What role might a clinical psychologist have in the decision making process? Discuss with reference to aspects such as consent, the specific impairments of people with autism, equal opportunities, etc.

July 2003

Year 1
Introduction

Autism is defined as an developmental impairment in social interaction and communication, and a restricted repertoire of repetitive and stereotyped patterns of behaviour, interests and activities (APA, 1994).

Approximately 0.05%-0.1% of the population are estimated to be autistic (Bryson, 1996; Fombonne, 1997). Of those, approximately 75% will have an associated learning disability (LD), (APA 1994; Happe, 1994; Rutter et al, 1994), defined as a significant impairment in intellectual functioning (with an IQ score below 70) and in adaptive/social functioning, beginning before adulthood (APA (1994). 50% will have a severe learning disability, with an IQ score below 50 (Howlin, 1998).

There are several key issues when deciding whether a person with autism and a LD should go on holiday. The first is that people are all individuals and should be treated as such, regardless of their autism or LD: “Just as every person is different, every person with autism is different, and so no single treatment program works well for all people with autism” (Holmes, 1998, p.28). Thus, what is appropriate for one person may be inappropriate for another, and clinical psychologists, with their emphasis on seeing people as “unique individuals” (BPS, 1994), have an important role to play in this decision-making process. However, the same key issues relate to all individuals with autism and a LD and a potential holiday, although the outcome may be different for each person.

Leisure

Various researchers have advocated the consideration of leisure needs as important for people with LDs and autism (Dattilo & St. Peter, 1991). For example, studies have suggested that social and leisure roles can provide stimulation (American Therapeutic Recreation Association - ATRA, 1985, cited in Dattilo & Schleien, 1994), increase self-esteem (ATRA, 1985, cited in Dattilo & Schleien, 1994; Beart, Hawkins, Stenfert-Kroese, Smithson & Tolosa, 2001; Hogg, 1993), provide opportunities to
acquire factual knowledge and cognitive skills (Beart et al, 2001), support a learning curriculum (Voeltz, Wuerch & Wilcox, 1982, cited in Dattilo & St. Peter, 1991), promote good mental health (Dattilo & Schlein, 1994), encourage healthy lifestyles (DoH, 2001a), and enhance a person’s quality of life, which is related to self-esteem and negative and positive affect (DoH, 2001a; Hogg, 1993; Holmes, 1990; Voeltz, Wuerch & Wilcox, 1982, cited in Dattilo & St. Peter, 1991). Most autistic adults have large amounts of leisure time but lack the skills to use this time constructively (Kraus, 1978; Wehman, 1983; both cited in Mesibov & Schaffer, 1986). A holiday could therefore be used as an opportunity to expand and practice a person’s leisure skills and interests.

One major role for a clinical psychologist could be in deciding whether the person needed any specialised leisure and recreation training, as advocated by Chinn & Joswiak (1981, cited in Dattilo & Schleien, 1994), Dattilo & St. Peter (1991), Meldrum (1990), and Mesibov & Schaffer (1986), before a decision about whether they should go on holiday was made. As part of this, the person’s leisure preferences, needs, motivations and aspirations could also be explored (Howe-Murphy & Charboneau, 1987; Montagnes, 1976: both cited in Dattilo & St. Peter, 1991).

For most people, a holiday would be seen as leisure time, and thus enjoyable. However, it is questionable whether this would be true for a person with autism and a LD. Therefore, the specific deficits and needs of a person with autism and a LD also need to be taken into account.

Communication

Difficulties in communication are a major impairment in autism, with studies showing that 50% of children with autism and pervasive developmental disorders don’t use verbal language as their primary means of communication (Prizant, 1996) and that the 50% of people with autism and an IQ of less than 50 are unlikely to develop any useful speech (Howlin, 1998).
This means that it may be difficult to explain to a person with autism and a LD key factors about a holiday such as what would happen, when and where it would happen, and who it would happen with, as well as the fact that they have a choice in whether it happens. (APLD, 1995). It may also be difficult for the autistic person to express any questions, fears or thoughts they have about the idea of a holiday or about being on holiday. Lack of language also means that the person would have no effective means of internal thought, making it difficult for them to reflect on the information presented to them (Jordan & Powell, 1996).

In addition, autistic people’s verbal expression may be better than their comprehension (Howlin, 1997; Green, Fein, Joy & Waterhouse, 1995) and many autistic people are echolalic (Elliot, 1990; Howlin, 1997). This may lead people to over-estimate the person’s abilities, thinking that the person understands more than they do, and are consenting when they are not. Echolalia is also likely to increase when people are distressed or anxious, (Rydell & Mirenda, 1994, cited in Howlin, 1998), which may happen when a person is put in a new situation or presented with information they do not understand. Poor comprehension may, in turn, lead to anxiety and distress and an apparent lack of co-operation (Howlin, 1998).

In particular, autistic people have difficulties with abstract language and following complex sequences of instructions or information (Howlin, 1998). This means that talking about something that a client may never have experienced before, such as a holiday, can be particularly difficult.

Many autistic people comprehend information better in a visual rather than a verbal format (APLD, 1995; Lockyer & Rutter, 1970; Ohta, 1987; Prior & Ozonoff, 1997; Venter, Lord & Schopler, 1992). Thus, one role for a psychologist may be in deciding whether enough information about a holiday can be given to the client visually so that they have some understanding of it.

A clinical psychologist, together with a speech and language therapist, could have a key role in assessing the person’s communication and understanding, in order to decide whether the client was able to understand any information given and what the
best way of presenting this information would be. This could involve both formal psychological assessments as well as observations and meetings with other staff.

**Routine**

Most people enjoy holidays because they offer a change from the routine and a chance to have new experiences. However, an autistic person may not see this change as positive. People with autism are unable to make connections between things, generalise, understand the overall purpose of activities or negotiate meanings in the same way as other people (Jordan & Powell, 1996). This manifests as an “apparently inflexible adherence to specific, non-functional routines or rituals” (APA, 1994). Autistic people are therefore often obsessive about their physical environments staying the same (APLD, 1995; Handleman, 1999; Kanner & Eisenberg, 1956), and various authors have suggested a structured, predictable environment is important for the autistic person in helping them to order and understand what seems to them chaotic and terrifying (Grandin, 1990; Holmes, 1998; Jolliffe, Lansdown & Robinson, 1992, cited in Howlin, 1998; Mesibov, Schopler & Harshey, 1994). Having a LD compounds these difficulties as not only do all situations have to be learnt afresh, but also all learning is hard (Jordan & Powell, 1996). Thus, a holiday may be particularly difficult for a person who is both autistic and has a LD.

Due to these difficulties, disrupting an autistic person’s routines and environment may cause stress and anxiety. This may lead to an increase in aggression and self-harm, as expressions of this anxiety, and stereotyped and repetitive behaviours which help the autistic person to impose some order on their life and thus reduce their anxiety (APLD, 1995; Howlin, 1998; Jordan & Powell, 1996; Runco, Charlop & Schreibman, 1986). These possibilities, and the risks associated with them, need consideration. Anxiety also reduces behavioural flexibility for all humans (Jordan & Powell, 1996). Due to the change in environment and routines an autistic person on holiday is likely to be more anxious, and therefore even less flexible than usual. This reduced flexibility would lead, in turn to increased anxiety about the change.
However, not all autistic people are reliant on such rigid routines and environments, (APA, 1994), and for these people, a break to their routine may not be so difficult. For some people, it may not be the routines themselves that are so important, but rather the predictability afforded by them (Howlin, 1997). For these people, a clinical psychologist could help by devising ways of helping the person predict the change, such as calendars with visual representations (Howlin, 1998). Other autistic people may be distressed by minor changes to their routines but not by a complete change, such as would happen on a holiday, as it would not mean changing any of the routines or environments that have particular meaning for them (Jordan & Powell, 1996). In addition, for some people a holiday may be beneficial, as environmental change can sometimes be used as a catalyst to alter problematic routines (Howlin, 1998).

Therefore, one of the roles of a psychologist may be to assess what rituals and routines a person had that were important to them, how modifiable these rituals and routines were, (perhaps by using some small behavioural experiments in which routines are changed), and what impact changing these routines would have on the person.

Fixations

Having ‘fixations’, an “encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus” (APA, 1994) is another possible feature of autism. However, rather than being seen as a difficulty needing to be overcome, these ‘fixations’ could be used as a focus in planning a holiday for a person with autism and an LD. For example, several authors have recommended directing fixations into constructive activities (Simons, 1974; Akerly, 1974: both cited in Grandin, 1987) and using them to motivate people in learning new skills (Grandin, 1987, 1990). In this way, a holiday could be beneficial for the person, in allowing them to spend time focusing on their fixation while expanding the fixation into a wider scope of interest and activities.
Generalisation

Another issue is autistic people's difficulty in generalising across situations (Elliot, 1990; Handleman, 1981; Wrestling & Floyd, 1990: both cited in Handleman, 1999; Olley & Gutentag, 1999), which Rincover & Koegal (1975) suggest may be due to learning tasks based on idiosyncratic rather than relevant cues. This means that when placed in a different situation, such as would happen on holiday, the autistic person may appear to 'lose' skills that they had previously mastered. Thus, one role for a clinical psychologist may be in helping to decide the extent to which the person is able to generalise their skills and thus to predict whether going on holiday would mean the person's functioning being too severely affected (Handleman, 1999). A clinical psychologist could also help to decide what support the person would need while on holiday in order to retain as many skills as possible.

Social Interaction

The impairments in social interaction present in people with autism may also cause some difficulties (APA, 1994). For example, lack of social awareness may lead to disturbed or disruptive and inappropriate behaviours in public (Happe, 1994; Howlin, 1998). This may be problematic when the person with autism is in a new environment and is consequently meeting new people who may not know how to react.

Time Lapse

People with autism often have difficulties with understanding time lapse, such as what 'in two weeks' signifies or the difference between 'soon', 'in an hour' and 'next week', and in understanding sequences (APLD, 1995; Clements & Zarkowska, 2000; Howlin, 1997). This means that they may have difficulty in understanding the concept of a holiday as something that will happen in the future, and in understanding that it will only happen for a specified time period. They may also have difficulty in
predicting what will happen when. Consequently the autistic person may feel very anxious as they may be expecting an imminent event that does not happen immediately. Thus, another role of a clinical psychologist may be in deciding when would be the most appropriate time to give the person information about the holiday. For example, it has been suggested that information about an event should only be given to people with autism and an LD close to the event (APLD, 1995).

Consent

Policies concerning working with people with disabilities are increasingly promoting the importance of consent (DoH, 2001a; Wong, Clare, Gunn & Holland, 1999). However, although it is important to allow people to make decisions for themselves when they have the ability to do so, it is also important to protect them from potentially harmful consequences when they do not (Brock, 1994, cited in Arscott, 1997).

According to English law, for consent to be valid, a person has to be capable of making the decision, must be acting voluntarily, and must have enough information to make the decision (BPS, 2001; DoH, 2001b). Having a learning disability does not immediately preclude this capacity, and capacity is assumed unless demonstrated otherwise (DoH, 2001c). No-one is able to give consent for another adult, but “Where an adult is ... not capable of giving consent ... the professional must act in the best interests of the client.” (BPS, 2001; DoH, 2001b).

In order to make the decision, the person has to be capable of understanding and remembering the information, manipulating it to come to a decision, appreciating the personal significance of the information, and communicating their decision (Berg, Appelbaum & Grisso, 1996; Law Commission, 1995; Weisstub, 1990: all cited in Wong, Clare, Gunn & Holland, 1999). All of these may be difficult for a person with autism and a learning disability.

Information given to the person must be appropriate, and they must be able to understand what is involved, the benefits and risks, the implications, and the
alternatives (BPS, 2001; DoH, 2001c). Thus one role of a clinical psychologist would be in deciding whether the person was able to understand the information, and how best to present it to ensure they understood it.

If a person is able to give valid consent, then they also have the right to make almost any decision regarding their own body or health, even if it is not in their best interests (Menard, 1997; BPS, 2001; DoH, 2001b). Thus, they would have the right to decide whether or not to go on holiday, regardless of the potential consequences for themselves.

However, a person should not be excluded from having any new experiences, which could include going on holiday, solely because they are unable to give valid consent. If a person is unable to consent then the role of the professional becomes one of deciding whether the proposed experience is "in the best interests of the client." (BPS, 2001). Even if it is decided that the person has no capacity, their views should be considered as far as possible (Wong et al, 1999), although it has been argued that in some circumstances consent should not be sought, when the person is judged to have an impaired capacity to consent and when their likely decision would not be in their own best interest (Sandford, Gralton & Donovan, 2001).

So, one key role for a psychologist would be in helping to decide whether the person had the capacity to give valid consent. (DoH, 2001c). The most commonly used approach to assess capacity is the functional approach. Using this, a clinical psychologists role would be to assess the extent to which the person’s understanding, knowledge and skills mean they are able to make the decision (Grissso, 1986, cited in Wong et al, 1999; Jackson, 1994; White, 1994: both cited in Arscott, 1997). However, capacity to consent may vary according to the decision needing to be made, and capacity should be judged in relation to the importance of the decision (Fulbrook, 1994, cited in Brennan, 1997). Therefore a clinical psychologist should not only carrying out standardised assessments for overall understanding, but also specific assessments looking at the person’s capacity to decide whether or not to go on holiday (Marson, Cody, Ingram & Harrell, 1994; Grisso & Appelbaum, 1998; both cited in Wong et al, 1999; Arscott, Dagnan & Stenfert-Kroeze, 1999). This may involve
adapting standardised questionnaires to fit the needs of the assessment (Arscott, 1997). It would be important to be aware of specific difficulties that might impair a person’s ability to consent, such as the tendency towards acquiescence and suggestibility in people with LDs (Arscott, Dagnan & Stenfert-Kroese, 1999). While making any decisions about capacity, it is important for the clinician “be aware of own beliefs and adopt a structured approach to minimise the impact of their own value systems” (Law Commission, 1991, paragraph 2.44, cited in Wong et al, 1999).

**Choice**

Another important issue is that of choice, i.e. is the person in question able to choose whether they want to go on holiday or not and what does this choice mean. Government literature and various authors support giving people with LDs choice over their activities and involvement in decision-making processes about their lives (Browder, 1991; DoH, 2001a; O’Brien, 1987, cited in Myers, Ager, Kerr & Myles, 1998).

In addition, several studies have shown that giving people choices about their activities can reduce social avoidance behaviours (Koegel, Dyer and Bell 1987; Dyer 1989; both cited in Holmes, 1998), reduce problem behaviours (Dyer, Dunlap & Winterling, 1990), increase task performance (Parsons, Reid, Reynolds and Bumgarner 1990, cited in Mithaug & Mar, 1980), increase spontaneous interaction (Dyer, 1987; Peck, 1985: both cited in Dyer, Dunlap & Winterling, 1990), and improve language learning (Koegel, Koegel & Surratt 1992, cited in Holmes, 1998). It is suggested that these positive benefits may be related to the perception of control, and indeed, people with autism seem to be more motivated on self-chosen task compared to other-chosen tasks, even when neither task is preferred (Vaughn & Horner, 1997), suggesting that making a choice may be empowering in itself (Caldwell & Hoghton, 2000). Thus, letting people have some involvement in choosing whether to go on holiday or not would generally be seen as beneficial.
In addition, as leisure is generally taken to be an activity that a person is free to choose and enjoys (Meldrum, 1990), for a person to have a real ‘holiday’, they must be able to choose it (Cavet, 1989, cited in Hogg, 1993; Reynolds, 2002).

However, choice-making can be stressful and complex for many people, particularly those with a LD (Fischoff, Slovic & Lichtenstein, 1980; Jenkinson, 1993: both cited in Carnaby, 1997; Caldwell & Hoghton, 2000). In order to make a valid choice the person must be able to understand the choices offered, and being offered choice without this understanding may be very distressing for the person (Caldwell & Hoghton, 2000). Most people with autism have difficulty in understanding abstract concepts, and a so a person who had never been on holiday would have difficulty in making a choice about something they had never experienced such as a holiday. Offering this choice may then be extremely anxiety-provoking (Morgan, 1996). Thus the person may refuse a holiday because they do not understand the concept and it is something new, rather than being based on a real understanding (Holmes, 1998). Thus, one role for a clinical psychologist would be in deciding whether the person is able to make a valid choice, and whether offering them this choice would be too anxiety-provoking for them. However, it must also be understood that learning to make responsible choices is a process, and one that people need to practice in order to improve (Bannerman, Sheldon, Sherman, James & Harchik, 1990, cited in Hogg, 1993; Stalker & Harris, 1998).

Equal Opportunities, Normalisation, Social Role Valorisation and Person Centred Planning

The question can also be addressed from the viewpoint of equal opportunities and normalisation. Most people enjoy going on holiday, financial circumstances allowing. Equal opportunities would thus suggest that people with autism and a LD should be given the opportunity to go on holiday, as “all people have the same human value” (BPS, 1994). This idea has been mainly promoted through the normalisation principle (Nirje, 1969, cited in Mesibov, 1990) The aim of normalisation is to provide people
with a LD with the same range of opportunities as other people (Elliot, 1990; Walmsley, 2001).

However, although the aim may be to provide people with LDs and autism as ‘normal’ a lifestyle as possible, it is also important to be realistic and acknowledge that a person’s difficulties may place limitations on their functioning and what is appropriate for them, and each client needs to be assessed individually (Mesibov, 1990). For example, structured leisure time is often seen as ‘not normal’, but people with autism may find lack of structure difficult and it may result in behavioural difficulties. Thus, the person’s lifestyle should take into account their behavioural needs (Elliot, 1990), with normalisation not being seen as an end in itself (Throne, 1975, cited in Mesibov, 1990), but rather as a way to facilitate the development of the person with a LD. As such, normalisation is about normalising environments and experiences, not about making people ‘normal’ (Wolfensberger, 1980, cited in Meldrum, 1990), and about helping the person to fulfil their potential as far as possible (Henley, 2001; Mesibov, 1990; Williams & Nind, 1999).

This individuality of people is at the heart of the government’s latest initiative in LD services, person centred planning (Kingston & Richmond PCTs, 2002). This places the person with a LD at the centre of the planning process, to look at what is important for them, their capacities and choices, and the support they need (Kingston & Richmond PCTs, 2002; Sanderson, 1997), with the aim of improving their quality of life (Sanderson, Jones & Brown, in press).

It has also been found that if people with LDs are associated with people without LDs, they tend to acquire positive imagery and role expectancies, with other people seeing them as having socially valid roles (Wolfensberger, 2000) This may be possible on holiday, particularly if the holiday involves being a member of the general community (e.g. staying in a hotel, participating in activities with people without LDs) with only a small number of other people with LDs (Meldrum, 1990).

Thus, one role for a clinical psychologist would be in balancing the idea of equal opportunities and normalisation with the specific needs of the person with autism and
a learning disability, and deciding whether promoting the 'normal' experience of going on holiday would be beneficial for the person, in providing them with the same opportunities and experiences as other people, or detrimental for them in terms of their specific difficulties.

Co-morbidity

Another issue is the co-morbidity of medical and psychiatric problems in autism, which may mean that additional factors need to be considered when deciding the suitability of different types of holidays and activities. For example, various studies have shown that rates of epilepsy are higher in people with autism and a LD than in the general population, with an average of 16.7%-1/3 estimated to develop epilepsy by adulthood (Fombonne, 1997; Gillberg, 1991; Sturmey & Sevin, 1994). If the person in question is epileptic, this then brings with it additional considerations such as the risk of seizures, which may possibly have no warning (Elliot, 1990) and the side-effects of medication.

It has also been suggested that some psychiatric disorders may be more common in people with LDs than in the general population (DoH, 2001a) and that people with autism may be more vulnerable to developing affective disorders (Clarke, Baxter, Perry & Prasher, 1999; Lainhart & Folstein, 1994).

Other studies have suggested higher rates of medical and organic disorders such as Fragile-X syndrome (Reiss & Freund, 1990, cited in Sturmey & Sevin, 1994) tuberous sclerosis (Gillberg, Steffenberg & Jakobsson 1987, cited in Sturmey & Sevin, 1994; Smalley, 1998), hyperlactosemia (Coleman & Blass, cited in Sturmey & Sevin, 1994), Gilles de la Tourette syndrome (Baron-Cohen, Scahill, Izaguirre, Hornsey & Robertson, 1999), and neurofibromatosis (Gaffney, Kuperman, Tsai, Minchin & Hessanein 1987, cited in Sturmey & Sevin, 1994) in people with autism or a learning disability compared to the general population, and Gillberg & Coleman, 1995, cited in Wainscott & Corbett, 1996) estimated that over a third of people with autism had an additional medical condition, although the known rate is estimated at 10% (Rutter,
Bailey, Bolton & LeCouter, 1994). In general, the lower the IQ of the person, the higher the likelihood there is of having additional diagnoses (Olley & Guttentag, 1999).

None of these disorders themselves preclude a person with autism and a LD from going on holiday, but rather mean that there may be additional factors, such as medical care, needing to be considered in the decision making process.

**Risk Assessment**

Risk-assessment is another important area to consider, and psychologists can play an important role in this. Risk-assessment refers to assessing the risk of issues such as aggression, self-injurious behaviour (SIB), and elopement, all of which could potentially be very harmful to the client or others, as well as the risk of entering new situations, and the potential benefits and drawbacks of this (Morgan, 2000).

People with LD and co-morbid autism display more maladaptive behaviours, in both quantity and severity, than people with just a LD (Bodfish, Symons, Parker & Lewis, 2000; Kraijer, 2000), and those with lower IQs show more severe challenging behaviours (Poustka & Lisch, 1993). Just under 10% of the autistic population and around 15-20% of adults with learning disabilities show SIB, with adults with a LD and autistic symptoms being more likely to express SIB (http://www.autismuk.com/index3sub3.htm~demo; Collacott, Cooper, Branford & McGrother, 1998). It is recommended that SIB is managed using a consistent response and by maintaining a basic routine, which may not be possible when going on holiday (Elliot, 1990). Elopement, or running away, is also a potential risk (Debbandt, 2002). This behaviour may not be significantly problematic in the person’s home environment, where safeguards have been put into place and others are aware of where the client may go if they elope. However, in a new environment elopement could pose serious risks to the client such as drowning, being run over or being at risk of harm from others.
It has been suggested that challenging behaviours have various functions – to indicate the need for help or attention, to escape from stressful situations or activities, to obtain a desired object, to protect against unwanted events or activities, to express frustration (e.g. at not understanding or being understood), and to obtain stimulation (Durand & Carr, 1991; Durand & Crimmins, 1988: both cited in Howlin, 1998; Freeman, 1998). Any situation which provokes anxiety or distress may result in challenging behaviour, and challenging behaviours which the client no longer exhibits may re-occur in times of stress (Elliot, 1990). Therefore a holiday may be seen as potentially too ‘dangerous’ for a client, even if they consent to going, due to the risk posed by their challenging behaviours. However, studies have shown that providing alternative sensory stimuli can, to some extent, reduce SIB (Favell, McGimsey & Schell, 1982; Smith, 1986; Smith & Belcher, 1992; all cited in Datlow-Smith & Philippen, 1999) and the right holiday may be able to offer this.

However, it has also been suggested that part of the duty of care is to take risks, in order for people to learn and be empowered through choice, and that it is impossible to avoid all risks or make 100% accurate predictions (Alaszewski, Alaszewski, Ayer & Manthorpe, 2000; Perske, 1972: both cited in Alaszewski & Alaszewski, 2002; Morgan, 2000; Vinestock, 1996). Going on holiday could thus be seen as an important learning experience for the client.

One role for a clinical psychologist in the decision-making process may be carrying out a functional analysis of behaviour (Marzillier & Hall, 1999) to see what situations trigger anxiety and distress in the person and what the person’s response to this is, as challenging behaviour is likely to increase when a person is anxious and distressed (Debbandt, 2002). The psychologist would also need to assess whether current behaviour-management techniques would continue to be effective when the client was more anxious and unsettled, as may happen in the new situation of being on holiday (Datlow-Smith & Philippen, 1999), and what support the person would need in managing their behaviour (Elliot, 1990). To fully assess risk, the psychologist would also need to look at the potential long-term risks to the client if the holiday was not successful, such as increased resistance to change, and balance this with the potential benefits of going on holiday.
Role of a Clinical Psychologist

Overall, it can be seen that a clinical psychologist could have several roles in the decision-making process. One key role would be in carrying out psychological assessments, such as psychometric tests, observations, and rating scales, to look at the client's strengths, weaknesses and needs (Handleman, 1999; Marzillier & Hall, 1999; http://www.nhscareers.nhs.uk/nhs-knowledge_base/data/5094.html). As well as giving a useful understanding of the client and their abilities, this could impact on the practical considerations of going on holiday such as who the person should go with, how far the person should go, and the level of support needed (Meldrum, 1990). A clinical psychologist may also provide support, advice and consultancy to other staff involved in the decision-making process (BPS, 1994). As previously stated, a clinical psychologist may also be involved in looking at specific issues relevant to the decision, such as the person's communication abilities and flexibility.

Conclusion

From looking at the issues, it can be seen that it is not possible to make an overall decision about whether people with autism and a learning disability should go on holiday, as each person is an individual and has different strengths, weaknesses, needs and circumstances. Ideally, the person should be given the opportunity to go on holiday, if it will not be potentially damaging for them. However, in order to decide this, each person needs to be individually assessed, and a clinical psychologist would have a major role in this decision-making process.
References


http://www.autismuk.com/index3sub3.htm~demo

http://www.nhscareers.nhs.uk/nhs-knowledge_base/data/5094.html
Critically discuss any two psychoanalytic concepts that a Clinical Psychologist might use to enhance their understanding and practice in work with children

December 2003

Year 2
The two psychoanalytic concepts focused on in this essay are containment (Bion, 1959) and splitting of the object (Klein, 1946).

**Splitting**

Splitting is a concept mainly attributed to Klein (1946), although it was originally defined by Freud (1927, cited in Baleman & Holmes, 1995) as the simultaneous holding of different ideas or a contradiction between reality and wishful fantasy. Klein (1946) sees splitting as a primitive defence engaged in during the paranoid-schizoid position that predominates during the infant's first three months of life in normal development. According to Klein, infants possess a rudimentary ego from birth, whose primary function is to manage anxiety. During the paranoid-schizoid position the infant is unable to perceive either himself or others as whole person so is able only to relate to part-objects (parts or aspects of objects) rather than whole objects. He also suffers severe anxiety about persecution. To avoid the anxiety of persecution and to try and make sense of what he sees as a chaotic world, the infant splits his world into 'good' and 'bad' experiences and hence splits objects into 'good objects' and 'bad objects'. The first example of this is the breast, which is perceived as a part-object on its own and is then split by the infant into the 'good breast' and the 'bad breast'. These two categories are kept entirely separate by the infant, who can then experience the good, loving, providing breast without having to be vulnerable to the bad, persecutory, denying breast, and without contaminating the 'good breast' with his rage towards the 'bad breast'. As the infant is unable to hold both good and bad objects in mind together, he does not experience any sense of absence, loss or regret, because if the 'good' is missing the infant feels it as something 'bad' rather than the absence of something 'good', and rather than relief at the removal of something bad the infant simply feels that there is 'good' rather than 'bad'. As the infant is unable to hold both good and bad objects in mind together, once the infant is distressed he finds it very difficult to be comforted as he is unable to hold in mind the good objects in his environment (Shuttleworth, 1989). Splitting of the object also leads to a corresponding splitting of the baby's ego, such that good parts of the ego are held separate from bad parts of the ego (Klein, 1946)
As a result of splitting, the infant is able to develop a sense of self, by taking in the 'good' object as the basis for this without the dread of immediate annihilation that would come if the infant also had to take in the 'bad' object. The infant is also able to begin the process of loving and trusting. However, on the opposite side, splitting also means that at times the infant may introject the 'bad' object and hence feel that he is totally evil. When this happens the infant then suffers from a strong persecutory anxiety and feels that he will be destroyed by a malevolent force, which partially arises externally and partially from the death instinct which the infant has projected onto others which is then returned. This is very traumatic for the infant and may result in the infant either splitting further in order to cope with it or attacking part of himself in a destructive death instinct. It is this further splitting that is thought to sometimes lead to the extreme fragmentation of psychosis (Klein, 1946, cited in Gomez, 1997).

Although splitting predominates during the first three months of life, it is also sometimes used later on in life. For example, people may 'split' in order to suspend their emotional distress to help them come to a decision, to make moral choices, or to form an intellectual judgement (Segal, 1975, cited in Baleman & Holmes, 1995; Radomisli, 1981).

**Containment**

Bion (1959) is normally credited with developing the container-contained model, although other theorists have discussed similar concepts (Winicott, 1960; Bick, 1968; Anzieu, 1989: all cited in Britton, 1992).

When young, the infant is unable to process his own emotional experiences. The infant thus projects into the mother those feelings that he finds intolerable (beta elements). The mother receives this projected terror while she is in a "maternal reverie", a state of mind in which she is able to receive the infant's projections, processes these elements, and returns them in a more tolerable and structured form that she has constructed (alpha elements). The infant then internalises, or introjects, both these more elaborated and structured meanings and the mother's ability to
contain them. Consequently, the infant slowly develops the ability to contain his own feelings (Bion, 1962a; Bion, 1962b; Segal, 1975, cited in Baleman & Holmes, 1995).

Being 'contained' gives the infant a sense of having safe and secure boundaries and gives meaning and internal coherence to thoughts (Bion, 1962b). Containment is therefore seen as necessary in order for the infant to develop the capacity to think and make sense of his own experience as well as to think about the minds of others, to tolerate frustration and to be curious about the world and hence to learn (Bion, 1959; Fonagy, 1995, cited in Barrows, 1999; Watts, 1999).

If the mother is unable to contain the infant's feelings the infant will attempt to project his feelings more forcefully onto the mother. If she is still unable to accept these projections the infant will introject an object that cannot accept projections and he will also be forced to reintroject his unbearable and unmodified feelings (Bion 1962a; Eskelinen-de-Folch, 1988; Segal, 1975, cited in Baleman & Holmes, 1995). Being an effective container is emotionally draining on the mother, as she is forced to experience the terrible emotional experiences that the infant is unable to cope with. If the mother is unable to cope with this she may try to defend her own mental state by getting rid of this mental discomfort by perceiving the infant's painful projections as deliberate attempts to damage and destroy her (Bion, 1962a).

Bion (1970, cited in Hinshelwood, 1987) identified three types of container-contents relationships, with the 'contents' being the child's projected emotional experiences. The first is when the container and contents are able to accommodate each other – the mother who is able to effectively contain the child and its projected emotions, meaning that both the mother and the child are able to develop and grow. The second is where the container overwhelms and crushes the contents – the mother who is unable to feel properly for her child and constantly disconfirms, dismisses or explains away her child's emotions. The third is where the contents explode the container – the mother is so overwhelmed by the infant's feelings that she becomes exhausted, depressed and unable to function as a containing mother (Hinshelwood, 1987). Only the first type of relationship leads to the child being able to re-introject both his modified terror and the ability to contain this terror. In the second type, the child
would introject an object that is unable to think about his feelings as well as introjecting the idea that his feelings are not valid. In the third type, the child would introject the idea that his feelings are too terrible to be contained as well as introjecting the guilt of having destroyed the object he projected them into.

Although theories about containment tend to stress the mother as the figure of primary importance, the father is also seen as important in containing the mother to enable her to be more free to contain the infant (Britton et al, 1989, cited in Britton, 1992).

It has been suggested that there is a link between containment and splitting, in that a lack of containment reduces the child's ability to integrate, thereby leading to disintegration and more splitting (McGregor-Hepburn, 1992).

**Criticism**

The concepts of containment and the concept of splitting have been criticised from both within and outside the psychodynamic literature.

Much of the evidence for splitting comes from adult psychotic and borderline patients, who tend to see others as all good or all bad and selves as all powerful or as totally inadequate and worthless (Britton, 1992; Grinker, 1977, cited in Radomisli, 1981). From these patients, Klein speculatively theorised backwards to what might be occurring during infants' early development, and supplemented this with infant observation and general reasoning and ideas about what is plausible. For example, a baby's screaming and kicking when distressed may be seen as the baby's attempts to rid itself of unwanted and unbearable distressing feelings.

It is not possible to either 'prove' or 'disprove' Klein's concepts of the paranoid-schizoid and depressive positions using infant observations or experiments, since it is extremely difficult and possibly impossible to access the thoughts and feelings of infants (Bott-Spillius, 1993). However, Anna Freud was sceptical about Klein's suggestion that defence mechanisms such as splitting start so early in life, although
she did agree that defence mechanisms begin at some point in childhood. Whereas Klein believed that the infant related to others from birth, and hence from birth had a primitive ego requiring defence mechanisms to protect it from anxiety, Anna Freud believed that the ego only developed gradually as the infant developed and hence that the beginnings of defence mechanisms were also delayed (Likeirman & Urban, 1999). Winicott (1962) also criticised Klein’s concept of early splitting, believing that the infant initially does not have strong enough ego-organisation and ability to separate from the mother to be described without the mother, and doubting whether the infant could split objects into ‘good’ and ‘bad’ before its ego-organisation is strong enough to distinguish benign and persecutory objects.

Some critics agree that splitting is a feature of some psychiatric difficulties such as schizophrenia and borderline personality disorder, but suggest that splitting does not represent a normal developmental stage (Radomisl, 1981). Other critics, while agreeing that splitting is a normal developmental stage, assert that splitting continues to be an important strategy that the child consistently uses for a much longer period that Klein suggests. For example, Bettleheim suggests that children use splitting to make sense of what they see as a chaotic world well into the Oedipal period of three to six or seven years (Bettleheim, 1977, cited in Radomisl, 1981). However, this has also been directly criticised by other theorists such as Mahler and Kernberg who assert that integration is usually complete by three years and state that there is no evidence for children of six or seven having difficulties with ambivalence (Mahler, 1975; Kernberg, 1975: both cited in Radomisl, 1981).

There does not appear to be a significant literature criticising the concept of containment. However, in terms of interventions, critics from outside the psychodynamic models point to the fact that there is currently insufficient evidence for the effectiveness of any forms of psychodynamic child psychotherapy for any of the common childhood complaints (Wolpert, Fuggle, Cottrell, Fonagy, Phillips, Pilling, Stein & Target, 2002). Nevertheless, and despite some disagreement from within the psychodynamic literature about the validity of the concept of splitting in particular, there is enough evidence to suggest the concepts of both containment and
splitting can be useful when thinking about and working psychologically with children and adolescents.

The use of splitting when working with children

The progression from splitting to integration may be very difficult for a child, as with integration comes a fear of loss and a feeling of mourning for the lost idealised object, as well as guilt for the aggressive impulses which have been directed at the ‘bad’ object which the child now realises is part of the ‘good’ object. These feelings mean that the child may be unable to sustain the integration brought about during sessions and may at times return to dealing with split objects, possibly oscillating between these two positions within a single session (Hirschhorn, 1988, cited in Prins, 2001; Steiner, 1992). Therefore understanding splitting, and the oscillation between these two states, could help the clinical psychologist understand why the child at times seems able to think and integrate and at other times appears to regress to a dichotomous way of thinking. It is also important as it can help the clinical psychologist to understand why at times the child may appear to idealise the psychologist while at other times the child may appear to hate the psychologist, without the two views of the psychologist being integrated to any great extent (Feldman, 1992).

It is also important to understand splitting in terms of transference. Children are likely to relate to the psychologist in the same way that they relate and related to their primary caregivers. Therefore if the child has a relationship with their mother characterised by splitting, it is likely that splitting will be an important feature of the child’s relationship with the psychologist (Ingram, 2000)

Splitting may also be a feature of the way the child relates to the clinical psychologist and their parents together. To avoid the difficulty of facing the fact that those closest to him, i.e. his parents, can be both ‘good’ and ‘bad’, and hence that he can both love and hate them, the child may split this goodness and badness and idealise the psychologist while denigrating his parents. It is important to be aware of this
possibility as it may result in a ‘rivalry’ arising between the parents and the psychologist, with the parents feeling demoralised and as though the psychologist is trying to be a ‘better parent’ than them (Lanyado, & Horne, 1999). If this seems to be occurring, one task of the clinical psychologist may be to help the child be able to express both positive and negative feelings towards those they love, such as their parents. Alternatively, some children may idealise their parents and be unable to bear the possibility of their vulnerability or failings. This can lead to children blaming themselves for their parents failings and any difficulties with their parents (Hughes, 1999). If these circumstances, one task of the clinical psychologist may be in helping the child come to a more realistic understanding.

Children may also split amongst the whole team, perceiving some team members as ‘good’ and others as ‘bad’ (Lanyado & Horne, 1999). This is more likely to occur if several members of the team are working with the family, and may lead to team conflict that can be destructive to the team. This therefore highlights the importance of open communication between team members in order to expose and counteract this as much as possible.

One role of a clinical psychologist in child work may therefore be to help the child explore issues related to splitting. It has been suggested that one way of doing this may be through play therapy, in which the child is able to act out the idea of ‘goodies’ and ‘baddies’, keeping things apart and bringing things together (Ingram, 2000).

The use of containment when working with children

The idea of containment in the mother-infant relationship can be seen as analogous to the process within the psychologist-client relationship whereby the client uses the psychologist’s containing capacity to learn to contain his own intolerable feelings (Lafarge, 2000). Winicott (1960) hypothesised that the disturbed child unconsciously uses projection to try to re-enact the early containment processes with the psychologist in order to improve on his early containment experiences (Winicott, 1960, cited in Watts, 1999). In this way, the clinical psychologist can be used by the child as a way
of developing a more containing internal object. It has also been suggested that if the child’s mother is unable to contain the child, then the child may develop an inner phantasy object of a father or father-figure as a ‘rescuer’, to rescue him from his relationship with his mother. This may mean that an uncontained child is more likely to perceive the psychologist as a potential ‘rescuer’ figure and idealise the psychologist (Gerrard, 1992).

It is very important when working with children that the psychologist helps the child to feel contained. If the child feels that the psychologist is able to perceive, contain and talk about his intolerable feelings, without being overwhelmingly shocked, distressed or angered, then the child will also begin to be able to perceive, contain and talk about these feelings (Eskelinen-de-Folch, 1988; Lanyado & Horne, 1999). Part of helping the child feel contained may involve practical issues, such as seeing the child at the same time in the same place on a regular basis, and this needs to be considered when planning work with children (Ingram, 2000). If the containing process is disrupted by the psychologist being unable to understand the child’s feelings or being unable to communicate this understanding, or if the psychologist seems to be closed and unresponsive to the child’s feelings, the child may try to force the psychologist to understand and contain his feelings by escalating his projections (Baleman, & Holmes, 1995; Britton, 1992).

The idea of containment is important in understanding how well a child is able to think about and relate to the world. According to Fonagy and Target (1996), in order for a child to be able to reflect on both his own and others’ mental states, he must have experienced and adult ‘thinking about his thinking’ – i.e. imagining what the child is thinking and reflecting this back to him in a contained but more elaborated form.(Fonagy & Target, 1996). Where the mother is unable to contain her child’s emotions it is likely that the child will not have experienced this, and therefore the child may have great difficulty in thinking about his own thinking and reflecting on this. Therefore one task of a clinical psychologist in these circumstance may be to help the child learn to reflect on his own and other’s mental states, by thinking and talking about the child’s thinking.
In order to effectively contain her child, the mother may be in need of containment herself (Shuttleworth, 1989). In some instances, this may be easily available to the mother, for example by the child’s father or the mother’s own parents. When this is not available the mother may then be unable to contain her child effectively. Therefore it is useful to bear in mind that one function of a clinical psychologist may be to contain the mother in order that she is then able to contain her child.

Bion (1959, 1962b) also discussed how a lack of containment in the mother-infant relationship can sometimes lead to an ego-destructive superego – a part of the person that is opposed to themselves. This can mean that the child will find integration particularly difficult (Shuttleworth, 1989).

**When are splitting and containment particularly useful concepts?**

Containment is a concept that may be useful to think about with various presentations. For example Britton (1992) described how an uncontained client may try to get rid of their alpha states by carrying out actions to physically remove them, such as repeatedly washing, flushing the lavatory or disposing of rubbish – all of which may suggest to the clinician a diagnosis of obsessive compulsive disorder. It has also been suggested that failing to meet a child’s dependency needs, which could in some cases be due to a failure in containment, can predispose the child to depression. This is due to self-directed anger or self-hatred directed towards the introjected lost object for abandoning the child (Freud, 1917, cited in Carr, 1999). The concept of containment may also be important when working with victims of trauma and looking at children’s adaptation to trauma, as the ability to process painful experiences is dependent on the child having a sense of containment (Hughes, 1999). Hence, those children who have not experienced a containing relationship may find it particularly difficult to cope with trauma. Containment may also be useful in thinking about those children who seem to sabotage or spoil any good experiences they have. This can be seen as the effect of being uncontained and having introjected a ‘bad’ internal object, and may be particularly important when working with children in foster-care who seem to sabotage even the most positive and accepting fostering environments (Ingram, 2000).
Containment is a particularly useful concept to think about when working with children with psychotic mothers, where there are likely to be particular difficulties in the mother’s ability to contain her child’s feelings (Hopkins, 1992). Where the mother’s mind is occupied with delusional thoughts, she is unable to contain her child’s feelings and is therefore unable to transform those feelings into something more manageable for the child. Without this, the child is exposed to extreme panic and anxiety. Psychotic mothers tend not only to be unable to contain their child’s feelings but also have a very limited capacity for containing their own feelings, which often results in them projecting their own feelings violently into the child rather than being able to accept the child’s own projected feelings. This quickly becomes terrifying for the child. Rather than internalising an object capable of containment, the child will internalise a psychotic object. Watts (1999) has suggested that this can lead to the child having difficulties in containing and processing their libidinal and aggressive anxieties. In addition, if the child continually uses the psychologist to project their terrifying internal states onto, this can provoke a need for the child to split as the psychologist object has become a ‘bad’ object containing all the ‘bad’ projected parts of the child. When working with children of psychotic mothers, it is also important to be aware that the psychologist’s ability to contain the child can be disrupted by the violence of the child’s projections into the psychologist which are due to the child’s psychotic internal object (Hopkins, 1992).

Containment and splitting are also useful to think about when working with conduct problems and delinquency. When children feel contained, they develop a sense of inner safety and coherence, where they are able to trust and relate to people and to accept the constraints necessary for socialisation. However, when children do not feel contained they tend to feel betrayed by their parent’s failure to protect them from their primitive anxieties and from disintegration. This results in them mistrusting others, feeling resentful and on-guard and being disinclined to comply with social constraints. Delinquency can be seen as an attempt to defend against these primitive anxieties by projecting their feelings onto others by acting in a way that makes others feel as the delinquent does, and as an expression of the resentment they feel (Wilson, 1999).
Punitive or neglectful parenting can lead children to split and internalise their experiences of being parented into the ‘good, caring parent’ and the ‘bad, punitive or neglectful parent’, with little integration. When these children interact with someone they experience a positive transfer towards and see as ‘good’ they will identify them with the good parent and act morally towards them, but when they interact with someone they experience a negative transfer towards and see as ‘bad’ they will identify them with the bad parent and act immorally towards them. A residential group-based treatment setting is seen as the most appropriate with these children, to help them integrate their good and bad introjections and internalise societal rules (Carr, 1999).

When working with abused children and parents who have abused their children, containment is again an important concept to consider. If parents have themselves not experienced a containing relationship as an infant and child, then they are likely to have a poorly developed psychological or reflective self, and hence are likely to find it difficult to respond in an emotionally containing way towards their child (Fonagy, Steele, Steele, Higgitt & Target, 1994, cited in Carr, 1999). This may lead to a poor early attachment between the child and its parents, and this is a significant predictor for child emotional abuse and neglect. Thus one role for a clinical psychologist in these circumstances may be in promoting the attachment relationship by providing a containing environment for the parents so that they are able to begin to contain their child.

Splitting can also be a particularly useful concept to think about when working with children with early-onset psychosis, as splitting is a central feature in psychosis. In these circumstance, splitting is seen as a fragmentation that occurs as a result of disintegrative splitting (Bott-Spillius, 1993; Steiner, 1992).

**Working with Groups**

It is also useful to have an understanding of the concept of splitting and containment when working with young people in group settings, for example in groupwork and in
residential settings such as therapeutic communities, adolescent units and children’s homes.

One of the primary functions of residential mental health institutions is containment. “Mental health institutions exist for people who cannot contain themselves.” (Hinshelwood, 1987, p.232). Within this, the institution or community can be seen as a containing ‘mother’ that clients are able to project into and hopefully re-introject from. If this containment is effective, with clients feeling that the institution is able to contain their distress and intolerable feelings, clients will then introject the capacity to face and understand their distress from the community. Where the institution tends to externalise individual distress into a shared set of attitudes and experiences then clients may also introject the collective support that the institution provides for their defensive mechanisms (Hinshelwood, 1987).

However, the institution may be unable to contain the client, either because the contents explode the container, resulting in a fragmented institution, or because the institution ‘crushes’ the contents because the institution is so rigid that it cannot accept clients’ own experiences (Bion, 1970, cited in Hinshelwood, 1987). It is therefore important that staff are aware of the importance of containment and how this containing function may break down, in order to promote the best possible functioning in their clients. Increasing staff awareness and analysing the system and how its containing function could be improved could therefore be an important role for a clinical psychologist working with such client groups.

Splitting can also be a useful concept to consider as there are many opportunities for splitting to occur in residential settings (Hinshelwood, 1987). Both clients and staff may ‘split’ other members of the institution into exaggerated positions, with some staff and clients being seen as all good, and others as all bad. In some cases the staff, due to their importance in the functioning and effectiveness of the institution, can be perceived as the idealised ‘good’ object which is able to save the client. It is therefore important for staff to be clear about their organisational and therapeutic roles, both to clients and within themselves, because only then are staff able to separate themselves from this idealised ‘good’ object and be perceived as realistically (Hinshelwood, 1987). Clients may at times split off the good parts of their personality and project
these onto staff, passing on any responsibility they have for other clients (Bion, 1998). The danger with this is that clients in doing so may come to perceive the staff as ‘all good’ and correspondingly themselves as ‘all bad’ and ineffective.

Clients may also split by perceiving the institution they are in as ‘good’, and the outside world, including outside services, as ‘bad’. In some cases there may be some evidence supporting this view, in other cases the view may simply arise from the group member’s own internal worlds and representations. This type of splitting can initially be seen by staff as beneficial, in terms of engaging the client and moving forward in therapeutic work, and in promoting the survival of the institution as ‘better’ than other alternatives. However, the consequences can in fact be negative. By perceiving the setting they are in only as ‘good’, clients are unable to deal effectively with any negative feelings they have towards their current setting or the people in it, instead projecting these feelings onto the world outside the institution. The outside world is then full of their terrifying projections and becomes a frightening place which the client is reluctant to re-enter or re-engage with (Hinshelwood, 1987).

Some organisational ‘splitting’ within institutions is inevitable and can be appropriate and adaptive. For example, clients and staff who spend time together in workgroups may spend more time talking to each other due to familiarity, and may feel more positively towards each other than ‘outsiders’, without having to perceive those within the group as entirely ‘good’ and those outside it as entirely ‘bad’. However, when splitting based on primitive defences occurs, it can lead to communications between groups being restricted by hostility, suspicion and guilt, with each group misconceiving the other groups’ communications and intentions (Hinshelwood, 1987).

These potential situations all mean that when working as a clinical psychologist with these populations, it could be very important to discuss the concept of splitting with staff groups, to make them aware of the processes that may be occurring within the group. Without this, staff may become demoralised and fail to understand clients’ thoughts, feelings and behaviours, leading to a breakdown in communication between staff and clients.
Conclusion

Although the concepts of containment and splitting have been criticised from both within and outside the psychodynamic literature, there is enough evidence to suggest that a clinical psychologist could use these two concepts to enhance their understanding and practice in work with children.
References


Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people.”

Critically discuss this statement

August 2003

Year 2
In general, ‘race’ is used as a biological term denoting people related by a common ancestry and ‘ethnicity’ is used to denote a shared ancestry, culture or lifestyle (Rack, 1982; Wilkinson, 1993, cited in Paniagua, 1998). However, these two terms tend to overlap considerably, with distinctions being ambiguous and the terms often being used interchangeably (Atkinson, Morton & Sue, 1998; Helms & Cook, 1999: both cited in Cardemil & Battle, 2003). Therefore, for the purposes of this essay, race and ethnicity will be considered as a single variable.

Incidence refers to the number of new cases over a given time-period in a population, whereas prevalence refers to all those with the specified difficulty at a notional time-point (Silman, 1995). Studies looking at mental health difficulties in older adults vary between using incidence and prevalence. However, both concepts are based on symptoms and assessment and are measured by screening, referral and diagnosis, meaning that the majority of criticism levelled at one concept could reasonably be levelled at the other (Mills & Edwards, 2002). Therefore, this essay will use information from studies measuring both incidence and prevalence.

**Incidence**

**Functional Mental Health Problems**

Studies suggest that incidence rates in older people vary according to race/ethnicity. Psychosis is more likely to be diagnosed in Afro-Caribbeans than other racial/ethnic groups and mood and anxiety disorders are more likely to be diagnosed in Caucasians, although Hispanics are also reported to have particularly high rates of depression and a higher proportion of Hispanics than any other group have two or more co-morbid mental health problems (Bastida & Gonzalez, 1995, cited in Haley, Han & Henderson, 1998; Husaini, Sherkat, Levine, Bragg, Holzer, Anderson, Cain & Moten, 2002; Mouton, 1997; Kales, Blow, Bingham, Roberts, Copeland & Mellow, 2000; Organista & Munoz, 1998). Asians reportedly have a lower incidence of mental health difficulties than other groups (Jenkins & Ramsey, 1993, cited in Paniagua, 1998). Overall, people from racial/ethnic minorities have lower rates of mental health service
utilisation than Caucasians (Brownlie, 1991, cited in Manthorpe & Hettiaratchy, 1993; McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibbin & Cleave, 1997).

Are the incidence rates valid?

In recent years people have begun considering whether incidence rates, which are based on diagnosis, are valid, or whether some populations are over-diagnosed or under-diagnosed. Several reasons for this have been proposed.

One reason suggested is misdiagnosis. Several studies have found misdiagnosis to be a common occurrence. For example, Coleman & Baker (1994) found that 7/8 middle-aged and elderly African-Americans with affective disorder were diagnosed as schizophrenic, and Baker (1995) found that 4/10 African-Americans diagnosed as schizophrenic actually had other psychiatric diagnoses instead. Solomon (1992) suggests four possible reasons for misdiagnosis: cultural expressions of symptomatology, unreliable research instruments and evaluation inventories, clinician bias and prejudice, and institutional racism.

Cultural factors can have significant effects on the formation, expression, perception and conceptualisation of mental health difficulties (Fabrega, 1996; Kleinman, 1996; Manson, 1996: all cited in Haley et al, 1998). For example, Asians tend to somatise, presenting with physical rather than psychological symptoms, meaning that their mental health difficulties may be under-diagnosed (Hsu & Folstein, 1997; Murray, 2000; Yamamoto, Silva, Justice, Chang & Leong, 1993, cited in Paniagua, 1998). This is compounded by and related to feelings of shame and guilt surrounding mental illness in Asian culture, meaning Asians are less likely to present to services with mental health problems (Paniagua, 1998; Wilhoit, 1995). Other studies suggest the diagnostic criteria used are not culturally valid, as different racial and ethnic groups may express mental health problems differently (Griffith, 1996; Rodriguez & O'Donnell, 1995; Rogler, 1996: all cited in Haley et al, 1998). For example, in the Western world the belief that evil spirits are possessing oneself may be seen as a symptom of psychosis. However, many Afro-Caribbean and Hispanic people believe
in the possession of people by evil spirits, and as a widely-held view within these groups it may not be indicative of mental health problems (Paniagua, 1998). Some racial/ethnic groups may also experience ‘culture-bound’ symptoms, with the cluster of symptoms only existing in and being described by specific ethnic groups - for example, ‘sinking heart’ as described by Punjabis (Krause, 1989, cited in Nazroo, Fenton, Karlsen & O’Connor, 2002). If clinicians do not understand culture-bound symptoms it can lead to misdiagnosis, and studies have found that taking cultural expressions of symptomatology into account can significantly increase the usefulness and reliability of standard mental health assessments (Good, 1996, cited in Haley et al, 1998).

Another key reason suggested for misdiagnosis is that the methods used to diagnose mental health problems are culturally and racially/ethnically biased, because all tests tend to reflect the culture they are devised in (Berry, Poortinga, Segall & Dasen, 1992, cited in Hays, 1996). For example, Asian patients may have lower scores on standardised measures of depression while reporting the same level of symptoms in interview as Caucasians (Comino, Silove, Manicavasagar, Harris & Harris, 2001). In addition, where patients do not speak English as their first language, it can compromise standardised assessment validity (Russell, 1988, cited in Paniagua, 1998). Studies have indicated that, where structured interviews and strict research diagnostic guidelines are used, and where data are corrected for factors such as socio-economic status, equal rates of mental health problems tend to be diagnosed for different races/ethnicities (Kales et al, 2000; Simon, Fleiss, Gurland et al, 1973, cited in Baker, 2000).

There is also evidence suggesting that clinicians may be biased or prejudiced when diagnosing people with mental health problems, meaning that even when Afro-Caribbeans and Caucasians exhibit similar symptoms they are judged and diagnosed differently (Lewis, Croft-Jeffreys & David, 1990; Whaley, 1997). However, other studies have found that although the routine clinical diagnosis of schizophrenia in Afro-Caribbeans is unreliable, schizophrenia does not tend to be over-diagnosed on the basis of race/ethnicity and Caucasian psychiatrists are no more likely to over-
diagnose schizophrenia in Afro-Caribbeans than Afro-Caribbean psychiatrists (Hickling, McKenzie, Mullen et al, 1999; Lewis et al, 1990).

Institutional racism can mean that people's beliefs, values and experiences are treated as bizarre or deviant (Lloyd & Moodley, 1992, cited in La Grenade, 1999; Wade 1993, cited in Dana, 1998). This can lead to over- or under-diagnosis due to failing to understand cultural expressions of symptomatology. The experience and fear of institutional racism can also lead to people from racial/ethnic minorities mistrusting services and therefore being reluctant to ask for help or comply with treatment (Delehanty,Dimsdale & Mills, 1991; The Sainsbury Centre for Mental Health, 2002).

Other researchers have suggested that studies may be measuring differences in incidence due to socio-economic status (SES) rather than race/ethnicity. SES is an important determinant of mental health status (Jenkins & Ramsey, 1991, cited in Paniagua, 1998; Nazroo, 1997; Weich & Lewis, 1998b: both cited in Nazroo & Sproston, 2002; Williams & Collins, 1995). In general, the SES of people from ethnic minorities in the UK and US is lower than Caucasians (Jenkins & Ramsey, 1991, cited in Paniagua, 1998; Nazroo, 1997; Weich & Lewis, 1998b: both cited in Nazroo & Sproston, 2002). This indicates that incidence studies are at least partially measuring SES differences not racial/ethnic differences. Indeed, some studies have found that when SES, age and sex are taken into account, racial/ethnic incidence differences disappear (Biafora, 1995; both cited in Mills & Edwards, 2002; Hargrave, Stoeklin, Haan & Reed, 1998; Williams, 1995). However, other studies have found that even when these factors are accounted for, racial/ethnic differences still remain, indicating that SES is probably not the only factor in different incidence rates (Holzer, Swanson & Shea, 1995, cited in Husaini et al, 2002).

A further difficulty is that incidence studies are usually based on those in treatment, possibly reflecting differences in pathways to treatment and treatments used (such as spiritual support) rather than differences in incidence (Kleinman, 1987; Wilhoit, 1995).
However, racial/ethnic differences may actually exist. Older people from minority racial/ethnic groups are at a higher risk of chronic disease than the general population (Siegel & Taeuber, 1986, cited in Jackson et al, 1990; Skinner 1995, cited in Haley et al, 1998). This is important as studies have shown that older people with a medical illness are twice as likely to be depressed than those without a medical illness (Gurland et al, 1983, cited in Arean & Miranda, 1996). However, again, physical health status is strongly related to SES (Williams & Collins, 1995). People from racial/ethnic minorities may also have more psychological and social stressors, such as racism, discrimination, low SES, and, if they were immigrants, being unable to return to their country of origin as they age (Haley et al, 1998; Marshall, 1990, cited in Manthorpe & Hettiaratchy, 1993). Although these factors are not specifically due to race/ethnicity, they are highly related to the current incidence of mental health problems of people from racial/ethnic minorities. Different racial/ethnic groups also provide different values to the social roles of older people, which can either ease or make more difficult the transition into “old age”, which may affect the likelihood of developing a mental health problem (Holzberg, 1992, cited in Hinton, Fox & Levkoff, 1999).

Dementia

Dementia affects large numbers of older people throughout the world (Levkoff, MacArthur & Bucknall, 1995, cited in Hinton et al, 1999). Studies have suggested that rates of dementia and dementia sub-types may vary according to race/ethnicity. For example, studies indicate that African-Americans have higher rates of dementia than Caucasian-Americans and Hispanic-Americans, whereas Chinese-Americans have lower rates of dementia (Folstein et al, 1987, cited in Dein & Huline-Dickens, 1997; Husaini et al, 2002; Kales et al, 2000; Lin 1983, cited in Espino & Lewis, 1998). However, other studies suggest that overall rates of dementia do not differ between racial/ethnic groups (De la Monte et al, 1989, cited in Richards & Abas, 1999; Henderson, 1987).

In terms of dementia sub-types, in Japan and China the incidence of vascular dementia exceeds that of Alzheimers, whereas in the western world the reverse is true (Graves,
Larson & White, 1994; Jorm, 1990, cited in Manthorpe & Hettiaratchy, 1993). Other studies have found a higher prevalence of Alzheimers in the West than Japan, but no differences in vascular dementia (Homma, 1994, cited Dein & Huline-Dickens, 1997). The incidence of vascular dementia has been found higher in African-Americans than in Caucasian-Americans, while the incidence of Parkinson's-associated dementia has been found higher in Caucasian-Americans than African-Americans (De la Monte et al, 1989, cited in Richards & Abas, 1999; Ritch, Ehtisham, Guthrie et al, 1996, cited in McCracken et al, 1997). However, while some studies have found a higher incidence of Alzheimers in African-Americans than Caucasians, other studies have found the reverse to be true (De la Monte et al, 1989, cited in Richards & Abas, 1999; Fillenbaum, Hughes, Heyman et al, 1988, cited in Espino & Lewis, 1998). One interesting study in Liverpool found no differences in dementia rates between English-speaking ethnic groups and the indigenous population, but higher levels of dementia in non-English speaking groups (McCracken et al, 1997).

Are the incidence rates valid?

It may be that differences in dementia incidence rates actually exist. Different racial/ethnic groups may be more or less likely to have risk factors increasing vulnerability to dementia or certain dementia sub-types (Larson & Imai, 1996; Tang, Stern, Marder et al, 1998: both cited in Haley et al, 1998). For example, African-Americans are more likely than Caucasian-Americans to have a history of strokes, hypertension and diabetes, all of which are risk factors for vascular-related dementia (Barnett, Armstrong & Casper, 1997; Heyman et al, cited in Richards & Abas, 1999).

However, as with other mental health problems, it may be that the methods used to diagnose dementia are culturally biased, leading to different diagnosis rates (Gurland, 1994, cited in Dein & Huline-Dickens, 1997; Rait, Burns & Chew, 1996). Biases could be related to difficulties in cognitive assessment language translation and to the different patterns of experience of different racial/ethnic groups, such as education and occupation, affecting results (Richards & Abas, 1999). For example, Mini-Mental State Exam results, (a screening instrument for dementia) are generally significantly higher in Caucasian-Americans than African-Americans (MMSE: Folstein, Folstein &
McHugh, 1975, cited in Haley et al, 1998). However, the mean education level is lower for people from ethnic minorities than Caucasians (AARP, 1997, cited in Haley et al, 1998; Baker, Robinson & Stewart, 1993; Escobar, Burnam, Kanno et al, 1986: both cited in Espino & Lewis, 1998). When the MMSE is adjusted for education level, it shows a similar sensitivity and specificity for detecting dementia and degree of impairment in daily activities regardless of race/ethnicity (Crum, Anthony, Bassett & Folstein, 1993; Ford, Haley, Thrower, West & Harrell, 1996; Murden, McRae, Kaner & Bucknam, 1991). Another study found that the MMSE is affective in diagnosing dementia by education but not race (Murden et al, 1991). A study comparing scores on the MMSE concluded that the lower scores found in Afro-Caribbeans than Caucasians could be principally explained by cultural bias in certain items (Stewart, Johnson, Richards, Brayne, Mann & Medical Research Council Cognitive Function and Ageing Study, 2002). Language difficulties may also mean that standard verbal assessments of dementia, such as the MMSE, may lead to over-diagnosis in people from racial/ethnic minorities with less fluent English (Lum, 1995, cited in Espino & Lewis, 1998).

Whether people with dementia present to services may also depend partially on expectations of the older person in terms of functional responsibility and on the extent to which families normalise cognitive impairment and will support the person with dementia, which varies across racial/ethnic groups (Dilworth-Anderson & Anderson, 1994, cited in Haley et al, 1998; Richards & Abas, 1999).

**Incidence - Conclusions**

Overall, no firm conclusions can be drawn as to whether race and ethnicity are important variables in the actual incidence of mental health problems in older people, due to the possible confounding variables of misdiagnosis, cultural bias in measures, socio-economic status, and the fact that for various reasons some racial/ethnic groups may be less likely to come into contact with services. It appears likely that mental health problems are either under-diagnosed or over-diagnosed in some racial/ethnic groups. However, this does not preclude the possibility that real differences in
incidence do exist. Therefore it is important for clinicians to be aware of these issues when diagnosing older adults with mental health problems, particularly when the older adults are from a minority racial/ethnic group.

**Treatment**

At present, differences do exist in treatment offered and given to people of different race/ethnicity. For example, older people from ethnic minorities present with mental health problems in higher numbers to primary care services but are referred less commonly than Caucasians to secondary mental health services even when presenting with similar symptoms, and are less likely to receive psychotherapy (Leo, Sherry & Jones, 1998; Lloyd & Bhugra, 1993, cited in Lloyd & Fuller, 2002; Odell, Surtees, Wainwright, Commander & Sashidharan, 1997). Afro-Caribbeans are prescribed more anti-psychotics and in higher doses than Caucasian Americans, and are more likely to have coercive treatment (Fernando, Ndegwa & Wilson, 1998, cited in Lloyd & Fuller, 2002; Health Act Comission 1999, cited in The Sainsbury Centre for Mental Health, 2002; Kales et al, 2000; Strakowski, Shelton & Kolbrener, 1993).

However, the more important question is whether differences should exist and if so, what they should be. Much of the research and literature on this topic is based on and aimed towards professionals working with the general adult population. However, as much of the treatment of older people is based on treatment of the general adult population, and as it has been suggested that race/ethnicity may even more important to older people’s sense of identity and security than younger adults, it would seem reasonable to assume that the research and literature would also be applicable to older people (Giordano, 1992).

Studies in America show that ethnic minority clients attending ethnicity-specific programs have higher return-rates and stay in treatment longer than those using mainstream services. However, it is not known which programs aspects, such as the use of minority ethnic professionals, treatment modifications or the services being provided in a culturally specific context, lead to these results (Takeuchi, Sue & Yeh,
1995). Some studies suggest that client/therapist racial/ethnic homogeneity can minimise problems in assessment and enhance rapport (Comas-Diaz & Griffith, 1988; Sue and Morishima, 1992: both cited in Ben-David, 1996; Fujino, Okazaki & Young, 1994). However, other studies show that client/therapist racial/ethnic homogeneity is neither a prerequisite nor a guarantee of the effectiveness of psychotherapy (Sue, Fujion, Hu, Takeuchi & Zane, 1991; Sue & Sue, 1990; Thompson, 1989, cited in Downing, 2000). What patients tend to value is the ability of professionals to see world from their perspective, which is not dependent on ethnic matching (Seeker & Harding, 2002, cited in The Sainsbury Centre for Mental Health, 2002).

**Culture and World-View**

It is generally agreed that for people to receive appropriate care, mental health professionals must know about their beliefs, their world-view and the basic organisation of their life (Tsai & Carstensen, 1996, cited in Abramson, Trejo & Lai, 2002; Barker, 1994). People's mental health is at least partially related to their beliefs and views, and these in turn are shaped by their culture and community (Hancock & Perkins, 1985, cited in Abramson et al, 2002). The perception of good mental health may vary between different racial/ethnic groups. For example, Western culture generally sees people as individuals, and good mental health is related to being independent. However, Eastern culture generally sees people as part of a collective group, and good mental health is based on being part of a social system and having a sense of togetherness (Sayed, Collins & Takahashi, 1998). Therefore in order to treat a person effectively, it is important to find out how that person would be seen by members of their own racial/ethnic group and culture. Tsai & Carstenson (1996) suggest that professionals ask directly about patient's backgrounds and beliefs, and Cardemil & Battle (2003) suggest that incorporating a discussion about race/ethnicity into therapy may be helpful in promoting an environment of trust and understanding and hence improving the therapeutic alliance and rapport (Cardemil & Battle, 2003; Tsai & Carstenson, 1996, cited in Haley et al, 1998).
Acculturation

Acculturation refers to the degree of integration of new cultural patterns into original cultural patterns (Dana, 1993b; Grieger & Ponterotto, 1995: both cited in Paniagua, 1998). In this case, it refers to the extent to which racial/ethnic minority elders integrate the dominant culture into their own culture. There are four modes of acculturation: integration, when both cultures are valued; assimilation, when the dominant culture is valued but the individual’s culture is devalued; separation, when the individual’s culture is valued but the dominant culture is devalued; and marginalisation, when both cultures are devalued (Berry & Kim, 1988, cited in Cardemil & Battle, 2003). Acculturation helps explain why people within a racial/ethnic group may differ vastly from one another in terms of beliefs, views and values (Helms, 1990; Lee 1996: both cited in Harris, 1998). Lower levels of acculturation in minority older adults are related to higher prevalence of depression but also to lower usage of mental health services (Hernandez, 1992; Lam, Pacala & Smith, 1997; both cited in Haley et al, 1998). The patient’s stage of acculturation can have important implications for the extent to which they will accept a therapist from a different racial/ethnic group and a treatment based on a culture other than their own (Sue & Sue, 1990).

Language

Older people from racial/ethnic minorities, particularly those who have emigrated to the UK/US as adults, may not speak fluent English. Even those who do speak English as a second language may find this more difficult when they are ill or under stress, and dementia in particular can severely affect a person’s ability to speak their second language (Rack, 1982; Schott & Henley, 2000). Among older Asians, language difficulties are one of the most common reasons for avoidance of health care services (Gilman, Justice, Saepham et al, 1992, cited in Espino & Lewis, 1998). Hence, access to services in which people can be treated by professionals speaking their own language may be preferable (Dana 1993b, citied in Paniagua, 1998; Takeuchi et al, 1995). When this is not available, translators are generally recommended (Paniagua, 1998). However, it is generally cautioned that it is advisable to use professional,
trained translators rather than family members, due to factors such as confidentiality, the shift in family power balance that using a family member as a translator may cause, and the tendency of untrained translators to interpret rather than just translate (Ho, 1987, cited in Hays, 1996; Pharoah, 1995). Language may also be important in terms of the necessity of providing written information in the person’s first language, as older people from ethnic minorities may be able to speak English while still being unable to read it (Kirklees Council, 1990, cited in Manthorpe & Hettiaratchy, 1993).

Religion

Different racial/ethnic groups may hold different beliefs about and explanatory models of mental health problems (Kleinman, 1980, cited in Haley et al, 1998). These beliefs are often closely tied to religious and spiritual beliefs, which tend to play an important part in the lives of Afro-Caribbeans and Hispanics (Dana, 1993b; Griffith, English & Mayfield, 1980; Levin & Taylor, 1993: all cited in Paniagua, 1998; Baker, 1995). For example, Afro-Caribbeans and Hispanics may hold beliefs that mental health problems are caused by occult or spiritual factors and that folk medicine and spiritual support from a church can be effective treatments (Baker & Lightfoot, 1993; Dana, 1993b; Levin & Taylor, 1993: all cited in Paniagua, 1998; Marwaha & Livingston, 2002). Chinese people may typically interpret dementia as retribution for family sins or as the person being possessed by evil spirits, whereas Cuban-Americans may typically assume it is due to bad blood in the family (Elliot, Minno, Lam & Tu, 1996, cited in Haley et al, 1998; Hernandez, 1992). Accepting these beliefs is important in understanding and working with the client, and such beliefs can often be helpfully incorporated into treatment, for example by the clinician working together with religious authorities (Dein, 1997; Organista & Munoz, 1998).

Family

Family structure and relationships also differ and can have important treatment implications. For example, Asians tend to place great importance on family relationships, with the person being seen first as part of a family and then as an individual (Paniagua, 1998). Children’s primary duty is to be good and respect their
parents and women are expected to marry, have children, be obedient and respect their husband’s authority (Sue & Sue, 1990). Again, in contrast to Caucasian families, Afro-Caribbean and Hispanic families tend to be multi-generational and older people are likely to be cared for by their children and grandchildren (National Council of La Raza, 1992; Tsai & Carstensen, 1996: both cited in Abramson et al, 2002). However, younger generations may not agree with or follow this (Harris, 1998). Understanding these issues, and the consequent expectations of themselves and others that older people from these groups may have, will help the clinician better understand the patient and hence treat them in ways synonymous with their culture.

**Where and how older people are cared for**

In general, ethnic minority families use more informal support and less formal support when caring for older relatives with mental health problems (Greene & Monahans, 1984, cited in Espino & Lewis, 1998; Miller, McFall & Campbell, 1994; Skinner, 1995, cited in Haley et al, 1998). Caucasian caregivers tend to have higher levels of depression and lower levels of life satisfaction than Afro-Caribbeans despite giving the same amount of care. This appears to be due to differences in stress-appraisals and coping responses (Adams, Aranda, Kemp & Takagi, 2002; Roth, Haley, Owen, Clay & Goode, 2001). Because of these statistics, professionals may perceive people from ethnic minorities as being less in need of formal services than Caucasians, assuming their families will care for them. However, this may result in people from ethnic minorities not being offered services they need. Indeed, in a review of studies of carers of dependent older people it was found that people from ethnic minorities expressed a greater need for formal services than Caucasians (Dilworth-Anderson, Williams & Gibson, 2002).

**Racism**

While being the subject of racism is not usually something that Caucasians, being the dominant racial group in the UK and US, often encounter, the majority of people from racial/ethnic minorities will have encountered it at some point (Haley et al, 1998). In situations where clients have frequently been subject to racism, focusing on
empowerment may be important in supporting the client to gain control over their own life (Paniagua, 1998).

Medication

Studies indicate that different races may react differently to some medications and may require different dosages (Bhui & Bhugra, 1999; Dein, 1997; Lawson, 1999; Rack, 1982). These differences need to be borne in mind when medical practitioners are prescribing medication to older people with mental health problems.

Asian Patients

Specific issues relevant to treating Asians are shame, guilt and somatisation. Within Asian families, shame and guilt are often used to enforce family norms. Consequently, Asians may come to treatment with a greater sense of shame and guilt than people from other racial/ethnic groups (Dana, 1993, cited in Paniagua, 1998). This could have important implications for treatment, in terms of needing to spend more time waiting for the client to begin talking about their difficulties when they feel comfortable enough to do so, and being more cautious about bringing up these issues than with other client-groups. Due to the feelings of shame and guilt surrounding mental illness, and the fact that sharing problems outside the family tends to be discouraged, Asians may often not seek help until a crisis is reached, meaning that it is often advisable to treat every initial appointment as a potential crisis (Paniagua, 1998; Sue & Sue, 1990). This sense of shame and guilt may partially explain why Asians somatise more than other groups (Hsu & Folstein, 1997; Murray, 2000; Yamamoto et al, 1993, cited in Paniagua, 1998). When this happens, it is important to acknowledge the somatic complaints and ensure physical investigations are carried out, while gently introducing statements that allow the client to move from somatic verbalisations to verbalisations involving mental health problems (Hughes, 1993, cited in Paniagua, 1998; Sue & Sue, 1990).
Approaches

There are relatively few studies comparing the effectiveness of psychotherapy between different racial/ethnic populations (Dick, Gallagher-Thompson & Thompson, 1999). However, of existing studies, CBT, Reminiscence and Life Review approaches have all been found effective with a wide range of racial/ethnic groups (Arean & Miranda, 1996; Bartlett, 1993; Natale, 1986, cited in Lagana & Shanks, 2002).

In general, goal- and action-oriented therapies emphasising immediate-focused learning factors, with a more authoritative, direct and structured approach, such as behavioural and cognitive-behavioural approaches, have been recommended with Afro-Caribbeans, Asians and Hispanics, particularly with older people who may be more traditional (Abramson et al, 2002; Boyd-Franklin, 1989, cited in Paniagua, 1998; Sue & Sue, 1990). Cognitive-behavioural therapy is thought to be particularly helpful because of the focus on psycho-education (Orlinsky & Howard, 1986, cited in Organista & Munoz, 1998). Therapies that emphasise social functioning and problem-solving skills rather than focusing on inner feelings are thought to be better received by Afro-Caribbeans (Boyd-Franklin, 1989, cited in Paniagua, 1998; Cheatham & Stewart, 1990, cited in Abramson et al, 2002; Franklin & Boyd-Franklin, 1990, cited in Downing, 2000). Insight-oriented and rational-emotive therapies should also avoided by clinicians working with Hispanics because these approaches emphasise internal conflict, blaming the client for their own problems, whereas Hispanics often believe that problems emerge because of external conflicts with the environment and therefore other people should be blamed (Paniagua, 1998). In general, it is suggested that, compared to younger people, older people may expect a more informal, social aspect to therapy (Greenberg & Motenko, 1994, cited in Hays, 1996). This may be particularly important for some ethnic groups, such as Hispanics (Greenberg & Motenko, 1994; Gutierrez, 1992: both cited in Hays, 1996; Organista & Munoz, 1998). However other groups, such as Asians, may initially prefer a more formal style of therapy, as this accords more with their own culture and expectations (Paniagua, 1998).
Treatment - Conclusions

Overall, it can be seen that there are many areas of treatment in which race-related and ethnicity-related factors need consideration. However, it should also be remembered that when presenting to services, people should be seen and treated as individuals. Within every racial and ethnic group there is considerable heterogeneity, with people differing across many factors including language, generational status, acculturation, socio-economic status, views and beliefs (Evans & Cunningham, 1996; Ivey et al, 2002, cited in Abramson et al, 2002; Sue & Sue, 1990). For example, within the category 'Asian' there are more than twenty different sub-groups, making it difficult to generalise about 'Asians' as a single category (Tsai & Cartensen, 1996, cited in Abramson et al, 2002). Race and ethnicity are simply one important variable among many, and consequently it could be argued that race and ethnicity are important variables only to the extent that all individual differences are important. For example, The American Psychological Association (1993) has suggested that service providers need to consider a number of factors when assessing and treating ethnically diverse populations, of which ethnicity is only one out of nine.

Conclusion

Overall, no conclusions can be drawn as to whether race and ethnicity are important variables in the incidence of mental health problems in older people. However, what can be said is that current means of diagnosing and assessing mental health problems in older people are inadequate in providing accurate incidence rates. In terms of treatment, race and ethnicity do appear to be important variables and should always be considered when working with older people. However, there are also many other variables, such as gender and cognitive ability, which are also important. When assessing and treating older people with mental health problems, the clinician should treat each person as an individual, whilst bearing in mind race-related and ethnicity-related factors and issues.


Evans, C.A. & Cunningham, B.A. (1996). Caring for ethnic elders: even when language is not a barrier, patients may be reluctant to discuss their beliefs and practices for fear of criticism or ridicule. Geriatric Nursing, 17 (3), 105-110.


Overview of Clinical Experience

Adult Mental Health Placement

Supervisor: Janice Rigby (Consultant Clinical Psychologist)
Location: Cheam CMHT, South West London & St. George’s NHS Trust
Dates: 10th October 2001 – 22nd March 2002

Clients seen were males and females (age range 19-70 years) from a predominantly White British background. Presenting problems included anxiety, depression, social phobia, OCD, EDNOS, phobias, health anxiety, paranoid psychosis, manic depression and a head injury. The main model used was CBT.

Assessments used included: BAI-II, BDI-II, Social Activities Distress Scale, Generalised Anxiety Disorder Scale, Social Phobia Rating Scale, Meta-Cognitions Questionnaire, Stirling Eating Disorders Scale, Health Anxiety Questionnaire, WAIS-IIIUK, WMS-IIIUK, Wisconsin Card Sorting Test, Trailmaking Test, NART-II, Test of Everyday Attention, Neale Analysis of Reading, Behavioural Assessment of the Dysexecutive Syndrome, Verbal Fluency, Crichton Royal Naming Test, Colour-Shape-Sorting-Test, Figure of Rey.

Additional experience included spending a day at the Henderson Hospital Therapeutic Community.

People with Learning Disabilities Placement

Supervisor: Karen Long (Consultant Clinical Psychologist)
Location: Thames Ditton, Kingston Service for People with learning Disabilities
Dates: 3rd April 2002 – 20th September 2002

Clients seen were males and females (age range 19-56 years) from a variety of cultural backgrounds with different degrees of learning disability. Presenting problems included challenging behaviour, query psychosis, bereavement issues, depression, dementia and needs assessment. The main models used were Systemic, CBT and Behavioural.

Assessments used included: Leiter International Performance Scale, Hampshire Assessment for Living with Others, ABC Charts, WAIS-IIIUK, WMS-IIIUK, WORD, WOLD, Neale-R.

Additional experience included co-running a “Keeping Safe in the Community” Group with another trainee and an assistant psychologist.
Overview of Clinical Experience

Child and Young People Placement

Supervisors: Marion Levick (Consultant Clinical Psychologist)
             Liz Croft (Clinical Psychologist)
Location: Tunbridge Wells CAMHS, Tunbridge Wells

Clients seen were males and females (age range 4-14 years) from a predominantly White British background. Presenting problems included attachment disorder, separation anxiety, behavioural difficulties, ADHD, physical health problems, enuresis, depression, maternal enmeshment, conduct disorder, Tourette syndrome, emetophobia, generalised anxiety and Aspergers. The main models used were CBT, Systemic, Consultation Model and Behavioural.
Assessments used included: Spence Children’s Anxiety Scale, Children’s Fear Inventory, WISC-IIIUK, WPPSI-R, WORD.

Older People Placement

Supervisor: Lynn Beech (Consultant Clinical Psychologist)
Location: Sutton OACMHT, South West London & St. George’s NHS Trust
Dates: 9th April 2003 – 26th September 2003

Clients seen were males and females (age range 65-84 years) from a predominantly White British background. Presenting problems included depression, dementia, anxiety, physical health problems, bereavement and grief, bipolar disorder, concern about memory difficulties and personality disorder. The main models used were CBT, IPT and Crisis Intervention.
Assessments used included: HADS, Middlesex Elderly Assessment of Mental State, NART-IIUK, WAIS-IIIUKWTAR, Behavioural Assessment of the Dysexecutive Syndrome, Rivermead Behavioural Memory Assessment.
Additional experience included co-running a workshop on “New Lifestyles Training: Person Centred Dementia Care” to residential home staff with supervisor.
**Overview of Clinical Experience**

**Pain Management Specialist Placement**

*Supervisor: Hilary Rankin (Clinical Psychologist)*  
*Clare Copland (Clinical Psychologist)*

*Location: Centre of Pain Education, Sutton, Epsom & St. Helier NHS Trust*

*Dates: 15th October 2003 – 26th March 2004*

Clients seen were males and females (age range 22-90 years) from a range of cultural backgrounds. In addition to pain in a variety of sites (including back pain, headaches, trigeminal neuralgia, carpal tunnel syndrome, arthritis and peripheral neuropathy) presenting problems included anxiety, interpersonal difficulties and low self-confidence. The main model used was CBT. A major part of the placement was co-running a CBT Pain Management group with a physiotherapist and a nurse specialist.

Assessments used included: Pain Self-Efficacy Questionnaire, Pain Diary, Roland Morris Disability Questionnaire, Pain Rating Scale, HADS, BDI.

Additional experience carrying out a neuropsychological assessment of a 56-year-old man with an intracerebral haemorrhage. Assessments used included: WAIS-III UK, NART-II, Doors and People Test, Modified Card Sorting Test, Stroop Test, VOSP, COWA, Graded Naming Test, Token Test Part V, AMIPB Information Processing Test, BIT Star Cancellation Task, MEAMS, HADS.

**Older Adults / Primary Care Specialist Placement**

*Supervisors: Clare Crellin (Consultant Clinical & Counselling Psychologist)*  
*Lynne Jordan (Consultant Counselling Psychologist)*

*Location: Haywards Heath OACMHT & Haywards Heath Clinical Psychology Service, West Sussex Health and Social Care NHS Trust*

*Dates: 7th April 2004 – 24th September 2004*

Clients seen were males and females (age range 22-81) from a White British background. Presenting problems included depression, anxiety, difficulty coping with retirement, dysphoria, “life crisis”, body dysmorphic disorder and bereavement.

Assessments used included: HADS, MEAMS, Rivermead Behavioural Memory Assessment, CORE, Young Schema Questionnaire. The main models used were psychoanalytic (Jungian) and Integrative (CBT, Schema Focused Therapy, Transactional Analysis, IPT).

Additional experience including a psychoanalytic observation in a residential home.
The assessment and treatment of a 40-year-old woman presenting with general anxiety disorder and social phobia, using a cognitive-behavioural model: A Summary

Identifying details have been changed to preserve the client’s anonymity and all names used in this report are fictitious

Reason for Referral
‘Christine’, a forty-year-old white Caucasian woman, was referred to the Community Mental Health Team by her GP for generalised anxiety disorder (GAD) and social phobia (SP).

History of Presenting Problem and Background Information
Christine reported symptoms concordant with long-standing GAD and SP. Her GAD focused mainly around issues of self-perfectionism, control, difficulty making decisions, and worrying about having upset or annoyed someone. She also reported significant concern about her worrying thoughts. Her SP centred on a fear of blushing, which she worried about in most social situations. Christine had previously seen a counsellor for her GAD and had attended a stress-management group, both of which she found helpful in understanding, but not reducing, her anxiety. She had also seen a psychodynamic psychotherapist which she did not find helpful. She had read several self-help books but found maintaining the strategies suggested and working through obstacles arising difficult.

Christine had a husband of 19 years who she described as “supportive” and six close friends whom she saw regularly. Due to chronic back pain she had given up work five years previously and instead volunteered part-time at a Volunteer Bureau. Christine described a difficult relationship with her mother, who she saw as very anxious, intolerant and controlling. She had a younger brother who though adult still lived with her parents. She reported a history of anxiety and social difficulties stemming back to childhood.
Initial Formulation
Christine’s difficulties were formulated using Wells’ (1995) cognitive-behavioural model of GAD and Clark and Wells’ (1995) cognitive-behavioural model of SP. In accordance with these models it was hypothesised that Christine’s early experiences of growing up with an anxious, intolerant and impatient mother predisposed her to worrying thoughts and a feeling of needing to be perfect and in control. At a later point she then became concerned about the worrying itself and that it might make her ill and depressed. Her worrying was maintained by her positive and negative worry beliefs (meta-worries), her behavioural strategies and her thoughts, emotions and symptoms. Christine’s SP seemed to be maintained by the vicious circle of perceived social danger, her safety behaviours and her somatic and cognitive symptoms.

Intervention
Sessions initially focused on identifying and modifying Christine’s negative automatic thoughts in terms of her GAD, moving on to identifying and modifying her conditional assumptions, rules and beliefs and then identifying and modifying her core beliefs. Later sessions also focused on identifying and modifying her self-processing in terms of her SP. Techniques included the use of thought diaries, behavioural experiments, using others as a reference point, cognitive continuums, historical tests, core belief worksheets, the formulation of more rational self-statements and the use of ‘coping cards’.

Outcome
On review, Christine highlighted her new, more adaptive beliefs, her increased assertiveness, and the skills and techniques that she could continue to use to address her negative beliefs. In particular, Christine reported the discovery of her core belief “I am unlovable” as helpful and a relief, as she felt that her anxiety and fears seemed more reasonable and understandable in terms of this belief. Over the course of the sessions Christine’s rating of GAD and SP fluctuated dramatically on the measures used, but overall there appeared to be a downward trend in terms of the amount of GAD and SP distress she experienced. An increase of distress in terms of her GAD and SP in the last two sessions was related to her anxieties about sessions ending.
Re-formulation
Wells' (1995) model of GAD and Clark and Wells' (1995) model of SP proved to be useful conceptualisations but additional information about predisposing and maintaining factors meant that modification of the initial model was necessary. Christine’s difficulties were therefore reformulated using Beck’s (1995) cognitive conceptualisation in order to provide a unifying framework for her difficulties in which her GAD and SP were simply different expressions of the same key experiences and beliefs. Fundamentally, the additional information suggested that Christine’s early experiences of being rejected and invalidated by her mother and of being bullied and humiliated at school gave rise to her core belief “I am unlovable” and underlying assumptions such as “My thoughts, opinions and feelings are not important”. These beliefs and her experiences led her to develop conditional assumptions such as “If I am not perfect then people will reject me” and “Blushing is a weakness and therefore leads to rejection”. These beliefs then maintained her GAD and SP.

Prognosis
Overall, it was felt that Christine’s psychological prognosis was good. She exhibited good understanding of and ability to use the cognitive models of GAD and SP and displayed significant motivation to change and good persistence when supported. However, the trainee was concerned about Christine’s ability to maintain her positive changes without the support of regular sessions.

Critique
Issues contributing to the success of the intervention were discussed, including Christine’s good motivation and the time spent developing a strong rapport with Christine before the trainee attempted to discuss particularly difficult issues with her.

In hindsight, he trainee felt that too much time was spent focusing on disparate issues rather than Christine’s core belief and that it would have been helpful to focus on her SP earlier in the sessions.
An extended assessment of a 38-year-old man with a moderate learning disability and a dual diagnosis: A Summary

Identifying details have been changed to preserve the client's anonymity and all names used in this report are fictitious

Reason for Referral
'Tynsley', a 38-year-old man of Afro-Caribbean descent whose first language is English, was referred to the trainee clinical psychologist for an assessment of his cognitive and adaptive functioning as part of an ongoing process to 'get-to-know' him better following his move into the area.

History of Presenting Problem and Background Information
Until he was three Tynsley had several short-term admissions into care due to his mother experiencing periods of mental illness, and at the age of three he was received into care permanently. From three to five he experienced eight different foster placements and from five to fourteen was placed in a residential home. His childhood behaviour was described as challenging, disturbed, obsessional and ritualistic and he found change difficult. From sixteen to twenty-one Tynsley lived in another residential placement where again he initially exhibited 'disturbed' behaviour although he eventually settled. At twenty-one he was admitted to a long-stay hospital following several incidents of severely cutting his wrists. For some time he appeared settled there but prior to a major change in the hospital became unsettled and withdrawn. In March 2001 Tynsley was moved to his current thirteen-bed residential treatment and assessment unit which had higher levels of 1:1 support.

Limited information was available regarding Tynsley's cognitive ability. Previously his IQ was assessed as 30, he had limited verbal communication and he had previously been diagnosed as autistic with reported evidence of psychosis and catatonic schizophrenia. He had a significant history of challenging behaviour including self-injurious behaviour, aggressive behaviour and ritualistic and repetitive behaviours, with no triggers for these having been identified.
**Initial Formulation**

Tynsley's difficulties could be understood as a combination of his severe learning disability, autism and mental health difficulties combined with a possible pattern of insecure attachment developed due to his childhood experiences of repeated separations. These difficulties were likely to mean that Tynsley would tend to find new situations difficult and might become easily frustrated due to finding it difficult to communicate his needs. This may at times have resulted in his exhibiting challenging behaviour. It could also explain his difficulties in social interaction and communication and his ritualistic and repetitive behaviours. However, it was concluded that further information was needed in order to understand Tynsley, his capacity and his challenging behaviour in order to effectively plan for his future.

**Intervention / Assessment**

The Leiter International Performance Scale was used to assess Tynsley's cognitive ability. The Hampshire Assessment for Living with Others was used as a measure of adaptive functioning and was carried out with several professional involved with Tynsley. ABC charts were used to monitor Tynsley's challenging behaviour.

**Results**

The results of the LIPS indicated that Tynsley had an IQ of 43, and thus a severe impairment in intellectual functioning. The results of the HALO indicated that Tynsley's skills were variable. He was described as a shy person who enjoyed being with people but would found making friends difficult and often refused to participate in group activities. He was able to adapt to new surrounding but found concurrent changes difficult. He did not display any inappropriate sexual behaviour but was thought to be vulnerable to exploitation from others. Tynsley had some independence in most areas of self-care but showed low participation in domestic tasks and was generally seen as very passive. He needed substantial staff support in most areas of community living and was unsafe to leave his residential accommodation alone. He had a limited range of leisure activities but found it difficult to occupy himself and tended to exhibit challenging behaviour when unoccupied, anxious or agitated.
An assessment by the community Speech and Language Therapist reported that Tynsley had some communication difficulties with better receptive than expressive vocabulary. The Consultant Psychiatrist reported that Tynsley needed to wear glasses and had some sensory impairment. Although he had no definite psychiatric diagnosis there were two working hypotheses – that he had intermittent florid psychotic episodes or that he had Post Traumatic Stress Disorder due to separation from his primary relationships at an early age, frequent changes in residential placements, institutionalisation, loss of his parents, possible physical and verbal abuse and neglect, and possible ‘treatments’ such as restraint. The Consultant Psychiatrist rejected the previous diagnosis of autism.

The ABC charts found no particular precipitating events or pattern to his challenging behaviour, suggesting that his challenging behaviour was likely to be due more to internal than external factors although there was possibly some environmental effect.

Recommendations
The results of the assessment were fed back to the service through a written report and through meetings with his day-centre and residential placement, and several recommendations were made surrounding issues such as the continuation of Tynsley’s individual education and skill-building programs, promoting Tynsley’s independence where possible, improving communication with Tynsley, increasing his leisure activities and continued monitoring of his behaviour.

Re-formulation
The information acquired during the extended assessment supported some of the previous hypotheses about Tynsley, contradicted others, and suggested some new hypotheses. In particular it was suggested that Tynsley might not be autistic but may suffer from either intermittent episodes of florid psychosis or from PTSD. It was thought that this could explain his challenging behaviour and why it did not seem to be related to external factors. It was also though that Tynsley’s institutionalisation and frequent changes in placements may have affected his behaviour by leading to him tending to be very passive and functioning at a level lower than could be expected given his intellectual capabilities. The effect on Tynsley of being in a significant racial
minority was also discussed. His challenging behaviour was thought likely to be caused by a number of factors including his possible mental illness, sensory impairment, difficulties with verbal communication and a possible history of neglect.

**Critique**

The trainee discussed factors that contributed to the success of the assessment, namely extensive liaison with the other professionals and staff involved in Tynsley’s care. The trainee discussed difficulty surrounding issues of consent and how this was obtained from Tynsley as far as possible.
The assessment and treatment of an 11-year-old girl presenting with low mood and attachment difficulties, using a cognitive-behavioural model with a psychodynamic reformulation: A Summary

Identifying details have been changed to preserve the client's anonymity and all names used in this report are fictitious

Reason for Referral

'Sasha', a twelve-year-old white Caucasian girl, was referred to the Child and Adolescent Mental Health Service by her GP who reported that Sasha’s mother ‘Clara’ was concerned about Sasha being low in mood, withdrawn, uncommunicative and tearful. Clara herself was reported as suffering from moderately severe depression. She was concurrently referred to ‘Anna’, a psychodynamic practitioner in the team, for individual work.

History of Presenting Problem and Background Information

Sasha presented with several interrelated issues: her fear of people leaving her and being alone; having difficulty trusting others, which caused her to isolate herself from others to emotionally protect herself from the fear they might leave her; feeling confused about her thoughts and feelings. From Sasha’s descriptions the trainee considered that Sasha felt very responsible for others, which made it difficult for Sasha to talk about her feelings of distress and confusion as she didn’t want to upset people. A risk assessment concluded that Sasha was at low risk of self-harm or suicide.

Sasha lived with her mother Clara, with weekend visits to her father who she reported as a strong, stable and supportive figure in her life. She was in her first year of secondary school where she was reported to be average to above average academically, helpful, well-mannered and conscientious. She had several female friends but described a relatively unstable friendship group, with frequent arguments and changing alliances. Sasha had been subject to several difficult life events,
including parental divorce, several deaths in the family and her mother’s depression as well as suffering from asthma and diabetes herself.

**Initial Formulation**

Sasha’s presenting problems seemed best understood within a cognitive-behavioural framework, using attachment theory to fully understand her difficulties. Clara’s depression during Sasha’s infancy meant she was sometimes emotionally unavailable for Sasha meaning that Sasha developed an insecure-ambivalent attachment and a fear of losing her mother and, subsequently, others. These difficulties, combined with Sasha’s asthma and diabetes as well as family circumstances, resulted in an enmeshed relationship between Sasha and her mother, with some role-reversal in their relationship. Consequently Sasha was confused about her own feelings because she was so involved with her mother’s feelings. However, this enmeshment protected Sasha from her fear of losing her mother.

From these early experiences Sasha developed core beliefs that she was bound to be abandoned and rejected and that people were unreliable and would always let her down. Hence, she developed life-rules about not trusting others and looking after everyone so they wouldn’t leave her. When she was feeling particularly vulnerable Sasha withdrew to protect herself from being further hurt, which then maintained her beliefs.

**Intervention**

Sessions focused on several key issues: Sasha’s confusion about her thoughts and feelings, to help her make links between them, between her past and current experiences and to evaluate her thoughts and experiences more realistically; how Sasha could best protect herself emotionally and get the support from her mother that she needed, which involved a joint session to facilitate a discussion between Sasha and Clara about this; Sasha’s fear of loss and difficulty trusting others, which involved thinking about who she could trust as well as discussing how she might find the sessions ending; testing out what would happen if Sasha didn’t always take the responsibility for others; relapse prevention.
Outcome
Sasha reported finding the sessions helpful and both she and her mother reported her mood as improved. From the trainee’s perspective Sasha made several positive steps during the therapy, including an increase in her ability to access support from family and friends and her ability to appraise situations more realistically and challenge her cognitive distortions. She also became able to talk about herself, her thoughts and feelings in a more coherent and organised way and became more positive about her future.

Re-formulation
Sasha’s difficulties were reformulated psychodynamically as it was felt that this provided a better model of understanding and working with Sasha’s difficulties. The reformulation focused on Clara’s own attachments and experiences which it was felt had led to her developing a preoccupied-entangled attachment pattern. This, combined with her own depression which meant that she was unable to ‘contain’ Sasha and Sasha’s infant rage, may have resulted in Sasha developing an insecure-ambivalent attachment pattern and being unable to separate from her mother. Malan’s triangle of conflict was used to explain how Sasha’s hidden feelings of anger have led to her anxiety that she is therefore unlovable and will consequently be rejected and abandoned. Her defence is thus to avoid expressing this anger by always being nice to everyone and taking emotional responsibility for others. This triangle of conflict, which comes from her relationship with her mother (past), can be seen as being repeated in her relationships with others (e.g. school-friends) and in the therapeutic transference (triangle of person). This meant that in sessions Sasha was very compliant and tried to protect the trainee from her (Sasha’s) anger and difficult feelings.

Thus, Sasha’s fear of loss, difficulty in trusting others, confusion about her thoughts and feelings, feelings of responsibility for others and compliance could all be seen to stem from these initial difficulties.
Prognosis
The trainee felt that Sasha’s prognosis was good. Of particular importance for this was Clara’s increased awareness of Sasha’s need to be protected and cared for and Clara’s own ongoing involvement with the psychodynamic practitioner. However, the trainee felt that Sasha may need a re-referral to the service in the future when her need to separate from her mother as she grows older becomes more important.

Critique
The trainee discussed factors contributing to the good outcome including Sasha’s good motivation and willingness to apply the sessions to her everyday life. However, formulating and working with Sasha psychodynamically would have enabled the trainee to focus on Sasha’s fear of loss, in terms of her relationship with the trainee and the sessions ending. This would have enabled the trainee to explore the feelings beneath Sasha’s defence of compliance and address her feelings of anger, tackling her difficulties on a much deeper level.
The assessment and treatment of an 84-year-old woman presenting with depression, using Interpersonal Psychotherapy informed by research on identity-threat: A Summary

Identifying details have been changed to preserve the client’s anonymity and all names used in this report are fictitious

Reason for Referral
‘Isobel’, an eighty-four-year-old Caucasian woman, was referred to the Older Adults Community Mental Health Team by her GP who reported that she was complaining of low mood, loss of confidence and forgetfulness, dating back to a time when she was upset by the co-ordinator of her hospital voluntary work.

History of Presenting Problem and Background Information
Isobel described two major incidents occurring prior to her depression. The first was when, after greatly enjoying working as a hospital volunteer for a year, she was suddenly told by the volunteering co-ordinator that she was no longer needed. She felt devastated, ashamed and as if she had lost her purpose in life, and found it difficult to talk to others about the incident. Several months later she became a volunteer at another local hospital but stopped due to an operation. The second incident occurred when Isobel fell over some workmen’s planks in a supermarket car-park, badly bruising her hip. However, the most devastating aspect of this for her was that nobody came to help, despite the car-park being fairly busy. Isobel also reported some memory difficulties and the trainee noted that at times she repeated large amounts of information with no apparent awareness that she was doing so. However she scored 11/12 on the Middlesex Elderly Assessment of Mental State, which was within the normal range for a person of her age.

Isobel had lived alone since her husband, a local GP, died of cancer seven years previously. They had no children together but she had some contact with her husband’s children from his first marriage. Isobel had sisters living in Scotland and her brother had died of cancer four years previously. She had a close friendship with a
local couple but did not appear to have a very wide social circle. Prior to her depression, Isobel was a regular Bridge player. However, in the months prior to the referral she had given this up due to her reduced self-confidence and worries about her memory. Isobel described herself as “a natural carer” and said that she enjoyed helping others. Until retirement she worked as a chiropodist and helped her husband in his GP surgery. She denied any self-harm or suicidal ideation.

**Initial Formulation**

Isobel’s presenting problems seemed best understood within an interpersonal framework informed by research on identity threat. During her life Isobel had developed a self-identity as a “carer” and a belief that if she cared for others they would care for her. She maintained these beliefs and her self-esteem by engaging in caring activities. However, the incident with the volunteering co-ordinator threatened this self-identity and made her feel humiliated and ashamed, at a time in her life when her protective factors were reduced. It also resulted in Isobel losing the vital caring role in her life, meaning she became subject to a “role transition”. Consequently, she became depressed. Her depression increased when she fell in the supermarket car-park and her belief in others caring for her was challenged. Isobel adopted the interpersonal coping strategy of isolation, which maintained her depression as she further removed herself from any forms of social support. The trainee was unsure as to whether Isobel’s slight memory difficulties were due to her low mood or due to some very mild memory impairment which was not picked up on the MEAMS due to her previous high-functioning.

**Intervention**

The intervention used IPT focusing on the area of “role transitions” and informed by research on identity threat. Sessions were an hour-and-a-half long due to Isobel’s poor memory which meant that conversation during sessions often needed repetition, which is not unusual when working with older adults. Sessions focused on Isobel’s feelings about the volunteering incident to enable her to come to terms with this, on the “role transition” that this incident had resulted in and how she could cope with this, and on Isobel resuming her previous activities of Bridge and voluntary work. The trainee also bore in mind the importance of increasing Isobel’s self-confidence and the possible
need for Isobel to become more comfortable about turning to others for support bearing in mind her age and possible memory difficulties. Due to her relative social isolation the trainee thought that Isobel might find termination particularly difficult. The trainee therefore gradually reduced the frequency of sessions from weekly to three-weekly towards the end and discussed the issue of termination with Isobel.

Outcome
On review, Isobel highlighted how valuable it had been to her to have somebody to talk to about her difficulties. She reported feeling “cheerful” and “back to my old self” in stark contrast to her original feelings of being low, lonely and tearful. She was no longer distressed by thinking about the volunteering incident. From the trainee’s perspective, Isobel made several positive steps during the therapy, the main ones being re-starting Bridge and starting some new voluntary work.

Prognosis
The trainee felt Isobel’s prognosis was good and future protective factors were discussed. Of particular importance to this was that Isobel had re-started the important activities in her life.

Reformulation
The initial formulation proved an effective way of conceptualising Isobel’s difficulties, and was supported by information subsequently obtained during the sessions. In particular, further information about Isobel’s childhood gave support to Isobel’s self-identity beliefs and the reasons for these.

However, although Isobel’s mood significantly improved, her memory difficulties remained. This indicates that her memory problems were more likely to be related to an underlying organic difficulty than her mood.

Critique
Although Isobel reported a positive outcome from the intervention, the trainee felt that the sessions may not have adequately addressed Isobel’s emotional need to care for
others and to perceive herself as "a carer". Reasons why the trainee did not address this were discussed.

The trainee also considered whether she should have carried out a more thorough assessment of Isobel's memory difficulties. However as this opportunity was offered to Isobel and she declined it was thought to be unethical and potentially damaging to Isobel to conduct further assessments.
A report of a neuropsychological assessment of a 55-year old man following an intracerebral haemorrhage: A Summary

Identifying details have been changed to preserve the client's anonymity and all names used in this report are fictitious

Reason for Referral
John was referred by a Consultant Physician for a neuropsychological assessment a week after his admittance to the hospital Stroke Unit. Initially John's deficits were considered so severe that it was unreasonable to administer a full neuropsychological assessment. However due to some recovery, three months later a neuropsychological assessment was then considered appropriate.

History of Presenting Problem and Background Information
John presented to the Accident and Emergency department complaining of sudden onset right-sided severe headache, neck stiffness, nausea and vomiting. He was diagnosed with a right cerebellar/occipital bleed and admitted. The next day he underwent a craniotomy for evacuation of the posteria fossa haematoma and was then transferred to the Intensive Care Unit. He was noted to have raised intracranial pressure. Two weeks later he was transferred to the Stroke Unit.

Since the stroke John was experiencing difficulties with walking, double vision and a shaking hand. He was noted to have some memory difficulties and was somewhat impulsive although able to self-correct given time. He reported feeling fine in mood.

John had been married for twenty-five years and had two teenage daughters. He had some higher education and worked designing platforms for North Sea Oil Rigs. He had a 20-year history of sleeping difficulties for which he was prescribed antidepressants plus one previous admission for severe depression in 1997.

Literature Review
The possible deficits suggested from John's presentation and difficulties were discussed, as well as the possible effects of his past depression and diabetes.
Hypotheses
Two hypotheses were suggested: that John might have specific visual and motor deficits, as predicted by a right cerebellar/occipital haemorrhage, or that John might have a range of diffuse cognitive deficits, as predicted by his raised intracranial pressure and craniotomy. Therefore a full neuropsychological assessment was administered.

Findings
Throughout the assessment John was engaged, motivated and able to persist even when he found tasks difficult. However, he occasionally needed reminders to concentrate. His speech was slightly slow and there was evidence of his diplopia and difficulties with fine motor performance. He had limited insight into his difficulties.

John's performance on the NART-2 gave him predicted IQ scores in the average range. However the NART-2 was considered possibly invalid as a measure of John's pre-morbid intellectual functioning, so a demographic regression equation was also used. According to this, his pre-morbid intellectual functioning was in the superior range.

On the WAIS-IIIUK John's Verbal Comprehension Index, Working Memory Index and Processing Speed Index were all lower than his estimated pre-morbid intellectual ability (NART-2), and his Perceptual Organisation Index was lower than his likely pre-morbid intellectual ability (demographic regression equation). His Verbal IQ fell within the low average range but due to the variability between the two Index scores making up the Performance IQ, his Performance IQ and Full-Scale IQ were not calculated. He had a relative strength in Perceptual Organisation Skills, which fitted with his pre-morbid pattern of occupation and probable pre-morbid strengths. He had a relative weakness in Processing Speed, with his Processing Speed Index falling within the extremely low range.

John's verbal and visual memory scores as assessed by the Doors and People Test and the Working Memory Index of the WAIS-IIIUK were significantly impaired, as was his information processing ability as measured by the WAIS-IIIUK Digit-Symbol
Case Report Summary: Specialist

Coding and the AMIPB Information Processing. Both of these domains were below what would be predicted by his pre-morbid intellectual functioning. On tests of Language (the Graded Naming Test and Part V of the Token Test) and visuo-spatial functioning (VOSP) his performance was within the average range but lower than would be predicted by his pre-morbid intellectual functioning. John's executive functioning as measured by the Stroop Neuropsychological Screening Test was significantly impaired, but it was difficult to interpret this score accurately as his score was severely affected by his slowed processing speed. His performance on the Modified Card Sorting Test was not abnormal and did not indicate any impulsivity or perseveration. However, his score on the COWAT was significantly impaired. These results suggest that John may have some executive functioning deficits, but it was difficult to assess the true extent of these due to the extent to which his scores were affected by his slowed processing speed and possibly by his poor memory. No major motor perseveration was noted during testing and according to his HADS scores John was not suffering from any significant anxiety or depression.

Discussion

John's pre-morbid IQ was estimated to be at least within the average range and was likely to be between the high-average and superior range. The assessment indicated a general cognitive loss from John's previous level of intellectual functioning with specific impairments in processing speed, executive functioning, both visual and verbal memory, some slight reduction in language skills and possibly some visual deficits. This pattern of deficits was to some extent consistent with a right cerebellar/occipital bleed followed by raised intracranial pressure and a craniotomy, as it is known that a stroke caused by a haemorrhage can lead to diffuse and widespread cognitive deficits. Possible reasons for the fact that the expected greater compromise to John's visual abilities was not evident were discussed.

The effects of John's difficulties on his ability to think through tasks were discussed, as were the implications of this in terms of his functioning and safety at home.
Recommendations
Recommendations were made regarding John’s potential safety at home and the support he may need, particularly in terms of his poor memory. It was recommended that John be re-tested in three months time, six months after the original stroke, and it was suggested that he may benefit from further work-related support and discussion following this re-assessment.

Critique
Discussion focused on how the testing could have been improved, such as including a more detailed assessment of his visual difficulties, a further test of executive functioning and a test of attention, as well as the reasons why further tests were not given.
An evaluation of CMHT staff members’ knowledge, understanding and opinions of the recent integration of Health and Social Services and the creation of a single line-management structure within their CMHTs

June 2002

Year 1
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Abstract

Title
An evaluation of CMHT staff members’ knowledge, understanding and opinions of the recent integration of Health and Social Services and the creation of a single line-management structure within their CMHTs.

Objective
To examine CMHT staff members’ knowledge, understanding and opinion of the recent integration of Health and Social Services and the creation of a single line-management structure within their CMHTs, and to identify their information and training needs as regards the integration.

Design
All non-psychiatric CMHT staff members were given the same questionnaire, with psychiatrists being given an amended version of the questionnaire with two irrelevant line-management related questions deleted.

Setting
Four multi-disciplinary Community Mental Health Teams.

Participants
All 53 staff members within the four CMHTs were invited to respond. 29 responses were received. Staff members comprised of psychologists, occupational therapists, speech therapists, community psychiatric nurses, social workers, administration staff, and psychiatrists.

Main Outcome Measures
A questionnaire containing 12 questions, including fixed-choice questions, Likert-style scales, and open-ended questions.

Results
In general, respondents felt positively about the integration. However they were unclear as to how the integration had affected them, feeling ill-informed and poorly trained in relation to any new responsibilities. A variety of potential benefits and drawbacks of the integration were highlighted. Some differences between the four CMHTs and between psychiatrists and non-psychiatrists were also reported.

Conclusions
Staff need to be provided with further information and training about the integration and how this affects them, and future integrations within the Trust should consider staffs’ views and the information and training needs of staff.
Introduction

On 1st June 2001, in response to the National Service Framework for Mental Health and the London Strategy for Action, the NHS Mental Health Trust and Social Services Department in this study formed a partnership, "for the purposes of establishing a singly managed integrated health and social care provider for mental health services" (Partnership Agreement, section 1.1).

The four Community Mental Health Teams (CMHTs) in the Trust consisted of psychiatrists, psychologists, community psychiatric nurses, occupational therapists and administration staff. Before the integration they worked solely with people with mental illness, prioritising those with severe and enduring mental illness. However, following the integration, the CMHTs also undertook Social Services’ responsibilities for social care of people with mental illness and vulnerable adults. Social workers (SWs), who had previously worked within the CMHTs while being employed and managed by Social Services, were instead seconded to the NHS Trust.

As part of this integration, a single line-management structure was created. Before the integration, all professionals within the CMHTs were managed only by their professional heads. However, as part of the integration, a Team Manager (TM) was appointed for each CMHT. All Team members except psychiatry were then line-managed by the TM, while their professional heads remained their professional manager. TMs were "responsible for ensuring the effective day to day performance management of the team and team members." (Partnership Agreement, section 6). Professional managers remained responsible for clinical supervision of work and professional development.

The Partnership also undertook responsibility for five key areas of work, previously the responsibility of Social Services. Of these, responsibility for vulnerable adults, and care management (purchasing care for clients) remained solely the responsibility of social workers, and as such also became the responsibility of the TMs. Acting as an ‘appropriate adult’ remained solely the responsibility of social workers, as it was not a statutory SW responsibility but was contracted to Social Services by the area’s police
service. However, the obligation to assess anyone who asks for an assessment, and carrying out carers’ assessments, became the responsibility of all CMHT staff.

Although the same policies were implemented in each CMHT, there were some structural differences between the four CMHTs. In CMHTs 1, 2 and 3, the TM was already working within the team as a practitioner and team co-ordinator. However in CMHT 4 a manager was brought into the team from Social Services. In addition, the TM in CMHT 3 was on long-term sick-leave, with another CMHT 3 staff member of acting-up as TM.

Staff were informed about the integration through open meetings. However, no direct evaluation of staff members’ experience of the integration had been carried out. Therefore the trainee psychologist, together with the line manager of CMHT 2, identified that such an evaluation was important, and could contribute towards measuring the success of the integration: “Evaluation will be based on the following success criteria... The degree to which staff feel involved in and informed about the process.” (Partnership Agreement, section 5). The trainee and line manager identified five key areas as important to the evaluation, and these formed the five research questions. The evaluation was carried out using an anonymous postal questionnaire.

It was decided that it was important to look both at staff’s knowledge and understanding of the integration and how it affected them, as well as their opinions about the integration. It was important to look at whether staff had a clear idea of their new roles, responsibilities and lines of accountability, as this has been identified as important in making teams successful (King’s Fund London Commissions, 1997; Ojnett & Ford, 1996: both cited in Norman & Peck 1999a; Gorman, 1998; Norman & Peck, 1999a; BPS 2001).

Over the next few years the NHS Trust intends to extend this integration to other services within the Trust and local borough, such as the Assertive Outreach Team, Resource Centres, and Older People’s CMHTs. This evaluation might therefore be useful both for the evaluated CMHTs, in informing them of the thoughts, opinions and
information and training needs of staff as regards the integration, and in planning for future integrations.

**Research Questions**

- To what extent are staff members aware of and understand what the integration and line management changes mean for them in terms of practice and role?
- How do staff members feel about the integration and new line management system?
- Do staff members feel informed enough about the integration and new line management system and, if not, what information and training would they like?
- What are staff members' hopes and fears about the impact of the integration and line management changes?
- Are there any differences in opinions or understanding between the four different CMHTs or between psychiatrists and non-psychiatrists?

**Method**

**Participants**
An anonymous questionnaire was sent out to all 53 staff members in the four CMHTs. Staff members comprised of psychologists, occupational therapists, speech therapists, community psychiatric nurses, social workers, administration staff, and psychiatrists. 29 questionnaires (55%) were returned.

**Materials**
The questionnaire was designed in conjunction with the line manager at CMHT 2, in order to reflect the needs of the service and to ascertain who was responsible for the five key areas of responsibility affected by the integration.

The questionnaire contained twelve questions. Fixed-choice questions (multiple response and yes/no) were used to measure knowledge and understanding of the
integration, what the integration meant for staff and what staff saw as their training and information needs. Likert-style scales were used to measure satisfaction with information and training given and staffs’ opinions of the integration. Open-ended questions were used to find out how staff thought their role had and would change, what staff perceived as the benefits and drawbacks of the integration and staffs’ hopes and fears about the future in an integrated service (See appendices A & B).

The evaluation was carried out using an anonymous postal questionnaire. It was felt that this was the best way of accessing the views of as many staff in the CMHTs as possible, and that anonymity would encourage respondents to be more honest in their opinions, particularly if they were critical. However, staff were asked to indicate their CMHT for data collection purposes and so that specific training and information needs for each CMHT could be highlighted. Different questionnaires for psychiatrists and non-psychiatrists also meant that this information (P/NP) could be recorded. This was thought potentially useful, as the fact that psychiatrists’ line-management accountability did not change with the integration might have meant that psychiatrists would have a different experience of the integration to non-psychiatrists. The literature also suggests that psychiatrists may have lower morale and different views of team membership than other mental health professional groups (Kendall & Pearce, 1997, cited in Norman & Peck, 1999a; Norman & Peck, 1999a, 1999b), which may potentially have led to differences between psychiatrists and non-psychiatrists.

**Design**

All non-psychiatric CMHT staff members were given the same questionnaire (NP), with psychiatrists being given an amended version of the questionnaire (P). The only difference between the two questionnaires was that in P, two irrelevant questions, related to line management, were deleted.

**Procedure**

Initially, the trainee discussed the questionnaire and its purpose with all four CMHTs at their team meetings. Questionnaires were then distributed to all staff, with a covering letter explaining the purpose of the questionnaire and what was required (see Appendix C). In total, 40 NP questionnaires and 13 P questionnaires were distributed.
Results

The overall response rate was 55% (50% for non-psychiatrists and 69% for psychiatrists), the breakdown of which is shown in Table 1.

<table>
<thead>
<tr>
<th>Team</th>
<th>Number of Respondents</th>
<th>Total Number of CMHT staff</th>
<th>Percentage of CMHT staff who responded</th>
</tr>
</thead>
<tbody>
<tr>
<td>CMHT 1 non-psychiatry (1NP)</td>
<td>7</td>
<td>9</td>
<td>78%</td>
</tr>
<tr>
<td>CMHT 2 non-psychiatry (2NP)</td>
<td>6</td>
<td>11</td>
<td>55%</td>
</tr>
<tr>
<td>CMHT 3 non-psychiatry (3NP)</td>
<td>4</td>
<td>10</td>
<td>40%</td>
</tr>
<tr>
<td>CMHT 4 non-psychiatry (4NP)</td>
<td>3</td>
<td>10</td>
<td>30%</td>
</tr>
<tr>
<td>CMHT 1 psychiatry (1P)</td>
<td>3</td>
<td>4</td>
<td>75%</td>
</tr>
<tr>
<td>CMHT 2 psychiatry (2P)</td>
<td>2</td>
<td>3</td>
<td>66%</td>
</tr>
<tr>
<td>CMHT 3 psychiatry (3P)</td>
<td>2</td>
<td>3</td>
<td>66%</td>
</tr>
<tr>
<td>CMHT 4 psychiatry (4P)</td>
<td>2</td>
<td>3</td>
<td>66%</td>
</tr>
<tr>
<td>Total non-psychiatry (NP)</td>
<td>20</td>
<td>40</td>
<td>50%</td>
</tr>
<tr>
<td>Total psychiatry (P)</td>
<td>9</td>
<td>13</td>
<td>69%</td>
</tr>
<tr>
<td>Total (All)</td>
<td>29</td>
<td>53</td>
<td>55%</td>
</tr>
</tbody>
</table>

Due to the small number of respondents, the results are not divided into different categories. Percentages for each CMHT and for psychiatrists and non-psychiatrists are reported in Appendix F. In one case, a particularly large difference between CMHT 3 and the other three CMHTs was noted. This is reported in “Opinions about the integration”. In two other cases, particularly large differences between psychiatrists and non-psychiatrists were noted. These are reported in “Roles and Responsibilities” and “Information and Training”.

Staff members were told that the questionnaires were anonymous, but were asked to indicate their CMHT for the reasons previously stated. Staff members were not asked to indicate their profession, as the small numbers of possible participants would mean that this would have seriously compromised anonymity. In order to improve the response rate, a second batch of questionnaires were distributed to all team members two weeks after the first batch.
Overall, only 14% of the qualitative comments were given by psychiatrists, even though 31% of the respondents were psychiatrists.

Roles and Responsibilities

**Table 2: Percentage (number) of respondents who correctly indicated who was responsible for the five key areas of change**

<table>
<thead>
<tr>
<th>Question</th>
<th>% correct</th>
<th>% who thought it was solely a SW responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Before</td>
<td>After</td>
</tr>
<tr>
<td>A: Vulnerable Adults</td>
<td>37% (10)</td>
<td>31% (9)</td>
</tr>
<tr>
<td>B: Obligation to assess anyone who asks for an assessment</td>
<td>62% (16)</td>
<td>40% (11)</td>
</tr>
<tr>
<td>C: Acting as an “appropriate adult”</td>
<td>70% (19)</td>
<td>59% (17)</td>
</tr>
<tr>
<td>D: Carrying out carers’ assessments</td>
<td>52% (13)</td>
<td>69% (20)</td>
</tr>
<tr>
<td>E: Care Management (purchasing care for clients)</td>
<td>86% (23)</td>
<td>69% (20)</td>
</tr>
</tbody>
</table>

**Key**

SW = task is solely a SW / SW + TM responsibility
T = task is the responsibility of all CMHT staff

For most of the questions, (all bar D), respondents were less aware of who was responsible for the five key areas after the integration than before it. However despite the fact that, before the integration, social workers were solely responsible for all five tasks, only 37% - 86% (depending on the task) of respondents thought that this was the case. This indicates some uncertainty either about who is and was responsible for specific areas, or about what exactly the questions were referring to. In general, respondents seemed to have some awareness that Health staff had taken on some of the Social Services’ responsibilities, as indicated by a reduction in the percentage who thought that social workers were solely responsible for all five tasks. However respondents were unclear as to exactly what had changed and who was now responsible.
There was no significant difference between the average number of questions respondents answered correctly for before and after the integration (Wilcoxon signed ranks test, $Z = -0.963, p > 0.05$, mean before = 2.79, SD = 1.780 mean after = 2.66, SD = 1.495).

**Table 3: Percentage (number) of respondents who thought their role had changed or would change**

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>9a: Thought role had changed</td>
<td>59% (17)</td>
<td>41% (12)</td>
</tr>
<tr>
<td>9c: Thought role would change in the future</td>
<td>79% (23)</td>
<td>21% (6)</td>
</tr>
</tbody>
</table>

Overall, 59% of respondents thought that their role within the CMHT had changed following the integration, and 79% thought that their role would continue to change. A higher percentage of non-psychiatrists than psychiatrists thought that their role had changed (65% NP: 45% P) and would change (95% NP: 45% P). The main changes highlighted were in having a higher workload because of taking on Social Services' responsibilities (55%:16), more work and higher expectations in general (17%:5), the blurring of professional roles and increased genericism (10%:3), and more paperwork (14%:4). Concern was also expressed about the line manager’s previous caseload being given to other staff, resulting in higher caseloads (7%:2).

**Table 4: Percentage (number) of respondents who thought they understood the role of their professional manager and the role of their line manager**

<table>
<thead>
<tr>
<th>Question</th>
<th>0 Not at all</th>
<th>1 Slightly</th>
<th>2 Moderately</th>
<th>3 Mostly</th>
<th>4 Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>4</td>
<td>0%</td>
<td>5% (1)</td>
<td>30% (6)</td>
<td>40% (8)</td>
<td>25% (5)</td>
</tr>
</tbody>
</table>

Nearly all (95%:19) of respondents thought that they at least moderately understood the difference between the role of their professional manager versus the role of their line manager, with a quarter claiming to understand it completely.
Opinions about the Integration and New Line Management System

Table 5: Percentage (number) of respondents who thought the integration was a good idea and had happened so far

<table>
<thead>
<tr>
<th>Question</th>
<th>0 Not at all</th>
<th>1 Slightly</th>
<th>2 Moderately</th>
<th>3 Mostly</th>
<th>4 Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>3% (1)</td>
<td>35% (10)</td>
<td>35% (10)</td>
<td>28% (8)</td>
<td>0%</td>
</tr>
<tr>
<td>3</td>
<td>7% (2)</td>
<td>7% (2)</td>
<td>28% (8)</td>
<td>48% (14)</td>
<td>10% (3)</td>
</tr>
</tbody>
</table>

Key
Q 2 = To what extent do you think the actual integration of Health and Social Services has happened yet within your CMHT?
Q 3 = Do you think the integration of Health and Social Services is a good idea?

The majority of respondents thought that the actual integration of Health and Social Services was in the process of happening but that it was not complete (98%:28 slightly-mostly), and that the integration was at least a moderately good idea (86%:25). Nearly half thought it was ‘mostly’ a good idea.

Table 6: Percentage (number) of respondents who were satisfied with the accessibility of their line manager

<table>
<thead>
<tr>
<th>Question</th>
<th>-3 Completely Dissatisfied</th>
<th>-2 Moderately Dissatisfied</th>
<th>-1 Slightly Dissatisfied</th>
<th>0 Neither</th>
<th>1 Slightly Satisfied</th>
<th>2 Moderately Satisfied</th>
<th>3 Completely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>5</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>5% (1)</td>
<td>10% (2)</td>
<td>5% (1)</td>
<td>35% (7)</td>
<td>35% (7)</td>
</tr>
</tbody>
</table>

The majority of respondents (70%:14) were moderately to completely satisfied with the accessibility of their line manager. However, CMHT 3 respondents all ranged between ‘neither satisfied nor dissatisfied’ to ‘completely dissatisfied’, making up 80% of the ‘neither’ and ‘dissatisfied’ group.
Information and Training

Table 7: Percentage (number) of respondents who were satisfied with the information and training they had been given about the integration

<table>
<thead>
<tr>
<th>Question</th>
<th>-3 Completely Dissatisfied</th>
<th>-2 Moderately Dissatisfied</th>
<th>-1 Slightly Dissatisfied</th>
<th>0 Neither</th>
<th>1 Slightly Satisfied</th>
<th>2 Moderately Satisfied</th>
<th>3 Completely Satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>25% (7)</td>
<td>18% (5)</td>
<td>7% (2)</td>
<td>25% (7)</td>
<td>11% (3)</td>
<td>14% (4)</td>
<td>0% (0)</td>
</tr>
</tbody>
</table>

Respondents were mainly negative about the information and training they were given about the integration and line management changes – nearly half (43%:12) were moderately to completely dissatisfied, and only a quarter were in any way satisfied. Psychiatrists appeared less satisfied than non-psychiatrists, with 67%(6) of psychiatrists reporting dissatisfaction compared to 42%(8) of non-psychiatrists.

Overall, 41%-59% of respondents wanted training about the new responsibilities taken on by Health from Social Services, although this varied from 0% - 100% between different CMHTs and questions. Only 10% wanted training about the role of their professional manager and how it had changed, and 14% wanted training about the role of their line manager.

The most popular way to receive training and information was through written information (66%:19). The second most popular was for the line manager to present within the regular CMHT meetings as issues arose (59%:17), with 41%(12) wanting the line manager to present within a special dedicated meeting and 35%(10) wanting a training course or meeting with an outside presenter. Other ideas suggested were professional meetings, a circulation folder, and using email and a website.
Benefits and Hopes, Drawbacks and Fears

Table 8: Percentage (number) of respondents who perceived possible benefits or drawbacks of the integration

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>10a: Perceived possible Benefits</td>
<td>63% (17)</td>
<td>37% (10)</td>
</tr>
<tr>
<td>10b: Perceived possible Drawbacks</td>
<td>83% (19)</td>
<td>17% (4)</td>
</tr>
</tbody>
</table>

63% of respondents perceived potential benefits arising from the changes, and 45%(13) stated things that they were hopeful about. These were mainly related to the benefits of integration, such as better communication with less bureaucracy, shared policies and training, joint working practices, statutory responsibilities and financial arrangements, and better continuity of care, all of which were seen as benefiting clients (41%:12). Also mentioned were potentially having more resources (17%:5), the benefits of having a line manager to mediate between individual professionals’ needs and the team (10%:3), hopes for equality in pay and status for all staff (10%:3), better managerial support for staff (7%:2) and clearer lines of responsibility and accountability (7%:2).

83% of respondents perceived potential drawbacks of the changes, with 66% (9) highlighting specific concerns. These were mainly related to the erosion of professional roles and subsequent genericism (34%:10), with the whole team being given SW responsibilities (17%:5). Also mentioned were staff leaving due to low morale (14%:4), increased paperwork (10%:3), the loss of support and training benefits that social workers had by being part of Social Services, combined with more pressure on social workers to conform to the medical model and to team concerns (10%:3), nothing changing (10%:3), more involvement in inappropriate cases with less prioritisation of the mentally ill (7%:2), and higher conformity to the medical model at the expense of social, person-centred, holistic and other professional models (7%:2).
Discussion

The majority of respondents thought that their role had changed or would change in the future, with the main change being perceived as Health taking on some of Social Services' responsibilities. However, respondents did not have a very good understanding of exactly how their roles and responsibilities had changed, and who was responsible for the five areas that previously only social workers had been responsible for.

Despite the difficulties highlighted in the evaluation, most respondents felt positive about the integration, although the majority thought that it was not yet complete. The majority of respondents were also satisfied with the accessibility of their line manager. However, respondents did not think that they had been given enough information about the integration and line management changes, with approximately half the respondents wanting information about the new responsibilities taken on by Health from Social Services. This suggests that staff should be provided with more information and training, in the ways most acceptable to them - written information and TM to present within regular CMHT meetings as issues arise. It also suggests that better ways of informing and training staff should be considered when the planned integration of other mental health services in the Trust is carried out.

Encouragingly, two-thirds of the respondents perceived possible benefits of and hopes about the integration, mainly related to having an integrated service. However, nearly all of the respondents also perceived potential drawbacks and fears about the integration, including increasing genericism and the whole team being given SW responsibilities. These fears about integration may be justified, given a study by Borrill, West, Shapiro & Rees (2000), which found that teams that were NHS and Social Services jointly commissioned were less innovative and reported lower levels of effectiveness than teams which were solely NHS commissioned. Respondents' fears about genericism are also understandable in terms of the current literature highlighting the potential dangers of genericism and the importance of difference and diversity within CMHTs (Bowen, Marler & Androes, 1985; Sainsbury Centre for Mental Health, 1997, cited in Onyett, 1999).
For most questions there were no significant differences between the four CMHTs. However, CMHT 3 respondents were significantly less satisfied with the accessibility of their line manager than other respondents, which is likely to be because the CMHT 3 TM was on long-term sick-leave and therefore unavailable. There were also some differences between psychiatrists and non-psychiatrists, such as significantly less psychiatrists than non-psychiatrists thinking their role had, or would, change, psychiatrists being less satisfied than non-psychiatrists with the information and training given, and a lower proportion of the psychiatrists than non-psychiatrists giving qualitative responses. It is postulated that these differences were related to the fact that, unlike other staff members, psychiatrists’ line-management arrangements did not change, leading to psychiatrists feeling less involved than non-psychiatrists in the integration and consequently having fewer opinions about it.

Limitations
This evaluation is limited by the response rate of 55%. The lack of demographic data collected in order to preserve anonymity meant that it was not possible to ascertain how, if at all, non-responders differed from responders. However, studies have shown that respondents are generally better motivated and more interested in the topic than non-responders (Cartwright, 1986; Jacoby, 1990). This may have led to some bias in the results, although it is impossible to ascertain in which direction this possible bias may be.

In addition, the lack of reliability and validity measures means that the reliability and validity of the evaluation may be limited.

Implications and Areas of Further Research
As highlighted, CMHT staff overall felt there was a lack of information and training about the integration. Therefore the main recommendation for this service is that CMHT staff are given further information and training, particularly in relation to changes in their roles and responsibilities.

Further areas of research are also indicated. As it is intended that the integration will be extended to other mental health services within the Trust, the evaluation results...
indicate that the Trust should focus on providing the staff involved with adequate training and information about any upcoming changes. Following this, it would be useful to evaluate these services to see if their integration experiences were any different to the experiences of staff reported in this evaluation.

It may also be useful to carry out a more in-depth study of the social workers in the Partnership, in order to fully understand the unique difficulties that they face as the only Social Services staff in a predominately Health-based system.
REFERENCES


Partnership Agreement. (2001). *Partnership Agreement. X Mental Health NHS Trust and Y Borough of Z.*


1 Reference anonymised in order to ensure service anonymity
APPENDICES

A  Questionnaire - Non-Psychiatry (NP)
B  Questionnaire - Psychiatry (P)
C  Covering letter for questionnaires
D  Service feedback information
E  Examples of responses from open-ended questions
F  Results Split by CMHT and Psychiatry/Non-Psychiatry
# Appendix A: Questionnaire – Non-Psychiatry (NP)

The Trust defines CMHT integration as the bringing together of Health and Social Care, providing clients with mental health problems with a single point of access and clinicians a single line management structure. As part of this, as of April 2001 all CMHTs within the now have a single line management structure as opposed to a multiple line management structure.

Please answer the following questions about the implications of the integration and line management changes.

1) a) Within your CMHT, who do you think is responsible for vulnerable adults (tick all that apply)

<table>
<thead>
<tr>
<th>Role</th>
<th>Before integration</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPNs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Team Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

b) Within your CMHT, who do you think is responsible for the aspect of the Community Care Act 1999 relating to the obligation to assess anyone who requests an assessment (tick all that apply)

<table>
<thead>
<tr>
<th>Role</th>
<th>Before integration</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPNs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Team Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

c) Within your CMHT, who do you think is responsible for acting as an “appropriate adult” (tick all that apply)

<table>
<thead>
<tr>
<th>Role</th>
<th>Before integration</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPNs</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical Staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychologists</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social Workers</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Team Manager</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Don’t know</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
d) Within your CMHT, who do you think is responsible for carrying out carers' assessments (tick all that apply)

<table>
<thead>
<tr>
<th>Role</th>
<th>Before integration and line management changes</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>CPNs</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medical Staff</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychologists</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Social Workers</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Team Manager</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Don’t know</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

e) Within your CMHT, who do you think is responsible for Care Management, which is about purchasing care for clients (tick all that apply)

<table>
<thead>
<tr>
<th>Role</th>
<th>Before integration and line management changes</th>
<th>Now</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>CPNs</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Medical Staff</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Psychologists</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Social Workers</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Team Manager</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Don’t know</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

2) To what extent do you think the actual integration of Health and Social Services has happened yet within your CMHT? (please circle one)

<table>
<thead>
<tr>
<th>Extent</th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Mostly</th>
<th>Completely</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>1</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>2</td>
<td>☐</td>
<td>☐</td>
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3) Do you think the integration of Health and Social Services is a good idea? (please circle one)

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4) How well do you understand the difference between the role of your professional manager versus the role of your line manager (in relation to you), for example, who to access for specific issues? (please circle one)

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5) How satisfied are you with the accessibility of your line manager? (please circle one)

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6) How satisfied are you with the information and training you were given about the integration, including the line management changes? (please circle one)

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<td>neither satisfied nor dissatisfied</td>
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<td>completely satisfied</td>
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</table>

7) How would you like / would you have liked to be given information and training about the integration and line management changes? (tick all that apply)

- Written information
- Line manager to explain within the regular CMHT meetings as issues arise
- Line manager to present within a special dedicated meeting
- Training course / meeting with an outside presenter
- Other (please specify) .................................................................

8) Which, if any, of the following issues would you like further information and training on? (tick all that apply)

i) Any responsibilities you have in relation to the following, and what this means:
   - Vulnerable adults
   - The Community Care Act 1999, which relates to the obligation to assess anyone who requests an assessment
   - Acting as an “appropriate adult”
   - Carrying out carers assessments
   - Care Management, which relates to purchasing care for clients

ii) The role of your professional manager, and how this has changed (if at all)

iii) The role of your line manager

iv) Other (please specify): .................................................................

9) a) Do you think your role within the CMHT has changed at all as a result of the integration and line management changes?
   Yes ☐ No ☐

b) If Yes, how do you think your role has changed?

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

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........................................................................................................
c) Do you think your role within the CMHT will change in the future as a result of the integration and line management changes?  
Yes ☐ No ☐

d) If Yes, how do you think your role will change?

10) Do you see any possible benefits or drawbacks of the integration and line management changes?  
Benefits: Yes ☐ No ☐
What are they?.................................................................................................................................

Drawbacks: Yes ☐ No ☐
What are they?.................................................................................................................................

11) In light of the integration and line management changes that have taken place, what are your hopes and fears about future implications?  
Hopes: ....................................................................................................................................................

Fears: .....................................................................................................................................................

12) Any other comments?

13) Please circle your team base

Thank you for filling out this questionnaire. Please return it in the stamped addressed envelope provided by Thursday 16th March.
Appendix B: Questionnaire – Psychiatry (P)

The Trust defines CMHT integration as the bringing together of Health and Social Care, providing clients with mental health problems with a single point of access and clinicians a single line management structure. As part of this, as of April 2001 all CMHTs within the now have a single line management structure as opposed to a multiple line management structure.

Please answer the following questions about the implications of the integration and line management changes.

1) a) Within your CMHT, who do you think is responsible for vulnerable adults (tick all that apply)

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b) Within your CMHT, who do you think is responsible for the aspect of the Community Care Act 1999 relating to the obligation to assess anyone who requests an assessment (tick all that apply)

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<td>Administration staff</td>
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c) Within your CMHT, who do you think is responsible for acting as an “appropriate adult” (tick all that apply)

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**d) Within your CMHT, who do you think is responsible for carrying out carers' assessments (tick all that apply)**

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**e) Within your CMHT, who do you think is responsible for Care Management, which is about purchasing care for clients (tick all that apply)**

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2) To what extent do you think the actual integration of Health and Social Services has happened yet within your CMHT? (please circle one)

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3) Do you think the integration of Health and Social Services is a good idea? (please circle one)

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4) How satisfied are you with the information and training you were given about the integration, including the line management changes? (please circle one)

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5) How would you like / would you have liked to be given information and training about the integration and line management changes? (tick all that apply)

- Written information
- Line manager to explain within the regular CMHT meetings as issues arise
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- Training course / meeting with an outside presenter
- Other (please specify) ..............................................................................................................

6) Which, if any, of the following issues would you like further information and training on? (tick all that apply)

i) Any responsibilities you have in relation to the following, and what this means:

- Vulnerable adults
- The Community Care Act 1999, which relates to the obligation to assess anyone who requests an assessment
- Acting as an “appropriate adult”
- Carrying out carers assessments
- Care Management, which relates to purchasing care for clients

ii) The role of the team line manager

iii) Other (please specify): ..............................................................................................................

7) a) Do you think your role within the CMHT has changed at all as a result of the integration and line management changes?

   Yes □  No □

b) If Yes, how do you think your role has changed?

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

c) Do you think your role within the CMHT will change in the future as a result of the integration and line management changes?

   Yes □  No □

d) If Yes, how do you think your role will change?

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8) Do you see any possible benefits or drawbacks of the integration and line management changes?

Benefits: Yes ☐ No ☐
What are they? ..........................................................................................................................

Drawbacks: Yes ☐ No ☐
What are they? ..........................................................................................................................

9) In light of the integration and line management changes that have taken place, what are your hopes and fears about future implications?

Hopes: ...........................................................................................................................................

Fears: ...........................................................................................................................................

10) Any other comments?

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

11) Please circle your team base

Carshalton Cheam Sutton South Wallington

Thank you for filling out this questionnaire. Please return it in the stamped addressed envelope provided by Thursday 14th March.
Appendix C:

Covering Letter for Questionnaires

27th February 2002

Dear CMHT staff member,

I am carrying out an audit to look at the effects that the integration of Health and Social Services and the change from a multiple line management structure to a single line management line structure has had on the four CMHT Teams ( ), and team members' understanding of this change.

The purpose of this study is twofold. Firstly, to inform the line managers, teams and the trust as to people's understanding of and views about the changes. Secondly, to inform the line managers and the trust about what staff see as their training and information needs related to the changes.

In order to do this, all CMHT staff members are being asked to complete the attached questionnaire. Please answer all the questions, but if you feel uncomfortable about answering any of the questions then leave those questions out. You are also asked to indicate your team base at the end of the questionnaire. This is in order to look at the specific training and information needs of each team.

All questionnaires are anonymous and, in order to ensure this anonymity, results will be reported as a group and the raw data will not be seen by anyone apart from me.

Psychiatry staff are asked to complete an adapted questionnaire with irrelevant questions deleted. This is because psychiatry staff have remained line managed by their professional managers and hence are not line managed by the team line managers. The questionnaires are identical to those given to the rest of the CMHT other than the deletion of questions relating to line management.

Please return your completed questionnaire in the sealed envelopes provided, directly to me, by Thursday 14th March.

If you have any queries about this questionnaire, please contact me at CMHT on Wednesdays, Thursdays or Fridays, on

Thank you for your help.

Yours sincerely,

Beth Freeman
Trainee Clinical Psychologist.
Appendix D:

Service Feedback Information

Ms Beth Freeman

12th November, 2002

Dear Beth,

Thank you for sending your report on your small scale research project on the views of staff following the merging of health and social care in our trust. The results were very interesting and useful in highlighting issues that we need to be dealing with.

I wish you all the very best with your studies.

Yours sincerely,

Consultant Clinical Psychologist
Adult Mental Health Service
8th September 2002

Dear

As you may remember, a few months ago I asked all the CMHT staff members to fill in a questionnaire looking at their views about the integration of Health and Social Services and the change from a multiple line management structure to a single line management line structure. I have now written up the results of this, and have enclosed a copy of my report for your team. If you have any questions, please contact me on

Yours sincerely

Beth Freeman
Trainee Clinical Psychologist
Appendix E:

Examples of responses from open-ended questions

Question 9: Do you think your role within the CMHT has or will changed at all as a result of the integration and line management changes?

Higher workload because of taking on Social Services work (55%:16)
“expectation to take on more roles seen previously as the expertise of Social Workers”
“other professionals will have to take on SW work such as care management”
“SW responsibilities being spread across the team – expectation that we will take on more work”

Having more work and higher expectations in general (17%:5)
“increased expectation to attend meetings”
“more responsibility”

The blurring of professional roles and increased genericism (10%:3)
“less distinctive professional roles”
“become more generic”

Having more paperwork (14%:4)
“more paperwork”
“more paper, statutory information and guidance”

Higher caseloads had resulted from the line manager’s caseload being given to other professionals in the team when they became the line manager (7%:2)
“It has become much more stressful – the Manager had to hand over her case load to other staff”

Questions 10 & 11: Benefits and Hopes

Better communication with less red tape and bureaucracy, shared policies and training, joint working practices, statutory responsibilities and financial arrangements, and better continuity of care, all of which were seen as benefiting clients (45%:13)
“better communication, integrated policies and integrated training”
“developing joint working practices, shared ethos – full integration in terms of statutory responsibilities”
“fewer problems with financial argument between what constitutes social or health care”
“that it will be less bureaucratic and reduce paper-chasing”

Having more resources (17%:5)
“it will attract more resources”
“better resources”
The benefits of having a line manager to mediate between individual professional’s needs and the team (10%:3)
“being able to discuss issues about my role with one person rather than the team as a whole”

Equality for all team members in terms of pay and status (10%:3)
“that there may be some parity in pay structures through the team”
“that each gives respect for each other in the team”

Better managerial support for all CMHT staff members (7%:2)
“team members will feel supported in their roles within the team”
“someone readily available on site to address your concerns and difficulties”

Clearer lines of responsibility and accountability (7%:2)
“easy, clear management structure and lines of responsibility”
“clearer lines of accountability”

Questions 10 & 11: Drawbacks and Fears

The erosion of professional roles and subsequent genericism (24%:7), with the whole team being given SW responsibilities (17%:5)
“loss of professional roles – becoming generic mental health workers”
“people’s professions will become non-existent – won’t be recognised as having specialist skills”
“we will be asked to take on SW duties”
“previous responsibilities of social workers will be spread to the whole team”

Staff leaving due to low morale (14%:4)
“I want to leave and previously loved my job”
“things will not work and staff will become resentful and bitter and leave”

Increased paperwork (10%:3)
“it should work for the benefit of users but presently increased paperwork is detracting from this”
“more bureaucracy and paperwork”

The loss of support and training benefits of social workers had by being part of social services, combined with more pressure on social workers to conform to the medical model and to team concerns (10%:3)
“less independence for social workers – more pressure to conform to team concerns and the medical model”
“Social Services staff have lost the good support from colleagues and training around Social Services issues”

Nothing actually changing (10%:3)
“I don’t expect any change”
“nothing actually changing”
More involvement in inappropriate cases with less prioritisation of the mentally ill (7%:2)
“loss of current model which aims to rightly prioritise severely mentally ill”
“more involvement in possibly inappropriate cases”

Higher conformity to the medical model at the expense of social, person-centred, holistic and other professional models (7%:2)
“more conformity – especially to the medical model at expense of social, person-centred, holistic and professional models”
Appendix F:

Results Split by CMHT and Psychiatry/Non-Psychiatry

All raw data is reported as percentages of the particular category
- = Not Applicable

Key

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Roles and Responsibilities

Question 4: How well do you understand the difference between the role of your professional manager versus the role of your line manager (in relation to you), for example, who to access for specific issues?

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Question 9a: Do you think your role within the CMHT has changed at all as a result of the integration and line management changes?

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Question 9c: Do you think your role within the CMHT will change in the future as a result of the integration and line management changes?

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Opinions about the integration and new line management system

Question 2: To what extent do you think the actual integration of Health and Social Services has happened yet within your CMHT?

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Question 3: Do you think the integration of Health and Social Services is a good idea?

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Question 5: How satisfied are you with the accessibility of your line manager?

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Information and Training

Question 6: How satisfied are you with the information and training you were given about the integration, including the line management changes?

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150
Question 7: How would you like / would you have liked to be given information and training about the integration and line management changes?

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Question 8: Which, if any, of the following issues would you like further information and training on?

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(ia) = Vulnerable adults
(ib) = The Community Care Act 1999, which relates to the obligation to assess anyone who requests an assessment
(ic) = Acting as an “appropriate adult”
(id) = Carrying out carers assessments
(ie) = Care Management, which relates to purchasing care for clients
(ii) = The role of your professional manager, and how this has changed (if at all)
(iii) = The role of your line manager

Benefits and Hopes, Drawbacks and Fears

Question 10: Do you see any possible benefits or drawbacks of the integration and line management changes?

- Benefits

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- Drawbacks

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Caucasian British Men's Views about People with Mental Illness

May 2003

Year 2
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Introduction

There have been numerous studies looking at beliefs about and attitudes towards people with mental illness (Ng & Chan, 2000). In general, these studies have found that these attitudes tend to be negative (Shokoohi-Yekta & Retish, 1991). For example, studies have found that people tend to judge those with a mental illness as more dangerous, unpredictable, weak, insincere, irresponsible, incompetent, unreliable and worthless than those without a mental illness (Green, McCormick, Walkey & Taylor; Nunnally, 1961; Patten, 1992: all cited in Read & Law, 1999; Read & Law, 1999; Pearson & Yiu, 1993, cited in Ng & Chan, 2000).

However, relatively few studies have looked specifically at men's views about people with mental illness. Those that have, have mainly found that men tend to hold more negative and less benevolent attitudes towards people with mental illness than women and to focus more on the negative dimensions of having a mental illness (Bhugra, 1989, cited in Ng & Chan, 2000; Cohen and Struening, 1962, cited in Fan, 1999; Read & Law, 1999).

There is evidence that attitudes and beliefs towards mental illness and people with mental illness have an important effect on people's accessing of mental health services and on the self-views that people with mental illness hold (Leong & Zachar, 1999; Read & Law, 1999; Sheikh & Furnham, 2000). Views about mental illness are therefore an important area for research. In particular, it is important to examine men's views as men have been found to be less likely to express the need for and to seek professional help and to have less positive views towards seeking professional help than women (Leong, & Zachar, 1999; Sheikh & Furnham, 2000).

The aim of this study was therefore to explore men's views about people with mental illness. However, bearing in mind the small sample size (four participants) and studies indicating that race and culture may have a significant impact on views about people with mental illness, this study will focus on Caucasian British men's views (Diala, Muntaner, Walrath, Nickerson, LaVeist & Leaf, 2001; Fan, 1999; Sheikh & Furnham, 2000; Shokoohi-Yekta & Retish, 1991).
The majority of previous studies have explored men’s views from the basis of a fixed questionnaire, from rating scales or from other quantitative measures. This study therefore set out to explore men’s views from a more exploratory, qualitative perspective in order to more fully explore the potential complexity of participant’s views.

Method

Participants

Due to time limitations, opportunity sampling was used to recruit participants from men known to the researchers. Close friends, family members and men who had a current or recent mental illness were excluded.

Interview Schedule

Four men were interviewed face-to-face about their views about people with mental illness. Before the interview participants were asked to complete a demographic information sheet. The interview schedule began with questions about their thoughts, feelings and images of people with mental illness, followed by questions about their knowledge of mental illness and what mental illness meant to them; their views about why people become mentally ill and who becomes mentally ill; how they thought they would react if someone close to them told them they had a mental illness; their views on how people with a mental illness could be helped; and how being interviewed by a trainee clinical psychologist had affected their responses. Throughout the interview the researchers asked participants where they thought their thoughts and ideas had come from. The interviews lasted between half an hour to an hour. All were audio-recorded and transcribed verbatim. The interview was modified on the basis of a pilot before being used.

Analytic Strategy

The data were analysed using Interpretative Phenomenological Analysis (Smith, 1996; Smith, Jarman & Osborn, 1999; Willig, 2001). IPA is a systematic way of analysing
qualitative data that is both phenomenological—it is concerned with an individual’s thoughts, feelings and experiences from their own perspective—and interpretative—it relies on these perceptions being interpreted by the researcher within his own interpretative framework, and on the interaction between researcher and participant.

To carry out the analysis, all four researchers initially read and re-read the transcripts, making notes on them about initial thoughts and observations. These notes included content summaries, connections and links between sections, and initial interpretations. Secondly, the individual researchers identified key themes within each transcript. The four researchers then came together to discuss these initial themes and to ensure that the themes were consistent and apparent in the transcripts. The four transcripts were then analysed together, in order to identify theme patterns across the transcripts as well as clusters of themes and links between the themes. A summary table of themes was produced to order the accounts.

When using IPA, the analysis is affected by the researcher’s own perspective and interpretative framework (Elliott, Fischer & Rennie, 1999). Therefore it is important to make clear that all four researchers were women and all were training to be clinical psychologists and hence had significant knowledge and understanding of mental illness. This difference in background between researchers and participants may have potentially led to misinterpretations of that data. However, it was hoped that the four researchers would be able, through discussion, to identify and overcome any idiosyncratic interpretations.

Due to the subjective nature of qualitative research, criteria such as reliability that are commonly used to evaluate quantitative research are inadequate. Therefore alternative criteria, which are more appropriate for evaluating qualitative research, will be used. The key criteria specifically relevant for this research is “grounding in examples”, using interpretations of the data and taking quotes from the interview transcripts (Elliott, Fischer & Rennie, 1999). In these quotations, empty brackets indicate omitted material, information within square brackets indicates added clarificatory material, and ellipsis points (... ) indicate a pause in the participant’s flow of speech.
Analysis

Demographic Information
Participant’s mean age was 25.25 years (range 23-29; SD 2.6). Two of the participants were students and two had professional jobs (International Labour Office, 1990). In terms of highest educational qualification, two participants had degrees and two had postgraduate degrees. All four participants were classified as single and none had children. All of the participants lived in or around London.

Themes
Seven main themes emerged from the interviews and were apparent in all four interviews. These are briefly described below. Because of space constraints, the main portion of the analysis will focus on only two of the key themes.

Images about people with a Mental Illness
Participants expressed a number of stereotypical views about people with a mental illness, which were generally negative.

Participants Negative Feelings about People with a Mental Illness
Participants expressed a range of negative feelings when thinking about people with a mental illness, including anxiety, concern, helplessness and fear.

Knowledge and Understanding
Participants all demonstrated some knowledge and understanding of mental illness but varied in the nature of their perceptions and recognised that their knowledge was limited. There were three predominant sources of their knowledge and understanding – the media, personal experience and society-based views.

Difference versus Normality
Participants talked about the similarities and differences between people with and without a mental illness, and how mental health problems could be on a continuum with normality.
Secrecy
Participants talked about the difficulty people, particularly men, may have in talking openly about mental illness and feelings and negative emotions in general. However they also talked about the benefits of talking to others about these things.

How Society Responds to People with a Mental Illness
All four participants gave spontaneous views on the role of society in response to people with a mental illness.

Gaps in Care and Support and What is Needed
Participants expressed views about the need for practical help and social support for people with a mental illness and how they feel this is lacking at present.

How Society Responds to People with a Mental Illness
All four participants gave spontaneous views on the role of society in response to people with mental illness. This can be further split into six main sub-themes, which will be discussed individually.

Stigma, stereotypes and judgements and prejudice
In general, participants thought society tended to stigmatise, make negative judgements about and be prejudiced against people with mental illness:
"we all, we all have prejudices at the end of the day whether we admit it or not, whether we're honest about them or not, whether we're conscious of them or not." (Patrick).
Andrew and Patrick also talked about the negative impact these views may have on people with mental illness:
"I think one of the major societal problems about mental illness is not specifically to do with the people with mental illness but to do with how society reacts to them [] with fear and with prejudice and with anxiety." (Patrick)
"Society helps people to stigmatise themselves." (Andrew)
Participants thoughts about stigma and stereotyping in society were linked to their own views and images about people with mental illness, which they suggested were likely to come from cultural and media stereotypes:

"I suppose in films you get a very black portrayal of people who have these [ ] more severe problems" (George)

These views echo results from previous studies indicating that social stigma and prejudice tends to be associated with mental illness (Ng & Chan, 2000; Read & Law, 1999). This sub-theme was also linked to the theme of secrecy, in that participants thought that people with a mental illness may be reluctant to tell others about it for fear of their reaction:

"If you say I’ve got a mental illness, if you tell your friends and family they’ll go ‘oh no’ and you’re thinking oh I wish I’d never mentioned it now” (David)

**Lack of sympathy**

Patrick also discussed his concern about the lack of sympathy for people with mental illness:

"The one large concern I do have about it is people’s reactions to the situation and perhaps a lack of sympathy"

Previous studies have indicated that people generally judge people with a mental illness more negatively than those without and may, in many cases, be unsympathetic towards them (Read & Law, 1999). However, there is a lack of studies specifically exploring sympathy towards people with mental illness.

**Lack of knowledge and understanding**

Three participants talked about how they thought there was a general lack of knowledge and understanding about mental illness:

"it is one of those things that isn’t well enough understood” (Andrew)

Patrick talked about what he thought the results of this lack of knowledge and understanding were:

"Well, I suppose, I mean, ignorance breeds and fear breeds aggression”

and how this could exacerbate the difficulty of the person with the mental illness:

"from the point of view of the person who’s suffering from that [borderline personality disorder], not only having the condition, but also in some cases having to
put up with other people’s reactions to it, if it is a reaction that is based on ignorance or perhaps a reaction which is aggressive and misunderstood."

Studies have shown that, in general, mental health knowledge is poor and the way people come to understand both their own and others’ mental illness is related to wider cultural mental illness beliefs (Fan, 1999; Read & Law, 1999; Sheikh & Furnham 2000). Thus the sub-theme of lack of knowledge and understanding in society was also linked to participants’ thoughts about their own lack of knowledge and understanding. This link was clearly stated by Patrick, who said that one of the ways he had acquired his knowledge and understanding was:

“through assumption... through people’s common perception”.

**Negative and labelling language**

All four participants talked about how the language that was used to describe people with mental illness was often used in a negative, labelling way, and how this could have a negative effect on people with mental illness or on people’s perceptions of people with mental illness:

“terms like nutters, loonies, weirdos and so on and so forth are applied, and you know, in casual pub conversation someone may say ‘what’s wrong with you, are you mental, are you a nutter’ if someone reacts in a strange way, and it becomes part of the common vernacular.” (Patrick)

“actually having that term [mental illness] I guess in a way could make you worry more and make you more anxious about it [] because it has negative connotations” (George)

This was, to an extent, illustrated throughout the interview by the overwhelmingly negative way in which the participants perceived having a mental illness, and by the negative feelings they talked about in association with this.

**Lack of care, not looking after people properly**

Andrew talked about how he thought society in general did not adequately care for people with mental illness:

“the people I have seen are usually people who aren’t being looked after, aren’t being cared for and are distressed [] I do believe that there aren’t the support structures in society at the moment [] Society can’t be arsed, it is easier to push it to the side.”
This sub-theme was linked to the separate theme about gaps in care and support and what participants thought was needed to support people with mental illness, which was discussed by all four participants.

Social pressures and expectations
Participants also talked about society in terms of its causal role in mental illness. For example, Patrick said that he thought larger families and higher social cohesion in some cultures to some extent protected people in those cultures from mental illness, and Andrew talked about how the lack of support networks for people in society and people's isolation could lead to them having mental illness. David also discussed how the societal pressures could lead to people developing a mental illness:

"if you're very high up the socio-economic class system you may feel people have very high expectations of you and you may feel you can't achieve them then you're probably more likely to get depressed and anxious"

These thoughts that society plays a causal role in mental illness are to some extent supported by current research, although the area is contentious ('Men need more health care', 1999). However, studies show that it is a widely held view among the general population (Jorm, Korten, Jacomb, Christensen, Rodgers & Pollitt, 1997; Wahl, 1987, cited in Read & Law, 1999). This sub-theme is also linked to the theme of gaps in care and support in terms of what is needed to protect people against mental illness, such as increased social support.

Difference versus Normality
All four participants talked about how people with a mental illness were different from people without. For example, George described people with a mental illness as:

"People who hmm are maybe apart from the rest of society, I suppose, who are different in some way"

The participants tended to see those without a mental illness as 'normal', and hence those with a mental illness as different or 'abnormal':

"People who have that presumably go into a normal situation [] and they are unable to cope at the same sort of level as a normal person" (David).
These comments are consistent with research showing that the general public tend to see people with mental illness as distinctively different from others, judging them more negatively on a range of personality and personal traits such as warmth, predictability, dangerousness and worth (Nunnally, 1961, cited in Ng & Chan, 2000; Ng & Chan, 2000; Read & Law, 1999). This sub-theme was related to the themes of participants’ negative feelings about people with a mental illness and their images about people with mental illness. For example, Patrick said:

“someone with a mental illness getting angry or confused and just killing someone else or something”.

At times the participants also specifically separated themselves from people with a mental illness, either by overtly saying why they were unlikely to become mentally ill themselves or by classifying themselves as ‘normal’, and hence without a mental illness:

“Depression, erm. I suppose people [] feeling down, feeling low, feeling unhappy. Possibly more-so than normal, although obviously that’s a, it’s a very subjective term, what is normal, [] people feeling down and unhappy [] and that becoming an ongoing thing rather than, you know, without saying normal people but all the rest of us” (Patrick)

“I believe in controlling my environment, I believe that I can positively influence that way that I think and my environment around me, and therefore I’ll make sure that I don’t get to a similar state” (Andrew)

Patrick also to some extent separated himself from the issue of mental illness by describing those people who he thought were likely to become mentally ill in a way that was obviously different to him:

“Possibly amongst, quote, the underclass of people on very low income, people on the breadline, possibly people on benefits and on welfare”

This finding echoes other studies suggesting that people tend to hold the concept of mental illness at a social distance from themselves. For example, Graubert & Adler found that, using a figure placement test, people placed the concepts of mental patients and mental hospitals furthest from themselves (Graubert & Adler, 1977, cited in Shokoohi-Yekta & Retish, 1991). Other studies have indicated that men may be more likely than women to believe there is something inherently wrong with people
with mental illness, which may help explain why the participants felt the need to distance themselves from people with mental illness (Leong & Zachar, 1999).

However, at other times participants also suggested that mental illness may be on a continuum of severity, and may be something that could affect them too:

“everyone gets low in mood from time to time and I suppose that’s [a less severe form of what you call depression]” (George)

“there is potential in all of us to be that way, just like there is potential for people not to be.” (Andrew)

“it can affect anybody” (David)

This accords with studies suggesting that the majority of people believe mental illness is caused by environmental stresses and traumatic events, and hence is something that could affect most people given the right circumstances (Jorm et al, 1997).

This contradiction between people with mental illness as separate and mental illness being something that could affect anyone could be partially explained by the fact that the participants seemed to hold different views about different mental illnesses. For example, depression was seen as being less severe and relatively common, whereas schizophrenia and other mental illnesses were seen as rarer and more serious. This is linked to the idea of mental illness being on a continuum, with mental illness varying in severity. For example, George said:

“I would think of first of all serious mental health problems people who had been ill for a long time, [people who are hallucinating, seeing things, hmm, you know, very disturbed, and [things like depression, and I suppose that would be less serious.]” and Andrew said

“it must be different for different types of ailments, for different types of mental illness”.

Thus it can be seen that participants held what may seem to be contradictory views about people with a mental illness being both similar to and different from other people, but this can be partially explained by their views about the differences between different mental illnesses and mental illness being on a continuum of severity.
Overview

This study indicates some of the key themes present in Caucasian British men’s views about people with mental illness. As previously discussed, these views are important as they impact on people’s accessing of mental health services. This is particularly important for men, who tend to be more reluctant than women to access services. This is therefore an important issue for services to address. Within the interviews, participants also highlighted the role of individuals’ views about people with mental illness in shaping others views and in impacting on people with a mental illness, as well as their own views about people with mental illness being both separate from and similar to themselves. This is important, as it highlights how men may hold very contradictory views on people with mental illness and how this can impact on others.

However, although this study aimed to explore Caucasian British men’s views about people with mental illness, the small sample size meant it was difficult to ensure that the sample was representative and the sample comprised wholly of well-educated men in their 20's. Bearing in mind research evidence suggesting that age, education and socio-economic status can all be important factors in men’s views about people with mental illness, any conclusions drawn from this study must be tentative because of concerns about how representative these views are of Caucasian British men (Johnson & Beditz, 1981, cited in Ng & Chan, 2000; Ng & Chan, 2000; Sheikh & Furnham 2000).

Nevertheless, this study highlights the importance of further research into men’s views of people with mental health problems, both looking further at a larger sample of Caucasian British men and extending the sample to include men from a wider variety of backgrounds.
References


Appendices

Appendix A: Interview Schedule

Appendix B: Information Sheet

Appendix C: Consent Form

Appendix D: Transcript
Appendix A:

Interview Schedule

PsychD Clinical Psychology, University of Surrey
Qualitative Research

Interview Schedule

Introduction
We are interested in people's views about mental illness. Mental illness is called different things by different people. Other terms include: mental health problems, mental disorder, madness and so on. What would you prefer to call it?

1. When you think of people with mental illness (or their term), what comes into your mind?
   - What thoughts go through your mind when you say that?
   - What pictures/images go through your mind when you say that?
   - What feelings does the term mental illness evoke for you?
   - What do you think people with mental illness look like?
   - Tell me what you mean by......?
   - Tell me more about it?

   - Where do you think your ideas come from?

2. What kinds of mental illness are you aware of? Can you give some examples?
   - What does X mean to you?
   - What do you think X is?
   - If someone had this now how would it affect them?
   - Can you think of any other kinds of mental illness?

   - How do you know about these? (Go through each one)

3. Why do you think people become mentally ill?
   - Can you think of any other possible causes?

4. Do you think some people are more likely to become mentally ill than others?
   If answer is "yes"
   - Who is more likely? (Determine views on gender, culture, age, socio-economic class)
   - What makes these people more likely to become mentally ill?
PsychD Clinical Psychology, University of Surrey
Qualitative Research

Interview Schedule

If answer is "no"
- Why do you think this?

For both
- Where do your ideas on this come from?

5. Imagine that someone close to you told you that they have a mental illness.
   How would you feel?
   How would you react?
   What would you think about them?
   How would it influence your relationship?
   Would it create any difficulties in the relationship?
- Where do you think these ideas come from?

6. Do you think people with mental illness can be helped?
   If “yes”
   Can you think of some ways that people with mental illness can be helped?
   If no?
   Why do you think this?

7. In what way has being interviewed about mental illness affected you?

8. In what way has being interviewed about by a trainee clinical psychologist affected what you’ve said?

9. Is there anything else you would like to add regarding your views regarding mental illness?

Thank you for your time
Appendix B:

Information Sheet

PsychD Clinical Psychology, University of Surrey
Qualitative Research Project
Participant Information Sheet

Title of Project: Caucasian British Men's Views of People with Mental Illness

Researchers:

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

The Project:

Research suggests that demographic differences (e.g. cross-cultural) may exist regarding views on people with mental illness. Yet, there is little information regarding any possible gender differences. As such, we are interested in considering men’s views on people with mental illness.

Why have I been chosen?

Participants are selected on the basis that they have no current or recent history of mental illness. This exclusion criterion has been introduced to reduce the possibility of causing participants unnecessary distress. Mental health professionals are also excluded from the study, as we are interested in the public's views of mental illness.

What will happen to me if I take part?

You will be asked to read and sign a consent form and to complete a background information sheet stating your age, ethnic origins, highest educational qualification, current occupation, current legal marital status and specifying whether or not you have any children. You will also be asked to complete a structured interview, which will be tape recorded for the purposes of transcription.

It should take no longer than one hour to complete the interview.

Confidentiality

All information collected during the course of the project will be kept entirely confidential. Your consent form will be separated from the tape recording and transcript of your interview and kept in a locked drawer. The tape recording and transcript will remain anonymous and the tape recording will be erased at the end of this project.
What are the possible disadvantages and risks of taking part?

There are no known risks, although participation might cause you to reconsider some of your experiences with other people. The interview might also give rise to difficult feelings particularly if you have a close friend or relative with a mental illness. If this is the case please discuss this with the researcher who has invited you to participate.

What will happen to the results of the study?

The results will be written up and submitted as Qualitative Research Projects as part of the PsychD in Clinical Psychology.

Who is organising the research?

The research is being organised by four Trainee Clinical Psychologists as part of the PsychD in Clinical Psychology:
The research is being supervised by, Department of Psychology, University of Surrey.

For further information about the study, please contact the trainee who has invited you to participate. Please also let the trainee know if you would like a copy of the report.
Appendix C:

Consent Form

PsychD Clinical Psychology, University of Surrey
Qualitative Research Project
Views on people with mental illness

CONSENT FORM

- I the undersigned voluntarily agree to take part in the above mentioned study.

- I have read and understood the Information Sheet provided. I have been given a full explanation of the nature and purpose of the study, and what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

- I agree to comply with any instructions given to me during the study and to co-operate fully with the investigator.

- I understand that all personal data relating to volunteers is held and processed in strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

- I understand that I am free to withdraw from the study without needing to justify my decision and without prejudice.

- I confirm that I have read and understood the above and freely consent to participation in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of investigator ..............................................

Name of volunteer ..................................................
(BLOCK CAPITALS)

Signed ...............................................................

Date .................................................................
Appendix D:

Transcript

Patrick - Interview Transcript

As you know, we are interested in people's views about mental illness. Mental illness is called different things by different people. Other terms include mental health problems, mental disorder, madness and so on. What would you prefer to call it?

Erm, I guess mental illness, that's OK.

When you think of people with mental illness, what comes into your mind?

Erm, a lot of things. Sick people, depressed people, confused people, sometimes people that are violent, sometimes people that are not. Er, I suppose a whole array of things, it’s hard for me, I suppose in a way, to think about it deeply, to empathise with it, in that I haven’t had any, sort of particular personal experience.

Right. So what thoughts go through your mind when you say all of this?

Well, I guess, just a bit confused, not really understanding, just thoughts about people being depressed or confused.

And what feelings does the term mental illness evoke for you?

Erm, I suppose a little bit of anxiety, a little bit of sorrow, something along the lines of wanting to understand.

Mmmm. What pictures or images go through your mind when you talk about people with mental illness?

Err, erm, I suppose all sorts of things really, again, maybe someone looking angry or depressed or confused. I think in a way possibly I do in some way associate it with violence in some way, so I suppose perhaps in some ways violent images, but I suppose all sorts.

What do you mean by violence and violent images?

Well, I guess, I don’t know, I mean maybe someone being confused and hurting someone else, maybe someone killing someone, like someone with a mental illness getting angry or confused and just killing someone else or something, I can’t remember what it was, but I’ve seen things in the papers.

What do you think people with mental illness look like?

I don’t know really, I mean what’s a stockbroker look like, what’s anyone look like. I wouldn’t necessarily know someone was mentally ill unless they said so or unless someone else said so. I can’t say I particularly associate someone looking in a certain way and therefore being mentally ill so it’s a bit hard for me to answer that question.

Where do you think your ideas come from?

I suppose, you know, in a small way having worked for Nightline when I was doing my undergraduate, a little bit of work I did for my Student Union, a few practical
issues. Apart from that I suppose the same as anyone else really, through the media and people’s common perception.

What do you mean by common perception?
Well I guess, just what people talk about, you know, in the pub, now I’ve said it I don’t really know. I guess they’ve probably all got their ideas from the media too, and maybe from people they’ve known.

What kinds of mental illness are you aware of? Can you give some examples?
I suppose borderline personality disorder is one I know of, ‘cause a friend of mine’s mother is diagnosed with that condition. Schizophrenia I suppose I’m aware of, again through the media, although on the other hand I am led to believe that that’s a sort of a catch-all phrase that’s used to describe a whole host of different conditions, all sorts of ones really.

So what does borderline personality disorder mean to you?
I don’t know, I don’t know that it..... oh God.

What do you think borderline personality disorder is?
Well a lot of this would be from, erm, based on making assumptions and based on what my friend who’s mother has the condition has said and from what I understand no doubt it is an ignorant point of view. I understand it’s maybe associated with mood swings and erm people having different approaches to life and different, well, you know, as it sounds, different personalities, different takes on situations in different moods and them changing.

If someone had borderline personality disorder now, how would it affect them?
Well, erm, you tell me! Again, this is all assumption. Possibly, without repeating myself, I would guess erm, you know, people having different moods or going through perhaps periods of anxiety or perhaps depression or perhaps confusion, and you know I suppose as well as that, as a reflection of that, from the point of view of the person who’s suffering from that, not only having the condition, but also in some cases having to put up with other people’s reactions to it, if it is a reaction that is based on ignorance or perhaps a reaction which is aggressive and misunderstood.

How do you think other people may react?
Well, I suppose, I mean, ignorance breeds and fear breeds aggression, so maybe in an aggressive way.

What does schizophrenia mean to you?
I suppose, again, that’s probably again one I associate with violence and people being temperamental and unpredictable, again this is based on things I’ve read as in nothing too serious, you know, newspapers TV and so forth. I think there have been some cases where people with schizophrenia have been let out of mental institution and in some cases killed people, and there have been outcries about that. So yeah, I suppose I do associate it with violence.

If someone had schizophrenia now, how would this affect them?
Erm, they’d maybe be confused, a bit unpredictable, I don’t really know.
You’ve mentioned depression. What do you think depression is?
Depression, erm. I suppose people feeling erm feeling down, feeling low, feeling unhappy. Possibly more-so than normal, although obviously that’s a, it’s a very subjective term, what is normal, but possibly feeling more down or unhappy than they should do and perhaps that becoming a cycle and so on and so forth, but I er suppose in a nutshell people feeling down and unhappy regularly and perhaps for no specific reason and that becoming an ongoing thing rather than, you know, without saying normal people but all the rest of us. Like myself, I’m pretty sure I don’t suffer from depression but you know, who knows, if I get a bad mark or if I crash my bike or something and I feel down but then I bounce back, so I suppose not bouncing back.

You said that ‘not bouncing back’ is one way someone might be affected by depression. How else do you think someone’s life might be affected by depression?
I suppose in the most severe cases it could lead to them taking their own lives. Erm, and it could have a very negative impact on the way they lead their lives, and on their outlook and on their ambitions and on their drive.

We’ve talked about borderline personality disorder and schizophrenia and depression. Are there any other types of mental illness that you know about?
Erm, not that I can think of, no.

Why do you think people become mentally ill?
Oh my God! I don’t know really. I could speculate that, erm, I suppose if I were to speculate there would have to be two probable areas. One would be potentially hereditary or genetic and one would be through some sort of process of socialisation. But specifically, I really couldn’t say.

Can you expand on that?
Well, erm I don’t really know, I guess, just their environment, I don’t really know.

Can you think of any other causes?
Erm, I suppose perhaps a specific event that caused a great deal of emotional upheaval or was very upsetting, like some sort of accident or a bereavement, like something like that, something quite spectacularly bad maybe.

Do you think some people are more likely to become mentally ill than others?
Erm, I’m not sure really. I mean, if one were to agree that it could be genetic and it could, some sort of symptom or syndrome and it could be hereditary then yeah, in that case it could. Or again, if one were to believe it was to do with the process of socialisation then, if one person were subjected to that, again, it could. You know, using the idea of it being associated with a specific incident or episode then it’s completely contingent on that.

So if some people were more likely to become mentally ill, who would be more likely?
Well I guess, I’d probably say men, and the reason I’d think that in western culture, because I can’t, I wouldn’t be able to, as a man, because I think men socialise in different ways and they’re less open and honest about their emotions and their feelings, around people generally and amongst other men particularly. Juxtaposing that with women I think it’s a very different situation, women are more likely to talk to their
friends and people about those kinds of things. I think, you know, with mentally ill
generally I’m not so sure about, but with something like depression, I mean, for
example, I do understand with men they’re more likely to successfully commit suicide
amongst other things.

What about socio-economic group? Do you think there are any differences there?
Erm, maybe, maybe not. Possibly amongst, quote, the underclass of people on very
low income, people on the breadline, possibly people on benefits and on welfare, but
that’s pure conjecture.

What makes these people more likely to become mentally ill?
Oh, I don’t know, I guess, just life being more difficult, erm, I don’t really know.

What about age? Do you think there are any differences there?
I suppose in one context age could have an effect, I mean, going through adolescence
can be stressful, so you might be more likely to have a mental illness, and retirement
can be stressful too, so then as well. On the other hand, some things might only onset
when you’re older, like Alzheimers or Parkinsons, so I guess, yeah, age may have an
effect.

What about culture? Do you think there are any differences there?
Well, Durkheim talked about suicide being more common in Protestant than Catholic
families, because Protestant families were less socially cohesive, had less community,
and also Catholics tend to have larger families, so possibly. I think cultures where they
have larger families and higher social cohesion, so the opposite to western culture,
they’re maybe less likely to suffer from depression and suicide.

Where do your ideas on this come from?
Again, they are conjecture. I suppose a mixture of things. I’ve never studied this area
formally so it wouldn’t be through any academic input. I imagine through, in one case
the friend of mine who’s mother suffers from it, from the media, and through
assumption.

Imagine that someone close to you told you that they have a mental illness. How
would you feel?
I’d feel concerned, obviously I’d feel concerned, and erm I think the way I’d react
would depend on who they were and how they wanted to respond to it and what the
illness was.

How would you think about them?
I don’t think I’d necessarily think about them any different. That said, it would depend
on the illness and the implications of that illness. I think I would, erm, I would want
them to seek help and I would want to help them, in seeking that help. I think perhaps
if they were, erm, not taking steps to seek help or to try and seek treatment if
treatment were possible and appropriate then I would feel more concerned.

How do you think it would influence your relationship?
Ooh, I would like to think it wouldn’t, but to be honest you know, we all, we all have
prejudices at the end of the day whether we admit it or not, whether we’re honest
about them or not, whether we're conscious of them or not. I certainly know, for
example when I walk down a street that depending on how people look and the way
they dress and lots of other things, I may or may not be nervous about them, I may or
may not think they're going to mug me, I may or may not think they're going to ask
me if I've found Jesus and try to recruit me into a cult or something like that, so I
suppose subconsciously it's possible I would feel different about them. I think in a
way it's a bit hard to answer the question without actually being there for real. I think
if you're there for real and it actually happens then you'd know for sure.

Thinking about it now, do you think it would create any difficulties in the relationship?
Erm, possibly, possibly. Again, it would depend so much on the nature of the illness,
the person, and how I felt about it at the time, so it's hard to comment specifically.

So how would different illnesses affect things differently?
Erm, I'd need to have a better understanding of the illnesses to be able to answer that.

Where do your ideas and thoughts about all this come from?
I think mainly through trying to guess how I would react in particular situations
through knowing myself, to a reasonable degree.

Do you think people with mental illness can be helped?
Certainly, erm, you know, there's a, from what I understand a large amount of
government spending dedicated to the area, although there have been cutbacks, mainly
under the Tories. But yeah, yeah.

Can you think of some ways that people with mental illness can be helped?
Specifically in terms of treatment it's hard for me to comment, because as I said, this
isn't my area. That notwithstanding, erm, I think one of the major societal problems
about mental illness is not specifically to do with the people with mental illness but to
do with how society reacts to them. I think there are a lot of elements in society, and I
wouldn't necessarily exclude myself from this, who may react with fear and with
prejudice and with anxiety if they're confronted with a person or a group of people
with mental illness. Hence, you know, terms like nutters, loonies, weirdos and so on
and so forth are applied, and you know, in casual pub conversation someone may say
'what's wrong with you, are you mental, are you a nutter' if someone reacts in a
strange way, and it becomes part of the common vernacular.

In what way has being interviewed about mental illness affected you?
Aah, that's a good one. Well, obviously, it's made me focus on it, it's made me draw
on my very small amount of knowledge about the area, and er, that's it really.

In what way has being interviewed by a trainee clinical psychologist affected what
you've said?
I suppose erm, perhaps I've thought about my reactions more than I might normally
do, perhaps I'm concerned I'm being analysed myself. Obviously it's made me think
about the issues more. I suppose the first question, for a politics student, would be if
you weren't a trainee clinical psychologist why would you ask me the questions in the
first place. That notwithstanding, the fact that you're qualified or semi-qualified or
want to be qualified in this area perhaps makes me think longer and harder about my answers, for fear of correction.

*Is there anything else you would like to add regarding your views regarding mental illness?*

Erm, not really, erm, as I say, I don’t consider myself particularly well informed about the area, I think as I said before, were I put in the particular situation and confronted by a friend or a family member who had this condition then obviously it would clarify my thoughts and make me find out a lot more. The one large concern I do have about it is people’s reactions to the situation and perhaps a lack of sympathy and also in some ways people not seeing mental illness as and illness but sometimes people feeling in a way it’s self-inflicted or self-induced, I think that’s very wrong, because it is an illness.
The relationship between paediatric asthma severity, maternal illness beliefs and psychological adjustment in mother and child

July 2004

Year 3
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Abstract

Title
The relationship between paediatric asthma severity, maternal illness beliefs and psychological adjustment in mother and child

Objectives
The study aimed to examine whether the relationships between asthma severity and psychosocial variables (maternal anxiety and depression, maternal parenting stress, child psychological and behavioural difficulties, child quality of life) are moderated by maternal illness beliefs.

Design
A within-subjects cross-sectional questionnaire design with three main measurement sections: mother-report, child-report and paediatrician-report.

Setting
Three paediatric asthma clinics in London and South-East England.

Participants
94 mothers of children aged 5-11 who had been diagnosed with asthma and who spoke English and were without a concurrent learning disability.

Measures
 Mothers were asked to complete the Illness Perception Questionnaire – Revised, the Hospital Anxiety and Depression Scale, the Parenting Stress Index/Short Form, the Strengths and Difficulties Questionnaire and the Paediatric Quality of Life Scale – Generic and Asthma Versions, as well as a demographic information sheet. Children were asked to complete the Paediatric Quality of Life Scale – Generic and Asthma Versions. The child’s paediatrician was asked to indicate the severity of the child’s asthma on a four-point scale.
Results
There were significant correlations between maternal illness beliefs and some of the mother-reported psychosocial variables. Child-rated child quality of life was related only to physical aspects of mother-rated child quality of life. Asthma severity was unrelated to any of the psychosocial variables but was related to maternal illness beliefs about the likely duration and consequences of the asthma. Overall the study found no clear unambiguous evidence that maternal illness beliefs moderate the relationship between paediatric asthma severity and maternal anxiety and depression, child psychological and behavioural difficulties, parenting stress or child quality of life. However there was evidence to suggest that, if maternal illness beliefs do have any moderating effect, they are to do with personal control and that these will moderate between asthma severity and mothers’ perceptions of their child’s functioning or their own parenting stress.

Conclusions
Overall the results of this study were in line with some previous findings but did not support others. Possible reasons why the findings were not in line with expectations are discussed as are limitations of the research and implications for future research and clinical practice.
1. INTRODUCTION

Paediatric asthma is the most common chronic childhood illness and can have significant physical and psychological effects for both the child and their parents. Previous research into paediatric asthma and other paediatric chronic illnesses has found relationships between mother and child psychological adjustment, parenting stress and child quality of life. However, the relationship between asthma severity and these psychosocial variables remains unclear. This study aims to contribute to the discussion on the relationship between paediatric asthma severity and psychological factors by examining the relationship between paediatric asthma severity, maternal illness beliefs, psychological adjustment in mother and child and child quality of life. In particular, the study aims to assess whether maternal illness beliefs moderate the relationship between paediatric asthma severity and the psychosocial variables.

The introduction first gives a description of paediatric asthma. It then reviews the literature surrounding the relationships between paediatric asthma severity and psychosocial factors, and discusses how maternal illness beliefs may moderate between these variables. Finally, the aims and hypotheses of this study are presented, along with an explanation of the sample group chosen.

1.1. Asthma

1.1.1. Description

Asthma in children is diagnosed on the basis of symptoms, (commonly wheezing, a dry cough, breathlessness and noisy breathing), combined with a detailed history and physical examination looking at factors such as severity of symptoms, the pattern of illness, personal or family history of atopic conditions and allergies, as well as a test of lung function. Following an initial possible diagnosis clinicians then assess how well the child responds to bronchodilators or regular preventor anti-inflammatory medications (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2004; National Asthma Campaign, 2002). However, many children diagnosed with “wheeze” or “possible asthma” at an early age may be “transient early wheezers” who then grow out of this severe wheezing, (which is often associated with colds), between
the ages of three and six (Martinez, Wright & Taussig, Holberg, Halonen, Morgan & The Group Health Medical Associates, 1995; Sheriff, Peters, Henderson, Strachan & the ALSPAC study team, 2001). When this wheezy illness is first diagnosed in early childhood, it is not known which of these children will have transient symptoms and which will continue to develop persistent asthma (National Asthma Campaign, 2002).

1.1.2. Treatment
In the UK, asthma in children is treated in a step-wise manner depending on the severity of the symptoms and the extent to which the prescribed medication controls the asthma. Treatment varies slightly for children aged 0-5, 5-12, and those over 12. As this study will focus on children aged 5-11, this section will describe the recommended treatment for children within that age-group.

The British Thoracic Society (2004) recommends that children are initially treated with an inhaled short-acting beta-agonist as required (a bronchodilator). If this is not effective then children should be prescribed this plus a low dose of inhaled steroid: 200mcg, increasing to 400mcg if necessary. If this is not effective then children should also be prescribed an inhaled long-acting beta agonist (LABA). If there is no response to the LABA then other medication, such as a leukotriene receptor antagonist (LTA), should be tried. If the low-dose inhaled steroid plus a LABA or LTA is ineffective then a high-dose inhaled steroid should be prescribed (>400 mcg and up to 800 mcg). Finally, if these are all ineffective, a daily steroid tablet should be considered1.

1.1.3. Aetiology
The exact causes of childhood asthma are not yet fully understood, but in general it is agreed that the multiple patterns of asthma suggest that there are likely to be numerous genetic, microbiological, environmental and age-related contributory factors (Bleecker, Postma & Meyers, 1997; Holt, Macaubus, Stumbles & Sly, 1999; Ross, Mjaanes & Lemanske, 2003). At present, the most clearly defined risk factor is a family history of asthma, with the strongest association with maternal asthma. Other factors which may

1 See Appendix A for Treatment Flowchart
contribute to the development of asthma are maternal smoking, air pollution and diet (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2004).

Of particular importance to the present study, it is generally agreed that psychological factors and family processes are not a significant factor in predicting the onset of asthma in children who are genetically at risk, although for 15-30% of people with asthma, stress and emotions may trigger asthma episodes (Gustafsson, Bjorksten & Kjellman, 1994; Marianne & Wamboldt, 2001; Mrazek, Klinnert, Mrazek, Brower, McCormick, Rubin, Ikle, Kastner, Larsen, Harbeck & Jones, 1999; Wright, Rodriguez & Cohen, 1998).

1.1.4 Prevalence
It is difficult to be entirely accurate when assessing the number of children with asthma due to variability in the definition of asthma used which makes comparisons of data difficult (Burney, 1997). However, it is generally agreed that asthma is the most common chronic illness reported in children, with approximately 12.5-15.5% of children in the UK suffering from asthma (Joint Health Surveys Unit, 1999; Lung & Asthma Information Agency, 2003; National Asthma Campaign, 2001, 2002). Over 80% of long-term respiratory illnesses and almost a third of all long-term childhood illnesses are due to doctor-diagnosed asthma (Joint Health Surveys Unit, 1999). Respiratory diseases, including asthma, account for 20% of weekly GP consultations in children, and asthma is the most common reason for childhood GP consultations (Lung & Asthma Information Agency, 2003). Asthma is also one of the leading causes of hospitalisation in children, with asthma in childhood accounting for more hospital admissions than any other single condition. In 2000/01, respiratory disease accounted for 15% of all children's hospital admissions in England, with almost a third of all lower respiratory admissions being due to asthma (Lung & Asthma Information Agency, 2003).

Asthma prevalence varies between countries, being highest in economically developed countries with a temperate climate (Paton, 2004). There are also social variations in asthma prevalence within countries that may reflect the impact of poverty and lack of access to health care (Paton, 2004; Woolcock & Peat, 1997). Asthma and wheezing in
children in the UK has increased over the last 35 years. It is thought that this is likely to be due to environmental factors, possibly diet or even excessive levels of hygiene, though a full explanation for this rising prevalence remains to be defined (Mattes & Karmaus, 1999; Paton, 2004; Woolcock & Peat, 1997).

1.1.5. Associated Risks

There are various risks associated with asthma. At the most severe end there is a risk of early mortality, although even children with mild asthma are at some risk of death due to their asthma (Robertson, Rubinfeld & Bowes, 1992). Around 1500 people die from asthma each year in the UK and in 1999 and 2000, 25 and 22 of those deaths respectively were of children (Lung & Asthma Information Agency, 2003: National Asthma Campaign, 2001). Approximately 8% of all childhood deaths are due to respiratory disease and while mortality rates for most respiratory diseases have fallen over the last two decades, mortality rates for asthma remain generally static (Lung & Asthma Information Agency, 2003).

Aside from mortality, there are other both long and short-term risks associated with asthma. Inhaled corticosteroids used to control asthma can lead to impaired growth if given at a high dose over a long period of time, although newer formulations have reduced this risk, and asthma that persists into adulthood is associated with lung function deterioration (Lange, Parner, Vestbo, Schnohr & Jensen, 1998; Pedersen & O'Byrne, 1997; Strachan, Griffiths, Johnston & Anderson, 1996). Children with asthma are more likely than children without asthma to miss school due to being symptomatic, and parents of young children with asthma may have increased work absence due to caring for the ill child (Eiser, 1993; Lung & Asthma Information Agency, 2003). As discussed later, asthma also affects quality of life, for example due to the presence of asthma attacks or by wheezing disturbing sleep (ISAAC, 1998; Varni, Burwinkle, Rapoff, Kamps & Olson, 2004).

1.1.6. Psychological Impact of Asthma

Having a chronic illness or having a child with a chronic illness such as asthma can involve many stressors, such as the need to adhere to daily treatment regimes, the need
to identify and avoid asthma triggers, having to cope with episodic events such as asthma attacks, hospital visits and missing school, and anxiety surrounding the fear of asthma-related death (Carr, 1999; Klinnert, McQuaid & Gavin, 1997; Wallander & Varni, 1992). As such, asthma can have implications for the psychological well-being of both the child with the illness and for their family.

1.1.6.1. Impact on the Child

Studies have shown that, in general, children with chronic health problems have approximately a 2.4 times greater risk of emotional disorders, behavioural problems and school-related adjustment problems than healthy children (Pless & Nolan, 1991; Silver, Westbrook & Stein, 1998). Specifically, children with asthma have shown an increased risk of having psychological and behavioural difficulties, particularly anxiety, compared with children without asthma, with the effect for internalising problems such as anxiety and depression greater than that for externalising problems such as conduct disorder and hyperactivity (Klinnert, McQuaid, McCormick, Adinoff & Bryant, 2000; Lavigne & Faier-Routman, 1992; McQuaid, Kopel & Nassau, 2001; Ortega, Huertas, Canino, Ramirez & Rubio-Stipec, 2002).

Many children with asthma experience symptoms which could be expected to compromise the quality of their lives (Eiser & Havermans, 1994). In general, studies have indicated that children with asthma have a significantly poorer quality of life than children without asthma, indicating that their asthma has a significant impact on their lives (Sawyer, Spurrier, Whaites, Kennedy, Martin & Baghurst, 2000; Thompson & Gustafson, 1996; Varni et al, 2004). Paediatric asthma has also been shown to be related to poorer social and school functioning as reported by both the child and parent, which is thought to be due to either the increased likelihood of psychological and behavioural difficulties in paediatric asthma, or to other factors such as increased school absence due to asthma (Eiser, 1993; Thompson & Gustafson, 1996; Varni et al, 2004). Poorly controlled asthma can also occasionally lead to difficulties with learning due to factors such as the effect of oral steroids, poor management of asthma and the stress associated with it (Annett & Bender, 1994; Celano & Geller, 1993). However, it has been suggested that the effect of childhood illness on the mental health of the
child and family members is primarily mediated by how well the family functions in general (Cohen, 1999; Lavigne & Faier-Routman, 1993).

1.1.6.2. Impact on the Parents

Studies have indicated that having a child with asthma is related to increased parental vulnerability to depression and anxiety, increased parenting stress and increased marital discord, although these difficulties may not necessarily be in the clinical range (Carson & Schauer, 1992; Quittner, Espelage, Opipari, Carter, Eid & Eigen, 1998; Wamboldt, 2001; Wallander, 1993). Parents report being in a constant state of "red alert" for the possibility that the child may have an asthma attack (Wasilewski, Clark, Evans, Feldman, Kaplan, Rips & Mellins, 1988). Mothers of children with asthma also tend to report a more problematic relationship with their child than mothers of healthy children, and having a child with asthma can affect parenting styles. For example, parents may be more overprotective and restrictive of children with asthma (Carson & Schauer, 1992; Eiser, 1993). One study found that in families with a genetic predisposition to asthma, family dysfunctional patterns such as low cohesion and high conflict only increased over time where the child actually developed asthma, suggesting that the dysfunction developed as a consequence of the child developing asthma (Gustafsson, Bjorksten & Kjellman, 1994).

1.2. Maternal and Paternal Differences

Studies have shown that when a child is diagnosed with a chronic illness fathers tend to respond differently to mothers, with fathers showing less distress, being less likely to seek social support and being less likely to show increased signs of depression and anxiety (Eiser, 1993; Silver, Westbrook & Stein, 1998). This may be partially due to different coping styles of men and women and partially due to the fact that fathers tend to be less involved in practical care than mothers (Eiser, 1993). In addition, studies have indicated that children tend to be more affected by maternal than paternal mental health problems, although this may be related more to whom the child's main carer is than to maternal and paternal differences per se (Smith, 2004).
1.3. Why is Psychological Adjustment Important?

Psychological adjustment in both mothers and children is important, as studies have shown links between child and maternal psychological adjustment and asthma treatment adherence and between child and maternal psychological adjustment and the number of asthma-related hospitalisations (British Thoracic Society, 1997; Chen, Bloomberg, Fisher & Strunk, 2003; Weinstein & Faust, 1997). There are similar findings for other chronic illnesses, such as cystic fibrosis and diabetes (Martin, Miller-Johnson, Kitzmann & Emery, 1998; Thatcher-Benza, 1999). Poor medication adherence has itself been shown to be related to deaths due to asthma, an increased need for hospital treatment and a reduced quality of life (Janson & Reed, 2000; National Asthma Campaign, 2001).

Although the majority of studies focus on mothers and children with clinically significant levels of anxiety, depression and behavioural difficulties, nevertheless the findings may still be applicable to a lesser extent to mothers with higher levels of anxiety and depression symptoms and children with psychological and behavioural difficulties even when these are not always necessarily clinically significant.

1.3.1. Maternal Depression

Maternal depression can have negative effects for both mother and child wellbeing. Studies have indicated that rates of depression in all mothers (not just those of children with a chronic illness) vary from 6-15%, with higher rates associated with having a child under seven (Smith, 2004). Thus it can be seen that maternal depression can potentially be a very significant problem.

Depression can involve low mood, loss of interest in activities, sleep disturbance, anxiety, loss of appetite, lack of energy, lack of concentration, and suicidal thoughts. As such, it can have a serious impact on a mother's ability to function in social, work and relationship domains (Rippere, 1994).

The effects of maternal depression, such as disturbed sleep, a diminished concentration capacity, memory impairments and lack of motivation can also affect a mother's ability to look after her child. A depressed mother may be preoccupied and
withdrawn and thus be uncommunicative with and unavailable to her child. She may find it difficult to organise and plan her life and as such may find it difficult to provide consistency and stability for her child. This can result in the child missing school and health checks because the mother does not take them there either on time or at all. Children’s living standards may be affected because a depressed mother may find it hard to look after the house. When a person is depressed they are more likely to become socially isolated, meaning that children of depressed mothers may be denied the possibility of developing extra-familial support networks (Duncan & Reder, 2000; Smith, 2004). When a mother is seriously depressed there is a risk that she may neglect her child, which can have long-term implications for the child’s health, development, well-being, social and educational functioning (Department of Health, 1999). Overall, studies have indicated that maternal depression can have a wide range of negative impacts on children and child development in many areas including language development, the development of social and emotional competence, sleeping patterns, and the parent-child relationship and attachment (Cleaver, Unell & Aldgate, 1999; Murray & Cooper, 1997).

Having a mother with depression can also affect how a child’s behaviour is managed. Some studies have suggested that depressed caregivers try to avoid conflict with their children by accommodating the child’s demands and tolerating non-compliance, which can have particularly serious results when a child has a chronic illness such as asthma and is reliant on medication. When depressed caregivers do try to set limits they are less likely to reach a compromise and can be overly-controlling, displaying harsh or ineffective discipline practices and using increased physical punishment (Kochanska, Kuczynski, Radke-Yarrow & Welsh 1987; Berg-Nielsen et al, 2002). Studies have indicated a relationship between inconsistent, controlling and lax parenting and externalising child behaviour problems, which may help to explain why depressed mothers tend to report more behavioural difficulties in their children (Loeber & Dishion 1984; Nobes & Smith 1997).

1.3.2. Maternal Anxiety
Maternal anxiety can include specific anxiety disorders such as generalised anxiety disorder, panic disorder, social phobia, posttraumatic stress disorder and agoraphobia,
as well as non-clinical levels of anxiety (Lindsay, 1994). All of these can have negative effects for both mother and child wellbeing.

For the mother, at the most severe end having an anxiety disorder can affect quality of life, work absence, and the likelihood of being unemployed (Fifer, Mathias, Patrick, Mazonson, Lubeck & Buesching, 1994; Massion, Warshaw & Keller, 1993; Salvador-Carulla, Segui, Fernandez-Cano & Canet, 1995). Women with anxiety disorders may avoid situations that make them feel fearful or anxious, leading to possible social isolation (Noyes & Hoehn-Saric, 1998). Thus anxiety, like depression, can affect functioning in social, work and relationship domains.

Studies have suggested that children of anxious mothers may be at increased risk for worry and fearfulness, separation anxiety, insecure maternal attachment, school difficulties, somatic complaints and of developing avoidant strategies for stressful or problematic situations (Capps, Sigman, Sena, Henker & Whalen, 1996; Fellow-Smith, 2000; Mufson, Aidala & Warner, 1994; Turner, Beidel & Costello, 1987). This increased risk is likely to be a combination of genetic and environmental factors such as the impact of maternal anxiety on parenting, attachment and the mother-child relationship and the modelling of anxiety behaviours by the mother (Fellow-Smith, 2000; Weissman, 1993).

1.3.3. Child Psychological and Behavioural Difficulties
Child psychological and behavioural difficulties can have an effect on both the child and the family. For the child, psychological and behavioural problems can have a negative impact in both the short and the long-term. Child psychological difficulties such as depression and anxiety can affect a child's school and social functioning due to factors such as lack of concentration, focusing on worry, nightmares, separation anxiety and reluctance to engage with activities (Carr, 1999). Behavioural difficulties can lead to children performing poorly at school and having difficulty in relation to their peers (Carr, 1999). Furthermore, children with psychological and behavioural difficulties often turn into adolescents with psychological and behavioural difficulties and are more likely to experience psychological, occupational and social difficulties as adults (Harrington, Brendenkamp, Groothues, Rutter, Fudge & Pickles, 1994; Kovacs,
1997; McGee, Feehan, Williams & Anderson 1992; Storm-Mathisen & Vaglum, 1994). Childhood psychological and behavioural problems can also have an impact on illness as they may be predictive of poor asthma health status, with depressed children being less likely to comply with medical advice and so being less adherent to asthma medication (British Thoracic Society, 1997; McQuaid, Kopel & Nassau, 2001; Weil, Wade, Bauman, Lynn, Mitchell & Lavigne, 1999). Having a child with psychological or behavioural difficulties can also be particularly stressful for parents, affecting relationships within the family and causing concern for parents (Carr, 1999).

1.3.4. Parenting Stress
The extent to which mothers feel that parenting their child is stressful is important as parents who find parenting stressful are likely to find it harder to parent well, which may lead to negative or even abusive parenting (Hashima & Amato, 1994). If mothers find parenting stressful then this may reduce their overall life-satisfaction. However, the majority of studies have focused on the factors that result in parenting stress rather than the effects of finding parenting stressful.

1.3.5. Quality of Life
Quality of life can be defined as the “physical, social and emotional aspects of a patient's well-being that are relevant and important to the individual” (Connolly & Johnson, 1999). As such, it is generally seen as self-defined and is related to a person’s present lifestyle, past experiences, hopes for their future, dreams and ambitions, and the extent to which they think that they will be able to achieve these (Eiser & Morse, 2001). Increasingly, quality of life has become accepted as one important measure of treatment outcome. This is important because as well as preventing mortality and reducing the risk of future morbidity, one purpose of treatment is to improve well-being and quality of life (Guyatt, Naylor, Juniper, Heyland, Cook & the Evidence Based Working Group, 1997). Quality of life is important because it is a direct measure of the individual’s own perception of outcome.
1.4. Relationships between Paediatric Asthma Severity, Psychological Adjustment in Mother and Child, Maternal Parenting Stress and Child Quality of Life

1.4.1. Mother and Child Psychological Adjustment and Parenting Stress
Previous studies have indicated relationships between maternal anxiety and depression and child psychological and behavioural difficulties for children with chronic illnesses (Lavigne & Faier-Routman, 1993). Studies have indicated that children of depressed mothers are more likely than other children to experience or exhibit both behavioural and psychological difficulties such as depression themselves (Rutter & Quinton, 1984; Smith, 2004; Weissman et al 1997). Parenting stress has also been shown to be related to both maternal depression and child psychological and behavioural difficulties (Abdin, Jenkins & McGaughy, 1992; Bendell, Stone, Field & Goldstein, 1989; Bigras, LaFreniere & Dumas, 1996).

1.4.2. Child-rated Child Quality of Life and Parent-rated Child Quality of Life
Children’s quality of life has been assessed by measures directed at both children and their parents. Studies have indicated small to large correlations between mother-ratings of child quality of life and child-ratings of child quality of life (Vami et al, 2004; Vami, Burwinkle, Seid & Skarr, 2003). Where parents and children differ, parents tend to rate their child’s quality of life as poorer than the children themselves (Guyatt, Juniper, Griffith, Feeny & Ferry, 1997; Williams & Williams, 2003; Woods, Hidalgo, Prihoda & Kromer, 1994). In terms of proxy-report, studies have found that parent, teacher and health-professional ratings of child quality of life are not strongly related, with lower agreement between raters for internalising problems than for externalising problems (Guyatt et al, 1997; Vami et al, 2004).

1.4.3. Mother and Child Psychological Adjustment and Child Quality of Life
Studies examining the relationship between quality of life and psychological adjustment are limited. In general, studies have found that lower quality of life is associated with higher anxiety and depression in adults and adolescents (Anderson, 1995; Hommel, Chaney, Wagner & McLaughlin, 2002). This suggests that a person’s own psychological adjustment may be related to their own quality of life. However,
no studies as yet have examined the relationship between maternal psychological adjustment and child quality of life.

1.4.4. Asthma Severity and Mother and Child Psychological Adjustment

The research examining the relationship between asthma severity and psychological adjustment in mother and child is inconclusive. Some studies have indicated that asthma severity may be related to child psychological and behavioural difficulties, while other studies have suggested that there is no relationship (Bender, Annett, Ikle, DuHamel, Rand & Strunk, 2000; Bennett, 1994; Eksi, Molzan, Savasir, Gueler, 1995; Klinnert et al, 2000; Lavigne & Faier-Routman, 1993). One study reported a curvilinear effect, with children with the mildest and most severe asthma having the most reported psychological and behavioural difficulties, and children with moderate asthma having the least (MacLean, Perrin, Gortmaker & Pierre, 1992). Overall, these studies demonstrate a lack of consistency about the strength of the relationship between illness severity and child psychological adjustment. A meta-analysis concluded that as asthma severity increases, child psychological and behavioural difficulties tend to slightly increase, although there was significant overlap between the categories (McQuaid, Kopel & Nassau, 2001). Thus it can be seen that, although there may be some relationship between severity and child psychological adjustment for some children, this relationship is not particularly strong or consistent.

Fewer studies have assessed the relationship between child chronic illness severity and maternal psychological adjustment. Those that have, have suggested that illness severity is unrelated to maternal psychological difficulties (Quittner et al, 1998; Silver, Westbrook & Stein, 1998; Wallander & Ventners, 1995). However, due to the lack of reported studies, and bearing in mind the inconclusive nature of studies with children, it is difficult at present to draw strong conclusions about the relationship between child asthma severity and maternal psychological adjustment.

1.4.5. Asthma Severity and Quality of Life

Although increased asthma severity is related to an increase in the frequency of asthma symptoms, asthma severity does not appear to be directly or linearly related to quality of life. In adults with asthma, asthma severity is modestly correlated with the
person's self-reported quality of life and it has been suggested that children with severe asthma may have a poorer quality of life than children with mild asthma (Hatziagorou, Karagianni, Vidalis, Bullinger, Tsanakas & the DISABKIDS group, 2002; National Asthma Campaign, 2000; Juniper, Guyatt, Ferrie & Griffith, 1993; Svetlana, Pljaskić-Kamenov, Dragoslav, Stojan & Borislav Kamenov, 2002).

1.5. What Might Explain the Inconsistent Relationship between Severity and Psychological Adjustment?
As discussed, studies examining the relationship between chronic illness severity and mother anxiety and depression, parenting stress, child psychological and behavioural difficulties, and child quality of life, have been inconclusive, and frequently have not found any relationship between severity and psychological measures. This is despite the fact that increased asthma severity may reasonably be expected to be related to increased asthma attacks, hospitalisation, days off school and risk of death. However, few researchers have considered the reasons for these inconsistent findings and the frequent lack of relationship. It is proposed that one reason for the lack of consistency in the relationship between paediatric asthma severity and factors such as psychological adjustment in mother and child, parenting stress and child quality of life may be the differing illness beliefs that people hold.

1.5.1. The Self-Regulatory Model of Illness Beliefs
According to Leventhal's Self-Regulatory Model, also known as the Common-Sense Model of Illness Representations, people create mental representations of their illness based on the information available to them (general 'lay' information, information from significant others or those perceived to be in authority such as doctors, and the person's own current experiences of the illness) and use this to make sense of and understand their illness (Hagger & Orbell, 2003; Leventhal, Benyamini, Brownlee, Diefenbach, Leventhal, Patrick-Miller & Robitaille, 1997; Leventhal, Nerenz & Steele, 1984). These illness representations then determine how a person copes with their illness. Using open-ended interviews, research studies initially established that these illness representations could be organised into four dimensions: cause, consequences, identity and timeline (Leventhal, Nerenz & Steele, 1984; Meyer, Leventhal & Gutmann, 1985). Further dimensions relating to beliefs about the cure and
controllability of an illness were added by subsequent studies (Lau, Bernard & Hartman, 1989; Lau & Hartman, 1983). Later work concluded that there were three further illness perceptions dimensions, namely cyclical timeline, illness coherence and emotional representation and that the cure/control dimension could be separated into personal control and treatment cure/control dimensions (Moss-Morris, Weinman, Petrie, Horne, Cameron & Buick, 2002). Consequently, there are now nine components of the Illness Representation model.

Within the Illness Representation Model the identity component indicates the extent to which a person identifies with the symptoms of their illness by asking them about the number of symptoms they have. The causal component comprises the person’s ideas about the cause or causes of their illness. The time-line (acute/chronic) component indicates the person’s perceptions about whether their illness will last for a short-time or a long-time. The time-line cyclical component questions the extent to which the person perceives their illness as changeable and unpredictable. The consequences component asks about the person’s beliefs in the severity of the consequences of the illness. The personal control component indicates the extent to which a person believes that they themselves have any control over the illness. The treatment cure/control component questions the extent to which a person believes that their treatment will be effective in either curing or controlling their illness. The illness coherence component indicates the extent to which a person feels that they understand their illness. The emotional representation component indicates the extent to which the person relates any negative affect to their illness.

Previous studies of adults and adolescents with chronic illness have shown significant correlations between people’s own illness beliefs and their psychological adjustment and quality of life (Scharloo, Kaptein, Weinman, Willems & Rooijmans, 2000; Urquhart-Law, Kelly, Huey, Summerbell, 2002). In particular, higher perceived illness consequences is related to higher anxiety and depression and a poorer quality of life and lower personal control is related to higher depression and anxiety (Fortune, Richards, Main & Griffiths, 2000; Jopson, Nicola & Moss-Morris, 2003; Murphy, Dickens, Creed & Bernstein, 1999; Rutter, Claire & Rutter, 2002). In a meta-analytic review, Hagger & Orbell (2003) found that a strong illness identity and beliefs that the
illness would last a long time (would be chronic) and have severe consequences was negatively correlated with psychological adjustment. Beliefs in the efficacy of treatment in curing or controlling the illness were found to be negatively correlated with psychological adjustment.

In terms of asthma, studies have found a relationship between personal control beliefs and quality of life, and one study found a relationship between asthma severity and personal control beliefs in adults (Xu, Wen, Zhao & Ruan, 2002; Beare, 2000). In children, Russell (2001) found a statistical trend for the relationship between children's own illness beliefs and the severity of their asthma. However, there have not been any studies relating maternal illness beliefs to child quality of life.

1.5.2. The Need to Examine Maternal Illness Beliefs

Previous studies using the self-regulation model of illness perceptions have tended to focus on adults' own illness beliefs. Little attention has been paid to maternal illness beliefs and the affect that these may have on psychological adjustment and quality of life in either the mother or her child. There are a small number of studies with carers of adults with chronic illnesses, which have shown that people close to the person with the chronic illness (such as a partner) can have a significant influence on the process and outcome of the illness, and that carers' illness perceptions are important determinants of both the patient's behaviour and the carer's and patient's wellbeing (Weinman, Heijmans & Figueiras, 2003). As discussed previously, paediatric asthma can have implications for both children and parents, and maternal psychological adjustment can have important implications for children. In addition, when a child has a chronic illness their parents play an important role in treatment management and adherence as well as carrying out regular child-care tasks, meaning that the extent to which mothers cope with their child's illness could have a significant effect on the child. However, the severity of the asthma does not seem to be predictive of psychological adjustment in either mother or child. Therefore it is important to investigate what factors might be contributing to the mother and child's psychological adjustment.
Since previous studies have found that a person's beliefs about their own illness are related to their own psychological adaption, and that carer's illness beliefs are related to their own and the patient's psychological adaptation, it is likely that mothers' illness beliefs are related to their own and their child's psychological adaptation. Indeed, previous studies have shown that mothers' beliefs about the severity of their child's chronic illness are more influential and predictive of both the mother and child's psychological adjustment than medical severity measures (Eiser, 1993; DeMaso, Campis, Wypij, Bertram, Lipshitz & Freed, 1991). Further to this, illness perceptions may help to explain the inconsistent relationship between paediatric asthma severity and psychological adjustment in mother and child, being a moderating variable between the two (see Figure 1). It is possible that when a mother holds certain, as yet unknown, types of illness beliefs, this may moderate between paediatric asthma severity and psychological adjustment in mother and child.

Figure 1: Relationship between Severity and Psychological Adjustment

Illness Severity → Psychological Adjustment in mother and child

Maternal Illness Beliefs

1.6. Research Aims and Hypotheses

The aim of this study was therefore to investigate the relationship between paediatric asthma severity, maternal illness beliefs and a range of mother and child psychosocial variables (maternal anxiety and depression, maternal parenting stress, child psychological and behavioural difficulties, child quality of life). Specifically, the study aimed to examine whether the relationships between asthma severity and the psychosocial variables were moderated by maternal illness beliefs.

Based on previous research a range of hypotheses were suggested. It was hypothesised that maternal anxiety and depression, child psychological and behavioural difficulties and parenting stress would all be positively correlated with one another and that mother-rated child quality of life and child-rated child quality of life would be
positively correlated with one another. However, although it was hypothesised that child psychological and behavioural difficulties and child quality of life would show a low correlation, due to a lack of previous research it was not possible to speculate on the relationship between maternal anxiety and depression and child quality of life.

It was hypothesised that asthma severity would not be correlated with either maternal anxiety or depression, parenting stress, or mother-rated and child-rated child quality of life, but that there would be a low positive correlation between asthma severity and child psychological and behavioural difficulties.

It was hypothesised that maternal illness beliefs would be correlated with maternal anxiety and depression, child psychological and behavioural difficulties and both mother-rated and child-rated child quality of life. Although no specific studies have examined the relationship between maternal illness beliefs and mother and child psychological adjustment, previous studies have found a relationship between a person’s own illness beliefs and psychological adjustment and between mother and child psychological adjustment. However, due to a lack of previous research, it was not possible to speculate on the relationship between asthma severity and maternal illness beliefs.

The main research hypothesis was that the relationship between paediatric asthma severity and maternal psychological adjustment, parenting stress, child psychological and behavioural difficulties and child quality of life will be moderated by maternal illness beliefs. It was hypothesised that holding certain types of illness beliefs would be associated with a lack of relationship between severity and psychosocial variables. However, holding other types of illness beliefs would be associated with a relationship between severity and psychological adjustment.

1.7. Population Selection

The previously discussed differences between mothers and fathers in terms of their response to the child’s chronic illness and their coping styles may mean that the illness beliefs of fathers differ to the illness beliefs of mothers, although this has not yet been investigated. In addition, as previously discussed, studies have indicated that children
tend to be affected more by maternal than paternal mental health problems (Smith, 2004). It was thought that these factors could have some possible impact on the study in terms of the relationship between parent and child psychological adjustment. Both of these issues suggest that grouping mothers and fathers together could potentially affect the results of any research into parental illness beliefs and psychological adjustment. From discussion with the paediatricians running the asthma clinics it became apparent that children were usually brought to the clinics by their mothers. Due to this, and the consequent low number of fathers attending the clinics, it was not possible to examine maternal and paternal illness beliefs separately. Therefore it was decided that the research should focus only on mothers of children with asthma.

This study focused on children aged between five and eleven years. The reasons for this were threefold. Firstly, and most importantly, using children aged five to eleven restricted the sample to school-age children (primary school and the first year of secondary school) but excluded adolescents. Starting school tends to mark a time of increased independence for children and of separation from their parents (Eiser, 1993). Adolescence, the period from around 12-18, can again be regarded as a separate developmental stage for children, characterised by the transition between childhood and adulthood with a gradual separation from the parents and with different difficulties and issues than those in childhood. These differences cover many different areas including biological, cognitive, emotional, identity and social (Carr, 1999; McClure, 2000). Studies have suggested that the issues surrounding having a chronic illness may be different for adolescents than for children and so it was seen as important not to risk confusing the study by including adolescents (Seiffge-Krenke, 1997; Eiser, 1993; Hill 1993). For example, adolescents are often expected to take more responsibility for their own health than younger children but are often perceived to be less compliant with medication and treatment than younger patients. Due to all of these factors, adolescence can also be a time of particular stress for parents (Eiser, 1993). These issues meant that including either children under five or adolescents in the sample could have significantly affected the extent to which the sample could be considered heterogeneous.
Secondly, it is unrealistic to expect children under five to be able to reflect on their quality of life, meaning that there are no quality of life questionnaires with child-report generic and asthma-specific modules for children aged under five. Therefore including children below the age of five would have meant that some participants were not able to be included in the child-report measure.

Thirdly, there are different treatment recommendations for asthma for children below five years and above twelve years, with children over twelve being treated as adults (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2004). Thus, in terms of assessing severity, it was simpler to restrict the sample to children with whom the paediatricians would be following the same treatment guidelines (i.e. five to eleven-year-olds).
2. METHOD

2.1. Participants
The sample was recruited from three paediatric outpatient clinics at three hospitals in London and the South-East of England. All mothers of children aged 5-11 who had been diagnosed by an experienced clinician as being asthmatic were invited to participate, so long as both the mother and child spoke English and neither had a learning disability. Data was collected over a period of six months.

A priori power analysis calculated using G*Power software (Faul & Erdfelder, 1992) indicated that for a medium effect size with \( r = 0.3 \), a total sample of 82 participants was required with alpha = 0.05 and a power of 80% (two-tailed test). For the multiple regression, for a medium effect size with \( f^2 = 0.15 \), a total sample of 68 participants was required with alpha = 0.05 and a power of 80%.

A medium effect size was seen as potentially significant since previous studies have found correlations ranging from small to large for all of the variables being used, with the majority of correlations being in the medium to large range, aside from the relationship between severity and illness beliefs for which there is a lack of current studies (Bigras, LaFreniere & Dumas, 1996; Hagger & Orbell, 2003; McQuaid, Kopel & Nassau, 2001; Vami et al, 2004; Vami, Seid & Rode, 1999).

2.1.1. Response Rate
196 mothers were contacted by letter prior to their child’s clinic appointment to inform them about the study and ask them to participate in the research. Of these, 60 children (30%) did not attend their clinic appointment, 22 (11%) mothers declined to participate, and 20 (10%) children attended the clinic but with someone other than their mother. Thus the overall response rate was 48 % (see table 1). Chi-square analysis was used to analyse whether there were differences in response rate across the different sites. The clinic was not significantly associated with response rate (\( \chi^2 (df = 2) = 0.6, p>0.05 \)).

---

2 See Appendix B for G*Power calculation
Table 1: Response rate across the three centres

<table>
<thead>
<tr>
<th></th>
<th>A N (%) for centre</th>
<th>B N (%) for centre</th>
<th>C N (%) for centre</th>
<th>Total N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participated</td>
<td>55 (46)</td>
<td>17 (52)</td>
<td>22 (51)</td>
<td>94 (48)</td>
</tr>
<tr>
<td>Did not attend their appointment</td>
<td>38 (32)</td>
<td>8 (24)</td>
<td>14 (33)</td>
<td>60 (30)</td>
</tr>
<tr>
<td>Mother did not attend appointment with child</td>
<td>13 (11)</td>
<td>6 (18)</td>
<td>3 (7)</td>
<td>22 (11)</td>
</tr>
<tr>
<td>Declined to participate</td>
<td>14 (12)</td>
<td>2 (6)</td>
<td>4 (9)</td>
<td>20 (10)</td>
</tr>
<tr>
<td>Total</td>
<td>120 (100)</td>
<td>33 (100)</td>
<td>43 (100)</td>
<td>196 (100)</td>
</tr>
</tbody>
</table>

The researcher attempted to acquire information about those patients who did not attend their appointment or declined to participate but was unable to do so. Therefore it was not possible to ascertain whether there were any differences between those who did and did not participate.

2.1.2. Demographic Information

Demographic information about the sample is provided in table 2.

Table 2: Demographic variables

<table>
<thead>
<tr>
<th>Descriptor</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Centre (94 responses)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>A</td>
<td>55</td>
<td>58.5</td>
</tr>
<tr>
<td>B</td>
<td>17</td>
<td>18.1</td>
</tr>
<tr>
<td>C</td>
<td>22</td>
<td>23.4</td>
</tr>
<tr>
<td>Gender of Child (94 responses)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>58</td>
<td>61.7</td>
</tr>
<tr>
<td>Female</td>
<td>36</td>
<td>38.3</td>
</tr>
<tr>
<td>Age of Child in years (94 responses)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>26</td>
<td>27.7</td>
</tr>
<tr>
<td>6</td>
<td>16</td>
<td>17.0</td>
</tr>
<tr>
<td>7</td>
<td>12</td>
<td>12.8</td>
</tr>
<tr>
<td>8</td>
<td>11</td>
<td>11.7</td>
</tr>
<tr>
<td>9</td>
<td>16</td>
<td>17.0</td>
</tr>
<tr>
<td>10</td>
<td>8</td>
<td>8.5</td>
</tr>
<tr>
<td>11</td>
<td>5</td>
<td>5.3</td>
</tr>
</tbody>
</table>

Mean = 7.2 (SD = 1.921)
### Duration of Asthma in years (94 responses)

<table>
<thead>
<tr>
<th>Duration</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>1</td>
<td>8</td>
<td>8.5</td>
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<td>2</td>
<td>5</td>
<td>5.4</td>
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<td>3</td>
<td>21</td>
<td>22.4</td>
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<td>5</td>
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<td>11.7</td>
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<td>6</td>
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<td>17.0</td>
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<td>7</td>
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<tr>
<td>9</td>
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<td>9.6</td>
</tr>
<tr>
<td>10</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>11</td>
<td>2</td>
<td>2.1</td>
</tr>
</tbody>
</table>

Mean = 5.06 (SD = 2.61)

### Main Wage Earner (94 responses)

<table>
<thead>
<tr>
<th>Main Wage Earner</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Partner</td>
<td>64</td>
<td>68.1</td>
</tr>
<tr>
<td>Self</td>
<td>27</td>
<td>28.7</td>
</tr>
<tr>
<td>Benefits</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1.1</td>
</tr>
</tbody>
</table>

### Socio-Economic Status (SES) (93 responses)

<table>
<thead>
<tr>
<th>Socio-Economic Status</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Managerial and professional occupations (A)</td>
<td>53</td>
<td>57.0</td>
</tr>
<tr>
<td>Intermediate occupations (B)</td>
<td>4</td>
<td>4.3</td>
</tr>
<tr>
<td>Small employers and own account workers (C)</td>
<td>11</td>
<td>11.8</td>
</tr>
<tr>
<td>Lower supervisory and technical occupations (D)</td>
<td>6</td>
<td>6.5</td>
</tr>
<tr>
<td>Semi-routine and routine occupations (E)</td>
<td>19</td>
<td>20.4</td>
</tr>
</tbody>
</table>

### Ethnicity

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>White (A)</td>
<td>68</td>
<td>72.3</td>
</tr>
<tr>
<td>Mixed (B)</td>
<td>2</td>
<td>2.1</td>
</tr>
<tr>
<td>Asian or Asian British (C)</td>
<td>11</td>
<td>11.7</td>
</tr>
<tr>
<td>Black or Black British (D)</td>
<td>10</td>
<td>10.6</td>
</tr>
<tr>
<td>Chinese or Other (E)</td>
<td>3</td>
<td>3.2</td>
</tr>
</tbody>
</table>

61.7% of the child participants were male. This is concordant with general rates of diagnosed asthma being more common in boys than girls, although the ratio in the
study was 6:4 compared to 6:5 in the general population (Joint Health Surveys Unit, 1999; The Scottish Health Survey, 1998).

The demographic data indicates a slightly higher proportion of participants in the managerial and professional occupations group and a slightly lower proportion in the intermediate occupations group compared to the general population (57% sample compared to 39.8% general population; 4.3% sample compared to 11.8% general population respectively). This is important as the standardisation populations for the measures used are likely to be based on the general population and using a slightly different socio-economic population may have resulted in differences from norms due to socio-economic status rather than asthma. The proportion from other occupational groups was similar to general population statistics, differing by no more than 5% (Office for National Statistics, 2004a). These results are interesting as studies have shown little difference by social class in the prevalence of diagnosed asthma or of wheeze in children (Lung & Asthma Information Agency, 2000). However, no data were available for the socio-economic status of children with asthma referred to paediatric outpatient clinics. These results therefore suggest that either the study sample was representative of the population from which it was taken (paediatric outpatient clinics in London and the South-East) or represents some bias in study participation, with mothers within the managerial and professional occupations group being more likely to attend clinic appointments and participate and mothers within the intermediate occupations group being less likely.

The proportion of participants from non-white ethnic backgrounds was higher than the proportion within the general population. In the sample, only 72.3% were from a white ethnic background compared to 92.1% in the general population. The sample contained higher percentages of people from Asian or Asian British backgrounds (11.7% compared to 4%), Black or Black British backgrounds (10.6% compared to 2%), and Chinese or Other backgrounds (3.2% compared to 0.8%). It contained a similar percentage from a Mixed background (2.1% compared to 1.2%) (Office for National Statistics, 2004b). This is likely to be a reflection of the fact that one of the areas covered by the clinic (A) had a higher proportion of people from non-white ethnic backgrounds compared to the general population (44.63%) (Office for National
Statistics, 2004b). Therefore overall, the proportion of mothers identifying themselves as from non-white ethnic backgrounds was concordant with the percentages of people from non-white ethnic backgrounds in the areas covered by the study, although it was above levels within the UK population as a whole. However, as with socio-economic status, the standardisation populations for the measures used were generally based on the general population and using a slightly different ethnic population may have resulted in differences related to ethnicity rather than asthma. However, the small numbers of mothers from each ethnic and SES group prevented comparisons according to ethnicity or SES within the study.

Table 3 shows the gender differences and the mean severity, age and asthma duration across the three centres. An analysis of variance (ANOVA) was used to calculate whether these four variables differed significantly between the centres. There were no significant differences between the mean severity, age, asthma duration or gender across the three different centres (Severity: F (2,91) = 0.8, p=0.923; Gender: F (2,91) = 0.797, p=0.454; Age: F (2,91) = 0.879, p=0.419; Asthma duration: F (2,91) = 0.436, p=0.648).

<table>
<thead>
<tr>
<th>Centre</th>
<th>Number of respondents (% for centre)</th>
<th>Severity mean</th>
<th>Gender (% for centre)</th>
<th>Age mean</th>
<th>Asthma Duration mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>55 (58.5)</td>
<td>2.42</td>
<td>M= 32 (58.2) F= 23 (41.8)</td>
<td>7.42</td>
<td>4.8</td>
</tr>
<tr>
<td>2</td>
<td>17 (18.1)</td>
<td>2.41</td>
<td>M= 12 (70.6) F= 5 (29.4)</td>
<td>7.00</td>
<td>5.5</td>
</tr>
<tr>
<td>3</td>
<td>22 (23.4)</td>
<td>2.50</td>
<td>M=14 (63.6) F=8 (36.4)</td>
<td>6.82</td>
<td>5.4</td>
</tr>
<tr>
<td>Total</td>
<td>94 (100)</td>
<td>2.44</td>
<td>M=58 (61.7) F=36 (38.3)</td>
<td>7.20</td>
<td>5.1</td>
</tr>
</tbody>
</table>

2.2. Design
The study utilised a within-subjects cross-sectional questionnaire design and had three main measurement sections: asthma severity (assessed by the child’s paediatrician);
maternal illness beliefs, maternal depression and anxiety, parenting stress, child psychological and behavioural difficulties and child health related quality of life, (assessed by the mother); child health related quality of life (assessed by the child).

2.3. Measures

2.3.1. Severity Measure

Asthma severity was measured on a four-point scale based on the asthma medication prescribed to the child by the paediatrician: Mild (Bronchodilator only); Moderate (Low dose inhaled steroid); Moderately Severe (Low dose inhaled steroid plus extra agents (LABA or LTA); Severe (High dose inhaled steroids (>400mcg/day BDP / BUD or >200mcg/day FP) or extra agent(s) (LABA or LTA)). The scale was agreed in consultation with the paediatricians involved in the study and was based on guidelines set by the British Thoracic Society (British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2003; British Thoracic Society & Scottish Intercollegiate Guidelines Network, 2004).

2.3.2. Demographic Information

The demographics questionnaire asked mothers about their child’s age, sex and years of asthma duration and about their own ethnicity and who the main wage earner in the house was. Social-economic status was classified according to the National Statistics Social-economic Classification (NS-SEC) self-coded method (2001).

2.3.3. Hospital Anxiety and Depression Scale (HADS: Zigmond & Snaith, 1983)

This is a 14-item self-report measure with two subscales measuring anxiety and depression. For each question participants tick the extent to which they agree with the statement about how they have been feeling in the past week on a four-point scale. Results can be coded on a four-point range of normal (0-7), mild (8-10), moderate (11-14) and severe (15-21). The HADS shows good reliability, and a review of 15 studies using the HADS found internal consistencies ranging from 0.68 - 0.93 (mean 0.83) for HADS Anxiety and 0.67-0.90 (mean 0.82) for HADS Depression (Bjelland,

3 See Appendix C for Severity Measure
4 See Appendix D for Demographic Information Sheet
5 See Appendix E for HADS
Dahl, Haug, & Neckelmann, 2002). The HADS is quick and simple to use, has been well-validated over a number of studies and is a sensitive case finder for anxiety disorders and depression, correlating well with other measures of psychological adjustment such as the Beck Depression Inventory and the General Health Questionnaire (correlations 0.6 - 0.8) (Bjelland et al, 2002; Zigmond & Snaith, 1983).

2.3.4. **Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)**

The SDQ is a 25-item parent-report measure that covers the main areas of psychological and behavioural difficulties in children aged 3-16. For each question parents read a brief statement and then indicate whether this is ‘not true’, ‘somewhat true’ or ‘certainly true’ of their child. The SDQ has five subscales measuring emotional symptoms, conduct problems, hyperactivity, peer problems and prosocial behaviour. Each subscale contains five items. The twenty questions in the first four symptom subscales are then added together to create a total difficulties score. The prosocial subscale is not included in this score. Scores from 0-13 are categorised as normal, scores from 14-16 are categorised as borderline, and scores above 16 are categorised as abnormal (i.e. having some psychological or behavioural difficulties). The SDQ has shown satisfactory reliability with an internal consistency reliability of 0.73, a test-retest reliability (6 months) of 0.62 and a cross-informant correlation of 0.34. It has shown good validity on a number of studies and good ability to discriminate between children with and without psychological or behavioural difficulties (Goodman, 1997, 2001).

2.3.5. **Parenting Stress Index/Short Form (PSI/SF: Abdin, 1995)**

The PSI/SF is a 36-item self-report measure of stress within the parenting system. It has three subscales, each with twelve questions, measuring parental distress (distress the parent experiences in their role as a parent, as a function of personal factors that are directly related to parenting), parent-child dysfunctional interaction (parents’ perceptions that their child does not meet with their expectations and the extent to which interactions with child are not reinforcing to the parent), and the difficulty of the child (basic behavioural characteristic of the child that make them easy or difficult

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6 See Appendix F for SDQ
7 See Appendix G for PSI/SF
to manage). Parents rate how much they agree with the statements on a five-point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’. Scores from 56 to 82 (15th to 80th percentile) are rated as normal and scores of 86 and over (85th percentile) are rated as high. The PSI/SF is derived directly from the original Parenting Stress Index and correlates exceptionally well with this. Both the full-length and short-form PSI have demonstrated good internal reliability (PSI/SF 0.91) and test-retest reliability (PSI/SF 0.84) and good validity in a large number of studies of different population groups (Abdin, 1995; Deater-Deckard & Scarr, 1996; Miller, Cate & Johann-Murphy, 2001; Smith, Oliver & Innocenti, 2001).

2.3.6. Paediatric Quality of Life Scale – Generic and Asthma Versions (Parent and Child) (PedsQL-Generic 4.0, PedsQL-Asthma 3.0: Varni, Seid & Rode, 1999)\(^8\)

The PedsQL is a modular quality of life scale containing both generic and disease-specific modules with both self-report (child) and proxy-report (parent) measures. Parent proxy-report forms are parallel to the child self-report forms, containing identical items and differing only in the use of first- or third-person tense. There are separate versions for children aged 5-7 and 8-12. Children complete the questionnaire themselves with help with reading, if necessary, by the researcher. The questionnaires ask how much of a problem things have been in the past month, with respondents being asked to indicate on a five-point Likert scale ranging from ‘not at all’ to ‘almost always’. The 5-7 year-old child-report version has been simplified to a three-point scale (‘Not at all a problem’, ‘sometimes a problem’, ‘a lot of a problem’) with responses anchored to a happy to sad faces scale.

For the purposes of this study the Generic and Asthma modules were used. The PedsQL Generic module contains 23 questions and has four subscales measuring physical, emotional, social and school functioning (8, 5, 5, and 5 questions respectively). The emotional, social and school subscales can be combined to create a psychosocial health summary score. All four scores can be combined to create a total score. The scale shows good internal reliability for children with asthma for both the child-report and parent-report versions (0.74-0.88 and 0.77-0.88 respectively). It has demonstrated good validity on a number of studies and is able to distinguish between

\(^8\) See Appendix H for PedsQL
healthy children and paediatric patients with either acute or chronic health conditions (Varni et al, 2004; Varni, Seid & Kurtin, 2001).

The PedsQL Asthma module contains 28 questions and has four subscales measuring asthma, treatment, worry and communication (11, 11, 3 and 3 questions respectively). The scale shows good internal reliability for both the child-report and parent-report versions (0.58-0.85 and 0.82-0.91 respectively) and good construct validity (Varni et al, 2004).

A meta-analysis concluded that the PedsQL compared well to other measures of paediatric general and asthma-specific quality of life (Eiser & Morse, 2001).


The IPQ-R contains seven subscales measuring different components of illness representations: Timeline (acute/chronic) (6 questions); Timeline Cyclical (4 questions); Consequences (6 questions); Personal Control (6 questions); Treatment Cure/Control (5 questions); Illness Coherence (5 questions); Emotional Representation (6 questions). These subscales are scored on a five-point Likert scale ranging from ‘strongly disagree’ to ‘strongly agree’. There are also two separate subscales measuring Identity and Causal beliefs. For the ‘Identity’ subscale respondents are asked to indicate whether they experience any of 14 different symptoms and whether they believe those symptoms are related to their asthma. The ‘Cause’ subscale gives 18 possible beliefs that people may hold about the cause of their asthma and respondents are asked to indicate the extent to which they believe that each item caused their asthma on a five-point Likert scale ranging from ‘strongly disagree’ to ‘strongly agree’.

The IPQ-R demonstrates good internal reliability (0.75 – 0.89), good test-retest reliability (0.46 – 0.88 at 3 weeks and 0.35 – 0.82 at 6 months) and good structural validity (Moss-Morris, Weinman et al, 2002). Further studies have indicated good

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9 See Appendix I for IPQ-R
construct validity and good discriminant validity of the different dimensions. (Hagger & Orbell, 2003; Moss-Morris et al, 2002).

The IPQ-R has been designed to examine people’s beliefs about their own illness. However, the developers of the IPQ-R have encouraged users to adapt the wording in the scale to suit particular populations (Moss-Morris et al, 2002). Therefore for this study the words “my asthma” were changed to “my child’s asthma” in order to assess mothers’ beliefs about their child’s asthma. Similar adaptations have been made in other studies using the IPQ and IPQ-R to examine carer’s beliefs about their partner’s illness (Heijmans, de Ridder, & Bensing, 1999; Weinman, Petrie, Sharpe & Walker, 2000).

2.4. Procedure

Three paediatric asthma clinics in London and the South-East of England were approached and asked to participate. Ethical approval was obtained from the Local Research Ethics Committees at all three sites and, following this, from the University of Surrey. Participants were recruited concurrently from all three clinics.

Potential participants were posted an information sheet prior to their child’s appointment at the asthma clinic. When potential participants arrived for their child’s appointment at the asthma clinic they were approached by the researcher and asked if they had received the information sheet and if they would like to take part in the research. Written consent was obtained from those mothers who agreed to take part. Consenting mothers were given the questionnaire booklet to complete independently while waiting for their child’s appointment. If they preferred, they were also offered the option of completing the questionnaire at home and returning it to the researcher in a stamped addressed envelope. The questionnaires were presented to mothers in a booklet to ensure that they always followed the same format and order. The booklet started with the demographics questionnaire and was followed by the SDQ, the IPQ, the HADS, the PSI/SF and the PedsQL (Generic module then Asthma module) The children were given their questionnaire separately, at the same time as

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10 See Appendix J for Ethical Approval Letters
11 See Appendix K for Participant Information Sheet
12 See Appendix L for Consent Form
the mothers (Generic module then Asthma module). Older children (8-12) were given their questionnaire to fill in independently, but were also given the option of having the researcher read them the questionnaire. The researcher administered the questionnaire to the younger children (5-7) as recommended in the PedsQL administration directions.

Immediately after the child’s appointment the paediatrician was asked to indicate the child’s asthma severity.

GP’s were informed by letter that their patient and the patient’s mother had taken part in the research\textsuperscript{13}.

\textsuperscript{13} See Appendix M for GP Information Letter
3. RESULTS

Part One of the results gives information regarding reliability, distribution of the data, statistical information for each of the individual variables and the relationships within each of the variables (i.e. their subscales). Part Two examines the research hypotheses.

PART 1

3.1. Reliability Analysis

Scale reliability was calculated using Cronbach's alpha coefficient\textsuperscript{14}. The reliability of all scales was above 0.60, the recommended alpha coefficient for a self-report scale to be seen as reliable for research purposes (Nunnally & Bernstein, 1994). The reliability of the majority of the scales was above 0.70, the recommended minimum alpha coefficient for group comparisons (Nunnally & Bernstein, 1994). Caution was used when interpreting results from calculations using those measures with reliability between 0.6 and 0.7 (IPQ-R Treatment Cure Control, IPQ-R Illness Coherence, PedsQL Asthma Child-report Treatment, PedsQL Asthma Child-report Communication).

3.2. Distribution of Data

The normality of the variable distributions was assessed by checking the values of skew and kurtosis\textsuperscript{14}. Using the criteria set out by West, Finch & Curran (1995) all of the variables were regarded as normally distributed thus permitting parametric statistical procedures to be used.

\textsuperscript{14} See Appendix N for Reliability, Skew and Kurtosis Data
3.3. Statistical Information for Variables

3.3.1 Severity
Mean scores in table 4 represent the average summed scores on the Paediatrician-rated severity scale.

Table 4: Paediatrician-rated severity

<table>
<thead>
<tr>
<th>Severity</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>2.44</td>
<td>2.00</td>
<td>0.85</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 5: Paediatrician-rated severity – breakdown of scores

<table>
<thead>
<tr>
<th>Mild</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate</td>
<td>45</td>
<td>47.9</td>
</tr>
<tr>
<td>Severe</td>
<td>12</td>
<td>12.8</td>
</tr>
</tbody>
</table>

Almost half the children were rated as having moderate asthma. Just over a quarter were rated as having moderately severe asthma, and just under an eighth each were rated as having mild or severe asthma. Thus, the majority of the children had moderate or moderately severe asthma.

3.3.2 Maternal Illness Representations
Mean scores in table 6 represent the average summed scores on the IPQ-R.

Table 6: Mother’s beliefs about their child’s asthma (IPQ-R)

<table>
<thead>
<tr>
<th>(N=94) (Scores 1-5)</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>4.44</td>
<td>4.00</td>
<td>2.61</td>
<td>0.00</td>
<td>14.00</td>
</tr>
<tr>
<td>Timeline (acute/chronic)</td>
<td>3.02</td>
<td>3.00</td>
<td>0.64</td>
<td>1.33</td>
<td>4.67</td>
</tr>
<tr>
<td>Timeline Cyclical</td>
<td>3.48</td>
<td>3.50</td>
<td>0.79</td>
<td>1.75</td>
<td>5.00</td>
</tr>
<tr>
<td>Consequences</td>
<td>2.71</td>
<td>2.50</td>
<td>0.80</td>
<td>1.17</td>
<td>4.83</td>
</tr>
<tr>
<td>Personal Control</td>
<td>3.47</td>
<td>3.50</td>
<td>0.54</td>
<td>2.17</td>
<td>4.83</td>
</tr>
<tr>
<td>Treatment Cure Control</td>
<td>3.85</td>
<td>3.80</td>
<td>0.51</td>
<td>2.20</td>
<td>5.00</td>
</tr>
<tr>
<td>Illness Coherence</td>
<td>3.82</td>
<td>4.00</td>
<td>0.85</td>
<td>1.00</td>
<td>5.00</td>
</tr>
<tr>
<td>Emotional Representation</td>
<td>2.98</td>
<td>2.92</td>
<td>0.87</td>
<td>1.00</td>
<td>5.00</td>
</tr>
</tbody>
</table>
On average most mothers rated their children as having four to five asthma-related symptoms. However, on average they also rated their child as having an additional two symptoms unrelated to asthma (unrelated symptoms mean 2.1, median 2, SD 2.29). This suggests that many of the children in the study had other difficulties as well as asthma, which may have affected the results in some way. Overall, the majority of mothers (80.9%) thought that they had a coherent representation or understanding of their child's illness. Most mothers thought their child's asthma had a cyclical and changeable pattern (67%) but they were not sure whether it was a permanent or a temporary condition (40.4% and 43.6% respectively). However, the majority believed that their child's asthma did not have major consequences on the child's life (56.4%). The majority of mothers felt that they had some personal control over their child's asthma and that their child’s treatment would be effective in curing or controlling the asthma (76.6% and 92.6% respectively). Some mothers reported that their child’s asthma made them feel depressed, upset, anxious and angry but others reported less emotional affect related to their child’s asthma (41.5% and 50% respectively). This is interesting as it suggests that although the mothers in the study held similar beliefs to one another about the controllability of their child’s asthma, the effect it would have on their child’s life, the predictability of the asthma and the extent to which they understood the asthma, the effects on them emotionally were more variable.

Pearson’s correlations were calculated to investigate the strength of relationships between different dimensions of maternal illness beliefs (table 7).

As expected from previous studies there were significant correlations between a large number of the IPQ-R subscales, mainly in the mild to moderate range, indicating a common trend for the way in which people organise their illness representations (Moss-Morris, Petrie & Weinman, 1996; Moss-Morris et al, 2002; Petrie & Weinman, 1997; Weinman, Petrie, Moss-Morris & Horbe, 1996).
Overall, those mothers who identified their children as having more asthma symptoms (Identity) also identified strongly with other physical aspects of the illness such as the asthma being more chronic (Timeline), more changeable and unpredictable (Timeline Cyclical), and having more severe consequences (Consequence). These mothers also found their child’s asthma more upsetting and anxiety-provoking (Emotional Representation), which may be a consequence of their negative beliefs about the asthma. There was a large correlation between Consequences and Emotional Representation indicating that, as may be expected, mothers who perceived their child’s asthma as having severe consequences felt more depressed, upset, anxious and angry about the asthma. Interestingly, Identity and Personal Control beliefs were not correlated in this study, whereas Moss-Morris et al (2002) found a strong correlation between these two variables. In addition, this study found correlations between Identity beliefs and Timeline, Consequences and Emotional Representation, whereas Moss-Morris et al’s (2002) study found no relationship between Identity beliefs and Timeline, Consequences or Emotional Representation.

Table 7: Correlations between subscales on the IPQ-R

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline</th>
<th>Timeline Cyclical</th>
<th>Consequences</th>
<th>Personal Control</th>
<th>Treatment Cure/Control</th>
<th>Illness Coherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Timeline</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Timeline Cyclical</td>
<td>0.22*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consequences</td>
<td>0.36**</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Personal Control</td>
<td>-0.14</td>
<td>0.15</td>
<td>-0.12</td>
<td>-0.06</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment Cure Control</td>
<td>-0.22*</td>
<td>-0.08</td>
<td>-0.10</td>
<td>-0.09</td>
<td>0.25*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness Coherences</td>
<td>-0.12</td>
<td>-0.01</td>
<td>-0.27**</td>
<td>-0.23*</td>
<td>0.28**</td>
<td>0.42**</td>
<td></td>
</tr>
<tr>
<td>Emotional Representation</td>
<td>0.33**</td>
<td>0.36**</td>
<td>0.31**</td>
<td>0.60**</td>
<td>-0.15</td>
<td>-0.13</td>
<td>-0.35**</td>
</tr>
</tbody>
</table>

** p<0.01, * p<0.05
Mothers who had a strong belief in the ability of the child’s treatment to cure or control the child’s asthma (Treatment Cure/Control) also tended to believe in their own self-efficacy (Personal Control). However, neither of these factors was related to Emotional Representation, suggesting that they did not affect mothers’ feelings about their child’s asthma. This is interesting as it conflicts with the results found by Moss-Morris et al (2002) who found strong correlations between Treatment Cure/Control, Personal Control and Emotional Representation.

Mothers who felt that they had a good understanding of their child’s asthma (Illness Coherence) tended to believe that both they and their child’s treatment could be effective (Personal Control and Treatment Cure/Control), perceived their child’s asthma as being more predictable and stable (Timeline Cyclical) and having less severe consequences (Consequences), and thus were less upset or anxious about the asthma (Emotional Representation). This is in line with results of previous studies (Moss-Morris et al, 2002).

3.3.2.1. Cause
Mother’s beliefs about the causes of their child’s asthma are shown in table 8. The Causes subscale asks responders what they believe was the original cause of their child’s asthma. The majority of mothers believed that their child’s asthma was due to hereditary factors or caused by pollution in the environment or a germ or virus. (It is possible for responders to agree with more than one cause: therefore the total does not equal 94). However, from the responses given it was clear that although the majority of mothers had answered this subscale in terms of the original cause of the child’s asthma, some mothers had answered it in terms of the day-to-day causes of the child’s asthma episodes and asthma attacks, and for several participants it was unclear about which way they had answered the subscale. Therefore this subscale was considered possibly invalid and not used any further in the analysis.
Table 8: Mother’s beliefs about the causes of their child’s asthma (IPQ-R)

<table>
<thead>
<tr>
<th>(N=94)</th>
<th>Agreement with item as cause of child’s asthma (N)</th>
<th>Agreement with item as cause of child’s asthma (%)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hereditary - runs in family</td>
<td>65</td>
<td>69.2</td>
<td>3.71 (1.41)</td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td>57</td>
<td>60.7</td>
<td>3.53 (1.2)</td>
</tr>
<tr>
<td>Germ or virus</td>
<td>35</td>
<td>37.3</td>
<td>2.81 (1.25)</td>
</tr>
<tr>
<td>Stress or worry</td>
<td>20</td>
<td>21.3</td>
<td>2.29 (1.21)</td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td>15</td>
<td>15.9</td>
<td>2.38 (1.06)</td>
</tr>
<tr>
<td>Diet or eating habits</td>
<td>14</td>
<td>14.9</td>
<td>2.27 (1.08)</td>
</tr>
<tr>
<td>Altered immunity</td>
<td>13</td>
<td>13.9</td>
<td>2.19 (1.16)</td>
</tr>
<tr>
<td>Child’s emotional state e.g. feeling down, lonely, anxious, empty</td>
<td>11</td>
<td>11.7</td>
<td>1.97 (1.02)</td>
</tr>
<tr>
<td>Family problems or worries</td>
<td>10</td>
<td>10.7</td>
<td>1.88 (1.00)</td>
</tr>
<tr>
<td>Mother smoking</td>
<td>9</td>
<td>9.6</td>
<td>1.77 (1.07)</td>
</tr>
<tr>
<td>Child’s behaviour</td>
<td>5</td>
<td>5.4</td>
<td>1.74 (0.88)</td>
</tr>
<tr>
<td>Child’s mental attitude e.g. thinking about life negatively</td>
<td>5</td>
<td>5.4</td>
<td>1.74 (0.89)</td>
</tr>
<tr>
<td>Overwork (in or out of school)</td>
<td>5</td>
<td>5.4</td>
<td>1.81 (0.91)</td>
</tr>
<tr>
<td>Mother’s behaviour</td>
<td>4</td>
<td>4.3</td>
<td>1.74 (0.83)</td>
</tr>
<tr>
<td>Poor medical care in child’s past</td>
<td>4</td>
<td>4.3</td>
<td>1.82 (0.84)</td>
</tr>
<tr>
<td>Accident or injury</td>
<td>3</td>
<td>3.2</td>
<td>1.55 (0.74)</td>
</tr>
<tr>
<td>Child’s personality</td>
<td>3</td>
<td>3.2</td>
<td>1.59 (0.77)</td>
</tr>
<tr>
<td>Mother’s personality</td>
<td>2</td>
<td>2.1</td>
<td>1.56 (0.73)</td>
</tr>
<tr>
<td>Child getting older</td>
<td>1</td>
<td>1.1</td>
<td>1.70 (0.73)</td>
</tr>
<tr>
<td>Mother drinking alcohol</td>
<td>0</td>
<td>0.0</td>
<td>1.48 (0.64)</td>
</tr>
</tbody>
</table>
3.3.3. Maternal Anxiety and Depression

Mean scores in table 9 show the average total summed scores on the Anxiety and Depression subscales of the HADS. Higher scores indicate higher anxiety or depression.

<table>
<thead>
<tr>
<th></th>
<th>(N=94)</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Anxiety</td>
<td>7.24</td>
<td>6.50</td>
<td>4.16</td>
<td></td>
<td>0</td>
<td>17</td>
</tr>
<tr>
<td>Depression</td>
<td>3.99</td>
<td>3.00</td>
<td>3.69</td>
<td></td>
<td>0</td>
<td>14</td>
</tr>
<tr>
<td>Total</td>
<td>11.23</td>
<td>9.00</td>
<td>7.23</td>
<td></td>
<td>0</td>
<td>30</td>
</tr>
</tbody>
</table>

The majority of mothers had anxiety scores within the ‘normal’ range (n = 54, 57.4%). Nineteen (20.3%) had scores with the ‘mild’ range, 16 (17%) had scores within the ‘moderate’ range and five (5.3%) had scores within the ‘severe’ range. The majority of mothers had depression scores within the ‘normal’ range (n = 77, 81.9%). Eleven (11.7%) had scores with the ‘mild’ range, six (6.4%) had scores within the ‘moderate’ range and none had scores within the ‘severe’ range. Thus, as expected, the majority of the sample did not have clinically significant anxiety or depression, suggesting that having a child with asthma does not automatically lead to clinical anxiety and depression. The results for depression were similar to those for the general population (normal 86%, mild 9%, moderate 3%, severe 2%) but the results for anxiety were above those for the general population (normal 61%, mild 13%, moderate 12%, severe 4%) (Crawford, Henry, Crombie & Taylor, 2001). However, these results are in line with other studies showing that most parents of children with a chronic illness do not have clinical levels of depression but that they may have slightly raised levels of anxiety and depression (Cohen, 1999; Quittner et al 1998; Gillis, Haaga & Ford, 1995; Dent & Salkovskis, 1986).

A Pearsons correlation indicated that anxiety and depression were significantly and positively correlated (r (94) = 0.7, p<0.01). This is consistent with previous studies using the HADS (Bjelland et al, 2002).
3.3.4. Parenting Stress

Mean scores in table 10 represent the average summed scores on the Parenting Stress Index/Short Form. Higher scores indicate higher levels of parenting stress.

<table>
<thead>
<tr>
<th>(N=91)</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
<th>Norms (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental Distress (possible scores 12-60)</td>
<td>25.13</td>
<td>26.00</td>
<td>8.95</td>
<td>12.00</td>
<td>51.00</td>
<td>25.0 (8.0)</td>
</tr>
<tr>
<td>Parent-Child Dysfunctional Interaction (possible scores 12-60)</td>
<td>20.79</td>
<td>21.00</td>
<td>7.52</td>
<td>12.00</td>
<td>46.00</td>
<td>19.0 (7.0)</td>
</tr>
<tr>
<td>Difficult Child (possible scores 12-60)</td>
<td>25.49</td>
<td>25.00</td>
<td>8.51</td>
<td>12.00</td>
<td>49.00</td>
<td>25.0 (8.0)</td>
</tr>
<tr>
<td>Total (possible scores 36-180)</td>
<td>71.84</td>
<td>71.00</td>
<td>22.01</td>
<td>36.00</td>
<td>140.00</td>
<td>69.0 (17.0)</td>
</tr>
</tbody>
</table>

The majority of mothers had Parenting Stress scores within the normal range (n = 41, 45%). Twenty-four (26.4%) mothers had scores within the low range, six (6.6%) mothers had scores in the normal-high range and 20 (22%) mothers had scores within the high range. Thus, the majority of mothers did not report clinically significant levels of parenting stress. The results are similar to PSI/SF norms, suggesting that parenting a child with asthma does not lead to increased parenting stress (Abdin, 1995). However, this contradicts results of a previous study of 41 mothers of children with asthma which found that parenting stress scores were significantly higher in mothers of children with asthma than mothers of healthy children (Carson & Schauer, 1992).

Pearson’s correlations indicated that the subscales of the PSI/SF were all significantly and positively correlated with each other.\(^\text{15}\)

\(^{15}\) See Appendix O for Subscale Correlations
3.3.5. **Child psychological and behavioural difficulties**

Mean scores in table 11 represent the average summed scores on the SDQ. Higher scores indicate higher levels of difficulties.

**Table 11: Levels of child psychological and behavioural difficulties (SDQ)**

<table>
<thead>
<tr>
<th>Emotional Symptoms (possible scores 0-10)</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
<th>Norms Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>3.27</td>
<td>3.00</td>
<td>2.52</td>
<td>0</td>
<td>10</td>
<td>1.9 (2.0)</td>
</tr>
<tr>
<td>Conduct Problems (possible scores 0-10)</td>
<td>1.74</td>
<td>1.00</td>
<td>1.75</td>
<td>0</td>
<td>9</td>
<td>1.6 (1.7)</td>
</tr>
<tr>
<td>Hyperactivity (possible scores 0-10)</td>
<td>4.01</td>
<td>3.00</td>
<td>4.01</td>
<td>0</td>
<td>10</td>
<td>3.5 (2.6)</td>
</tr>
<tr>
<td>Peer Problems (possible scores 0-10)</td>
<td>1.67</td>
<td>2.00</td>
<td>1.58</td>
<td>0</td>
<td>6</td>
<td>1.5 (1.7)</td>
</tr>
<tr>
<td>Prosocial Behaviour (possible scores 0-10)</td>
<td>8.51</td>
<td>9.00</td>
<td>1.64</td>
<td>3</td>
<td>10</td>
<td>8.6 (1.6)</td>
</tr>
<tr>
<td>Total (possible scores 0-40)</td>
<td>10.69</td>
<td>9.00</td>
<td>6.45</td>
<td>1</td>
<td>31</td>
<td>8.4 (5.8)</td>
</tr>
</tbody>
</table>

The majority of mothers reported psychological and behavioural difficulties for their child on the SDQ within the ‘normal’ range (64, 68.8%). Eleven (11.8%) mothers reported difficulties within the ‘borderline’ range and eighteen (19.4%) mothers reported difficulties within the ‘abnormal’ range. Thus the majority of children did not have clinically significant levels of psychological or behavioural difficulties according to their mothers. These results are above those for a normal population (normal 82%, borderline 8%, abnormal 10%) but similar to those for patients in paediatric outpatient clinics with non-brain disorders (normal 71%, borderline 11%, abnormal 18%) (Glazebrook, Hollis, Heussler, Goodman & Coates, 2003). The means are similar to those for the standardisation sample for Conduct Problems (t (92, 10297) = 0.790, p>0.05), Hyperactivity (t (92, 10297) = 1.882, p>0.05), Peer Problems (t (92, 10297) = 0.678, p>0.05) and Prosocial Behaviour (t (92, 10297) = -0.540, p>0.05), but higher for Emotional Symptoms (t (92, 10297) = 6.559, p< 0.01) and Total Difficulties (t (92, 10297) = 3.787, p< 0.01) (Meltzer, Gatward, Goodman & Ford, 2000). This suggests that children with asthma have higher levels of emotional symptoms than children without a chronic illness.
Pearson's correlations indicated that the subscales of the SDQ used in the total analysis were all significantly and positively correlated with each other\textsuperscript{15}. The Prosocial behaviour subscale, which is not used in the total analysis, was significantly negatively correlated with Conduct Problems and Hyperactivity but was not correlated with Emotional Symptoms or Peer Problems.

### 3.3.6. Child Quality of Life

Mean scores in tables 12 and 13 represent the average summed scores on the Paediatric Quality of Life Questionnaire. Vami et al (2003) suggest that for the PedsQL Generic module one standard deviation below the population mean is seen as a meaningful cut-off point for children at risk of an impaired quality of life compared to the general population. For this study, Vami et al's (2003) healthy population was used for the population sample, with a cut-off of 60.7 for PedsQL Generic Child-report and 65.4 for PedsQL Generic Mother-report. Lower scores indicate poorer quality of life.

#### 3.3.6.1. Mother-rated child quality of life

Table 12 shows the average summed scores for mother-rated child quality of life.

<table>
<thead>
<tr>
<th>Module (N=94) (possible scores 0-100)</th>
<th>Subscale</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generic</td>
<td>Physical</td>
<td>75.03</td>
<td>75.00</td>
<td>18.81</td>
<td>12.50</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Emotional</td>
<td>69.20</td>
<td>70.00</td>
<td>19.24</td>
<td>20.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td>75.32</td>
<td>80.00</td>
<td>20.36</td>
<td>35.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>School</td>
<td>64.31</td>
<td>65.00</td>
<td>18.97</td>
<td>20.00</td>
<td>95.00</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
<td>69.61</td>
<td>71.67</td>
<td>15.86</td>
<td>31.67</td>
<td>95.00</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>71.50</td>
<td>73.91</td>
<td>15.54</td>
<td>25.00</td>
<td>96.74</td>
</tr>
<tr>
<td>Asthma</td>
<td>Asthma</td>
<td>63.68</td>
<td>62.50</td>
<td>17.40</td>
<td>20.45</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>80.85</td>
<td>84.09</td>
<td>16.13</td>
<td>40.91</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>80.67</td>
<td>91.67</td>
<td>24.42</td>
<td>0.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>70.12</td>
<td>75.00</td>
<td>26.84</td>
<td>0.00</td>
<td>100.00</td>
</tr>
</tbody>
</table>
According to Varni et al’s (2003) criteria, thirty-one mothers (33%) rated their child’s quality of life on the PedsQL Generic module within the range that may be considered at risk of an impaired quality of life. Thus the majority of mothers (63: 67%) did not rate their child’s quality of life as falling within the levels considered to be indicative of the child being at risk of an impaired quality of life. However, the scores were consistent with the standardisations for an asthma population with the means on the current study all being within 1/8th of a standard deviation of the means on the standardisation study (Varni et al, 2004). As expected from the standardisation sample, a Pearson’s correlation indicated that the subscales of the PedsQL Generic mother-report were all significantly and positively correlated with each other15 (Varni et al, 2004; Varni, Seid & Kurtin, 2001)

As the PedsQL Asthma module is only intended for use with children with asthma, it was not possible to compare the results with those of healthy children in order to provide a cut-off below which quality of life may be impaired. However, the scores were consistent with the standardisations for an asthma population with the means on the current study all being within 1/5th of a standard deviation of the means on the standardisation study (Varni et al, 2004). This indicates that the sample investigated was similar to the standardisation sample in terms of mothers’ beliefs about their child’s quality of life. A Pearson’s correlation indicated that the subscales of the PedsQL Asthma mother-report were all significantly and positively correlated with each other apart from the Asthma and Communication subscales which were not correlated15. This is mainly concordant with the results of the PedsQL Asthma standardisation sample, which found positive correlations between all the subscales with the smallest correlation for Asthma/Communication (Varni et al, 2004).
3.3.6.2. Child-rated child quality of life

Table 13 shows the average summed scores for child-rated child quality of life.

<table>
<thead>
<tr>
<th>Module (N=93) (possible scores 0-100)</th>
<th>Subscale</th>
<th>Mean</th>
<th>Median</th>
<th>Standard Deviation</th>
<th>Min</th>
<th>Max</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic</td>
<td>Physical</td>
<td>79.07</td>
<td>81.25</td>
<td>14.95</td>
<td>25.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Emotional</td>
<td>68.60</td>
<td>70.00</td>
<td>18.15</td>
<td>20.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Social</td>
<td>75.79</td>
<td>80.00</td>
<td>22.40</td>
<td>10.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>School</td>
<td>67.64</td>
<td>70.00</td>
<td>17.53</td>
<td>20.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
<td>70.67</td>
<td>73.33</td>
<td>15.71</td>
<td>33.33</td>
<td>98.33</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>73.60</td>
<td>76.09</td>
<td>13.76</td>
<td>30.43</td>
<td>97.83</td>
</tr>
<tr>
<td>Asthma</td>
<td>Asthma</td>
<td>65.55</td>
<td>63.64</td>
<td>15.73</td>
<td>31.82</td>
<td>95.45</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>76.84</td>
<td>79.55</td>
<td>14.38</td>
<td>27.27</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>80.06</td>
<td>83.33</td>
<td>24.15</td>
<td>0.00</td>
<td>100.00</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>60.30</td>
<td>66.67</td>
<td>28.51</td>
<td>0.00</td>
<td>100.00</td>
</tr>
</tbody>
</table>

On the PedsQL Generic module thirty-three children (37%) rated their quality of life within the range that may be considered at risk of an impaired quality of life whereas fifty-six (63%) rated their quality of life within levels not considered indicative of a risk of impaired quality of life (Varni et al, 2003). However, the scores were consistent with the standardisations for an asthma population with the means on the current study all being within $\frac{1}{8}$ of a standard deviation of the means on the standardisation study (Varni et al, 2004). A Pearson’s correlation indicated that the subscales of the PedsQL Generic Child-report were all significantly and positively correlated with each other which is consistent with the results of the PedsQL Generic standardisation sample (Varni et al, 2004; Varni, Scid & Kurtin, 2001)

As previously discussed, the PedsQL Asthma module is an asthma-specific measure and therefore there is no cut-off score for a risk of impaired quality of life. However, the scores were consistent with the standardisations for an asthma population with the means on the current study all being within $\frac{1}{2}$ a standard deviation of the means on the standardisation study (Varni et al, 2004). A Pearson’s correlation indicated that the
subscales of the PedsQL Asthma Child-report were all significantly and positively correlated with each other apart from the Worry and Communication subscales which were not correlated with each other\textsuperscript{15}. This differs slightly from the PedsQL Asthma standardisation sample which found positive correlations between all of the subscales (Varni et al, 2004).

PART 2

Testing of hypotheses followed Baron and Kenny’s (1986) structure for testing moderation. Relationships between variables were analysed using Pearson’s correlations. Due to the large number of correlations being carried out, Holm’s (1979) correction criteria for Type 1 experiment-wise errors was used.

3.4. Relationships between Dependent Variables

3.4.1. Are mother anxiety and depression, child psychological and behavioural difficulties, and parenting stress correlated?

As hypothesised, results indicated that there were significant positive correlations between all of these measures - HADS Anxiety and Depression, SDQ and PSI/SF (table 16). This indicates that the mothers’ own mood and difficulty ratings were self-consistent – i.e. those mothers who were depressed and anxious also found parenting stressful. Parenting stress was moderately correlated with mothers’ ratings of both their own and their child’s psychological adjustment. This is consistent with the factor structure of the PSI/SF which contains both parent- and child- factors. However, there was only a small correlation between mother and child psychological adjustment, suggesting that mothers’ ratings of their child’s psychological and behavioural difficulties were not entirely determined by their own anxiety or depression.

Table 16: Correlations between the HADS, SDQ and PSI/SF

<table>
<thead>
<tr>
<th></th>
<th>HADS Anxiety</th>
<th>HADS Depression</th>
<th>SDQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS Depression</td>
<td>0.70*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SDQ</td>
<td>0.24*</td>
<td>0.27*</td>
<td></td>
</tr>
<tr>
<td>PSI/SF</td>
<td>0.55*</td>
<td>0.62*</td>
<td>0.52*</td>
</tr>
</tbody>
</table>

* significant correlations
3.4.2. Is mother-rated child quality of life correlated with child-rated child quality of life?

Correlations between the PedsQL mother-report and child-report scales are shown in table 17.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Mother-report / Child-report correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic Physical</td>
<td>0.29*</td>
</tr>
<tr>
<td>Generic Psychosocial</td>
<td>0.15</td>
</tr>
<tr>
<td>Asthma Asthma</td>
<td>0.37*</td>
</tr>
<tr>
<td>Asthma Treatment</td>
<td>0.33*</td>
</tr>
<tr>
<td>Asthma Worry</td>
<td>0.00</td>
</tr>
<tr>
<td>Asthma Communication</td>
<td>0.10</td>
</tr>
</tbody>
</table>

* significant correlations

As hypothesised, the PedsQL Generic Physical, Asthma Asthma and Asthma Treatment mother-report and child-report subscales were significantly correlated. However the Generic Psychosocial, Asthma Worry and Asthma Communication subscales were not significantly correlated. These results indicate that there is a positive relationship between physical aspects of mother-rated and child-rated child quality of life but not between psychosocial aspects such as worry and communication. This differs from the PedsQL Asthma standardisation sample where correlations were found between all parent-report and child-report measures (Varni et al, 2004).

3.4.3. Is child quality of life correlated with mother anxiety and depression, child psychological and behavioural difficulties and parenting stress?

The relationship between the PedsQL measures and mother anxiety and depression, SDQ and parenting stress was analysed using Pearson’s correlations (tables 18 and 19). The PedsQL child-report measures showed no significant correlations with any of the mother-reported psychological measures, indicating that how the child perceives their own quality of life is not related to their mother’s anxiety, depression or parenting stress and is not related to how their mothers perceive their psychological and behavioural difficulties.
However, the PedsQL mother-report measures (both Generic and Asthma) showed significant correlations with all four psychological measures. These results suggest that how mothers perceive their child’s quality of life is to some extent related to their own anxiety, depression and parenting stress and is highly related to their perception of their child’s psychological and behavioural difficulties. Interestingly, mothers’ perceptions of the level of their children’s physical functioning (Generic Physical and Asthma Asthma) was not correlated with their own anxiety although it was correlated with their depression and parenting stress.

**Table 18: Correlations between PedsQL Mother-report and HADS, SDQ and PSI/SF**

<table>
<thead>
<tr>
<th></th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
<th>SDQ</th>
<th>PSI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic Physical</td>
<td>-0.21</td>
<td>-0.40*</td>
<td>-0.43*</td>
<td>-0.28*</td>
</tr>
<tr>
<td>Generic Psychosocial</td>
<td>-0.39*</td>
<td>-0.49*</td>
<td>-0.64*</td>
<td>-0.53*</td>
</tr>
<tr>
<td>Asthma Asthma</td>
<td>-0.25</td>
<td>-0.30*</td>
<td>-0.35*</td>
<td>-0.34*</td>
</tr>
<tr>
<td>Asthma Treatment</td>
<td>-0.33*</td>
<td>-0.33*</td>
<td>-0.39*</td>
<td>-0.42*</td>
</tr>
<tr>
<td>Asthma Worry</td>
<td>-0.21*</td>
<td>-0.40*</td>
<td>-0.22</td>
<td>-0.29*</td>
</tr>
<tr>
<td>Asthma Communication</td>
<td>-0.12</td>
<td>-0.19</td>
<td>-0.30*</td>
<td>-0.40*</td>
</tr>
</tbody>
</table>

* significant correlations

**Table 19: Correlations between PedsQL Child-report and HADS, SDQ and PSI/SF**

<table>
<thead>
<tr>
<th></th>
<th>HAD Anxiety</th>
<th>HAD Depression</th>
<th>SDQ</th>
<th>PSI</th>
</tr>
</thead>
<tbody>
<tr>
<td>Generic Physical</td>
<td>0.17</td>
<td>0.03</td>
<td>-0.18</td>
<td>0.04</td>
</tr>
<tr>
<td>Generic Psychosocial</td>
<td>0.10</td>
<td>-0.06</td>
<td>-0.13</td>
<td>-0.03</td>
</tr>
<tr>
<td>Asthma Asthma</td>
<td>0.09</td>
<td>-0.05</td>
<td>0.01</td>
<td>0.08</td>
</tr>
<tr>
<td>Asthma Treatment</td>
<td>0.14</td>
<td>-0.02</td>
<td>-0.12</td>
<td>-0.01</td>
</tr>
<tr>
<td>Asthma Worry</td>
<td>0.13</td>
<td>0.09</td>
<td>-0.06</td>
<td>0.12</td>
</tr>
<tr>
<td>Asthma Communication</td>
<td>0.01</td>
<td>-0.15</td>
<td>-0.09</td>
<td>-0.14</td>
</tr>
</tbody>
</table>

* significant correlations
3.5. Relationships between the Independent Variable (Severity) and the Dependent Variables

3.5.1. *Is asthma severity correlated with mother anxiety and depression, child psychological and behavioural difficulties and parenting stress?*

As hypothesised, and consistent with results of previous studies, results indicated that there were no significant correlations between severity and mother anxiety or depression or parenting stress. Contrary to the hypothesis, there was also no correlation between asthma severity and child psychological and behavioural difficulties (table 20).

**Table 20: Correlations between severity and the HADS, SDQ and PSI/SF**

<table>
<thead>
<tr>
<th>Severity</th>
<th>HADS Anxiety</th>
<th>HADS Depression</th>
<th>SDQ</th>
<th>PSI/SF</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0.20</td>
<td>0.08</td>
<td>-0.07</td>
<td>0.15</td>
</tr>
</tbody>
</table>

* significant correlations

3.5.2. *Is asthma severity correlated with mother-rated child quality of life or child-rated child quality of life?*

Severity was not found to be significantly correlated with any of the PedsQL measures (table 21). As discussed in the introduction, this is consistent with results of previous studies which have not found a linear relationship between asthma severity and quality of life.

**Table 21: Correlations between Severity and PedsQL mother-report and child-report**

<table>
<thead>
<tr>
<th></th>
<th>Generic</th>
<th>Asthma</th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Physical</td>
<td>Psychosocial</td>
<td>Asthma</td>
<td>Treatment</td>
<td>Worry</td>
<td>Communication</td>
</tr>
<tr>
<td>Mother-report</td>
<td>-0.10</td>
<td>-0.11</td>
<td>-0.16</td>
<td>-0.02</td>
<td>-0.00</td>
<td>0.12</td>
</tr>
<tr>
<td>Child-report</td>
<td>0.01</td>
<td>-0.08</td>
<td>-0.06</td>
<td>0.11</td>
<td>-0.10</td>
<td>-0.06</td>
</tr>
</tbody>
</table>

* significant correlations
3.6. Relationships between the Independent Variable (Severity) and the Moderating Variable (Maternal Illness Beliefs)

3.6.1. Is severity correlated with maternal illness beliefs?

The relationship between severity and maternal illness beliefs was analysed (table 22).

**Table 22: Correlations between Severity and the IPQ-R**

<table>
<thead>
<tr>
<th></th>
<th>IPQ-R Identity</th>
<th>IPQ-R Timeline</th>
<th>IPQ-R Timeline Cyclical</th>
<th>IPQ-R Consequences</th>
<th>IPQ-R Personal</th>
<th>IPQ-R Treatment</th>
<th>IPQ-R Illness Coherence</th>
<th>IPQ-R Emotional Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severity</td>
<td>0.14</td>
<td>0.31*</td>
<td>0.10</td>
<td>0.28*</td>
<td>0.13</td>
<td>0.11</td>
<td>0.14</td>
<td>0.17</td>
</tr>
</tbody>
</table>

* significant correlations

Severity was correlated only with IPQ-R Timeline and IPQ-R Consequences. This indicates that, as may be expected, mothers whose children had more severe asthma were more likely to think that their child’s asthma was a chronic and permanent condition and were more likely to think that their child’s asthma had serious consequences. Interestingly however, severity was not correlated with the Identity subscale, indicating that the number of symptoms mothers reported was not related to the objective asthma severity.

3.7. Relationships between the Moderating Variable (Maternal Illness Beliefs) and the Dependent Variables

3.7.1. Are maternal illness beliefs correlated with mother psychological adjustment, child psychological and behavioural difficulties and parenting stress?

Pearson’s correlations were used to analyse the relationship between mother’s illness beliefs and asthma severity, mother anxiety and depression, parenting stress, and child psychological and behavioural difficulties (table 23).
Table 23: Correlations between the IPQ-R and HADS Anxiety and Depression, SDQ and PSI/SF

<table>
<thead>
<tr>
<th></th>
<th>IPQ-R Identity</th>
<th>IPQ-R Timeline</th>
<th>IPQ-R Timeline Cyclical</th>
<th>IPQ-R Consequences</th>
<th>IPQ-R Personal Control</th>
<th>IPQ-R Treatment Cure Control</th>
<th>IPQ-R Illness Coherence</th>
<th>IPQ-R Emotional Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAD Anxiety</td>
<td>0.12</td>
<td>0.30</td>
<td>0.29</td>
<td>0.39*</td>
<td>0.05</td>
<td>-0.13</td>
<td>-0.24</td>
<td>0.53*</td>
</tr>
<tr>
<td>HAD Depression</td>
<td>0.07</td>
<td>0.13</td>
<td>0.10</td>
<td>0.32</td>
<td>-0.14</td>
<td>-0.22</td>
<td>-0.34*</td>
<td>0.40*</td>
</tr>
<tr>
<td>SDQ</td>
<td>-0.38*</td>
<td>0.18</td>
<td>0.28</td>
<td>0.29</td>
<td>-0.18</td>
<td>-0.13</td>
<td>-0.26</td>
<td>-0.16</td>
</tr>
<tr>
<td>PSI/SF</td>
<td>0.07</td>
<td>0.21</td>
<td>0.09</td>
<td>0.26</td>
<td>-0.03</td>
<td>-0.10</td>
<td>-0.29</td>
<td>0.25</td>
</tr>
</tbody>
</table>

* significant correlations

A large number of different correlations were found. In general, those mothers who thought they had a coherent understanding of their child’s asthma, who did not report anxiety, depression, fear and anger in relation to the asthma, and who believed that the asthma was a temporary condition, was predictable and not too changeable and did not have serious consequences, reported lower levels of anxiety and depression, lower levels of parenting stress, and lower levels of psychological and behavioural difficulties in their child. However, different illness beliefs correlated with different measures.

However, when corrected for Type 1 experiment-wise errors using Holm’s (1979) criteria, only five correlations remained. IPQ-R Identity (number of reported symptoms) was positively correlated with the SDQ, indicating that mothers who reported higher numbers of symptoms in their child also reported more psychological and behavioural difficulties in their child. IPQ-R Consequences was positively correlated with HADS Anxiety, indicating either that the more serious mothers perceived the consequences of the asthma to be, the more anxious they were, or that more anxious mothers tended to perceive the asthma as having more serious consequences. IPQ-R Illness Coherence was negatively correlated with HADS Depression, indicating that mothers who were more depressed felt that they had less
understanding of their child’s asthma. IPQ-R Emotional Representation was positively correlated with both HADS Anxiety and HADS Depression. This indicates that either mothers’ overall anxiety and depression scores were significantly affected by the anxiety and depression they experienced in relation to their child’s asthma, or that mothers who were in general more anxious and depressed also felt more anxious and depressed about their child’s asthma. However, due to the nature of the study, it was not possible to look at the direction of the effects.

3.7.2. Are maternal illness beliefs (IPQ-R) correlated with child quality of life?
Pearson’s correlations were used to analyse the relationships between maternal illness beliefs and child quality of life as measured by mother and child. No significant correlations were found between the child-rated child quality of life scales and maternal illness beliefs indicating that, as may be expected, children’s self-perception of their quality of life is not related to their mother’s beliefs about the illness. However, significant correlations were found between six mother-rated child quality of life dimensions and maternal illness beliefs.

PedsQL Asthma Asthma was related to IPQ-R Identity, Consequences and Timeline Cyclical. This suggests that, as may be expected, mothers who indicated that their child had a larger number of asthma symptoms, who thought that their child’s asthma was changeable and unpredictable and would have serious consequences perceived the asthma as having more of an effect on the child’s life in terms of physical functioning.

PedsQL Asthma Treatment was related to IPQ-R Identity and Consequences indicating that mothers who thought that their child had more symptoms and who thought that the asthma had serious consequences also thought that their child had more difficulties with their treatment. This suggests that either when a child has a high number of asthma symptoms with serious consequences mothers tend to believe it is related to difficulties with treatment or that the children have a high number of symptoms with serious consequences due to difficulties with their treatment.

16 See Appendix P for Correlations between IPQ-R and PedsQL
PedsQL Generic Psychosocial was related to IPQ-R Consequences. This indicates that mothers who thought their child’s asthma would have serious consequences reported their child as having more psychosocial difficulties.

3.8. Do maternal illness beliefs act as a moderating variable on the relationship between mother anxiety and depression, child psychological and behavioural difficulties, child quality of life, and parenting stress?

In order to test whether maternal illness beliefs acted as a moderating variable on the relationship between asthma severity and psychological adjustment in mother and child, 80 separate moderated multiple regression analyses were calculated, with HAD Depression, HAD Anxiety, SDQ, PSI/SF and the PedsQL subscales as dependent variables (calculated separately), Severity as the independent variable, and the eight illness belief subscales on the IPQ-R as moderating variables. For each moderated regression the independent variable and the moderating variables were entered simultaneously into the regression equation (Baron & Kenny, 1986; Tabachnick & Fidell, 2001). The majority of the multiple regression analyses were not significant, indicating that in general, illness beliefs did not act as a moderating variable on the relationship between asthma severity and mother anxiety and depression, child psychological and behavioural difficulties or parenting stress. However, eight analyses were significant. Due to the large number of calculations, only those that were significant are reported. Table 24 displays the correlation coefficients for the significant multiple regressions.

Table 24: Significant multiple regressions where maternal illness beliefs are the moderating variables and paediatric asthma severity is the independent variable

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Predictor</th>
<th>Beta</th>
<th>t</th>
<th>Sig.</th>
<th>Adusted r²</th>
<th>F</th>
<th>d.f.</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>PedsQL Child Asthma Communication</td>
<td>Severity</td>
<td>0.00</td>
<td>0.02</td>
<td>0.99</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Timeline</td>
<td>-0.11</td>
<td>-1.03</td>
<td>0.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Timeline</td>
<td>0.35</td>
<td>3.31</td>
<td>0.00</td>
<td>0.10</td>
<td>4.24</td>
<td>3, 85</td>
<td>0.01</td>
</tr>
<tr>
<td>PSI/SF</td>
<td>Severity</td>
<td>0.09</td>
<td>0.86</td>
<td>0.40</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Timeline Cyclical</td>
<td>0.12</td>
<td>1.14</td>
<td>0.26</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Timeline Cyclical</td>
<td>0.29</td>
<td>2.76</td>
<td>0.01</td>
<td>0.07</td>
<td>3.37</td>
<td>3.87</td>
<td>0.02</td>
</tr>
<tr>
<td>PedsQL Child Asthma Treatment</td>
<td>Severity</td>
<td>0.07</td>
<td>0.62</td>
<td>0.54</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Timeline Cyclical</td>
<td>-0.00</td>
<td>-0.04</td>
<td>0.97</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Timeline Cyclical</td>
<td>0.29</td>
<td>2.70</td>
<td>0.01</td>
<td>0.06</td>
<td>2.86</td>
<td>3.85</td>
<td>0.04</td>
</tr>
<tr>
<td>SDQ</td>
<td>Severity</td>
<td>-0.11</td>
<td>-1.05</td>
<td>0.30</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Personal Control</td>
<td>-0.13</td>
<td>-1.23</td>
<td>0.22</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Personal Control</td>
<td>0.25</td>
<td>2.36</td>
<td>0.02</td>
<td>0.06</td>
<td>2.93</td>
<td>3.89</td>
<td>0.04</td>
</tr>
<tr>
<td>PSI/SF</td>
<td>Severity</td>
<td>0.09</td>
<td>0.86</td>
<td>0.39</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Personal Control</td>
<td>-0.01</td>
<td>-0.13</td>
<td>0.90</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Personal Control</td>
<td>0.24</td>
<td>2.28</td>
<td>0.03</td>
<td>0.05</td>
<td>2.43</td>
<td>3.87</td>
<td>0.07</td>
</tr>
<tr>
<td>PedsQL Parent General Psychosocial</td>
<td>Severity</td>
<td>-0.07</td>
<td>-0.75</td>
<td>0.46</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Personal Control</td>
<td>0.20</td>
<td>2.06</td>
<td>0.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Personal Control</td>
<td>-0.33</td>
<td>-3.29</td>
<td>0.00</td>
<td>0.15</td>
<td>6.58</td>
<td>3.85</td>
<td>0.00</td>
</tr>
<tr>
<td>PedsQL Parent Asthma Treatment</td>
<td>Severity</td>
<td>0.03</td>
<td>0.29</td>
<td>0.78</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Personal Control</td>
<td>0.06</td>
<td>0.54</td>
<td>0.59</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Personal Control</td>
<td>-0.28</td>
<td>-2.58</td>
<td>0.01</td>
<td>0.04</td>
<td>2.83</td>
<td>3.85</td>
<td>0.02</td>
</tr>
<tr>
<td>PedsQL Parent Asthma Communication</td>
<td>Severity</td>
<td>0.15</td>
<td>1.49</td>
<td>0.14</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>IPQ-R Personal Control</td>
<td>0.14</td>
<td>1.41</td>
<td>0.16</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Severity x IPQ-R Personal Control</td>
<td>-0.26</td>
<td>-2.49</td>
<td>0.02</td>
<td>0.08</td>
<td>3.59</td>
<td>3.85</td>
<td>0.02</td>
</tr>
</tbody>
</table>
The only moderating effects found were between maternal illness beliefs (Timeline, Timeline Cyclical, Personal Control and Emotional Representation) and parenting stress, mother-report child quality of life, and mother-report child psychological and behavioural difficulties. This suggests that, if illness beliefs do have any moderating effects, it is likely to be between severity and mother’s perceptions of their child’s functioning or their own parenting stress rather than between severity and their own anxiety and depression or their child’s perceptions. IPQ-R Personal Control in particular was found to moderate between severity and five other variables: SDQ, PSI/SF and parent-report PedsQL Generic Psychosocial, Asthma Treatment and Asthma Communication. This suggests that mothers’ beliefs about the extent to which they have any personal control over their child’s asthma could be a particularly important variable in terms of moderating the relationship between severity and mother and child psychosocial variables.

However, using Holm’s (1979) correction criteria for Type 1 experiment-wise errors resulted in none of the multiple regressions reaching significance. This suggests that there is no clear unambiguous evidence for the moderating effect of maternal illness beliefs on the relationship between paediatric asthma severity and psychological adjustment in mother and child.
4. DISCUSSION

4.1. Summary of Findings
The principal research question was to test whether maternal illness beliefs moderated the relationship between paediatric asthma severity and maternal anxiety and depression, child psychological and behavioural difficulties, parenting stress and child quality of life. Overall, the results suggest that paediatric asthma severity as measured by medication prescribed does not predict maternal anxiety or depression, child psychological adjustment, parenting stress, or child quality of life. Severity is however related to mother’s beliefs about the likely duration of their child’s asthma and the consequences of the asthma.

Mothers’ levels of anxiety were slightly above the normal range but levels of depression were within the normal range. Mothers did not report higher levels of parenting stress compared to the general population. They rated their child as having higher levels of psychological and behavioural difficulties, specifically emotional difficulties, than mothers of healthy children. One third of mothers and one third of the children themselves reported difficulties suggesting an impairment of quality of life compared to healthy children, although there was an imperfect relationship between the two scales. Mothers’ reporting was in general self-consistent, in that mothers who felt anxious and depressed also tended to report higher levels of parenting stress, more behavioural and psychological difficulties in their child and a poorer quality of life in their child. There were significant correlations between maternal illness beliefs and between maternal illness beliefs and some of the mother-reported psychosocial variables. Child-rated child quality of life was unrelated to any of the mother-rated variables except mother-rated child quality of life.

4.2. Exploration of Results

4.2.1. Severity
Almost half the children had moderate asthma, just over a quarter had moderately severe asthma, and just under an eighth each had mild or severe asthma. Thus, the majority of the children had moderate or moderately severe asthma. However, this is
likely to be a biased sample of children with asthma compared with the incidence of asthma in the general population. The British Thoracic Society Guidelines (2004) recommend that asthma can generally be diagnosed and treated in a primary care (GP) environment, but that referral to specialist services (e.g. paediatric outpatients) may need to be considered when the diagnosis is uncertain, when there are other complicating factors, when a child fails to respond to conventional treatment, or when parents are particularly anxious or need reassurance. This means that the sample used was likely to contain a larger proportion of children with severe and moderately-severe asthma than in the general population and a larger proportion of mothers who may have been anxious or who were particularly concerned about their child’s asthma. Consequently the results of the study could be considered only as potentially able to be applied to a paediatric outpatient asthma population and not to the general asthma population.

Concordant with some previous research, severity was found to be unrelated to any of the psychosocial variables (HADS, SDQ, PSI/SF or PedsQL). However, this lack of relationship between severity and psychosocial variables may be partially due to the limited variance within the primary independent variable of severity, with the majority of the children being classified as having moderate or moderately severe asthma. This meant that there was a limited amount of variance to be ‘shared’ with the dependent variables which may have biased correlations downwards. Consequently correlations between severity and psychological adjustment in mother and child which may exist within the general population of asthmatic children were not found in this study.

However, severity was correlated with IPQ-R Timeline and Consequences beliefs. This indicates that, as may be expected, mothers whose children had more severe asthma were more likely to think that their child’s asthma was a chronic and permanent condition and were more likely to think that their child’s asthma had serious consequences. Interestingly though, mothers of children with more severe asthma were no more likely to report more asthma symptoms or more impairment in child quality of life than mothers of children with milder asthma. This suggests either that although mother’s beliefs about their child’s asthma may be affected by or related to actual severity, the amount of impact these symptoms have on their child’s
behaviour is not, or that these correlations may also have been affected by the limited variance within severity.

4.2.2. HADS
The majority of mothers had anxiety and depression scores within the ‘normal’ range. About twice as many mothers had anxiety scores above the ‘normal’ range than had depression scores above ‘normal’, and the mean anxiety score was higher than the mean depression score (7.24, which is between the ‘normal’ and ‘borderline’ range, compared to 3.99 which is within the ‘normal’ range). In addition a small percentage of mothers were classified as severely anxious whereas none of the mothers were classified as severely depressed. Although the majority of the sample did not have clinically significant levels of anxiety or depression, maternal anxiety levels would appear to be slightly raised compared to the general population. However, this may be because, as previously discussed, the sample used was likely to contain a large proportion of mothers who were anxious about their child’s asthma. Consistent with previous studies using the HADS, maternal anxiety and depression scores were positively highly correlated.

4.2.3. SDQ
Just over two thirds of mothers reported child psychological and behavioural difficulties within the ‘normal’ range, with approximately a tenth in the ‘borderline’ range and a fifth in the ‘abnormal’ range. These results were significantly above those for a healthy population but were similar to results for patients in paediatric outpatient clinics with non-brain disorders. This suggests that mothers of children with asthma perceive higher levels of psychological and behavioural difficulties in their children than mothers of children without asthma. In particular, mothers reported their children as having significantly more Emotional Difficulties than in a healthy population, which is concordant with previous research findings that children with asthma are particularly likely to have higher levels of internalising difficulties compared to healthy children. Possible reasons for these higher levels of psychological and behavioural difficulties perceived by mothers will be discussed shortly.
4.2.4. PSI/SF

Scores on the PSI/SF were consistent with the results of the general population standardisation study indicating that just over two thirds of mothers had levels of parenting stress within the normal to low range and just under a quarter had scores within the high range. Thus the majority of mothers did not report clinically significant levels of parenting stress. This is interesting as previous research has found raised levels of parenting stress in mothers of children with asthma, and common-sense views would suggest that the range of stressors involved in having a child with asthma such as the need to adhere to daily treatment regimes and having to cope with episodic events such as asthma attacks would lead to increased parenting stress (Carr, 1999; Carson & Schauer, 1992; Klinnert, McQuaid & Gavin, 1997; Wallander & Varni, 1992). It is not known why this study failed to find raised levels of parenting stress. However, one possibility is that mothers who found parenting more stressful were either more likely not to attend their child’s appointment or more likely to decline to participate.

4.2.5. The relationship between mother anxiety and depression, child psychological and behavioural difficulties, and parenting stress

Consistent with previous studies, significant positive correlations were found between mother anxiety and depression, child psychological and behavioural difficulties and parenting stress. The moderate correlation between parenting stress and mothers’ ratings of both their own and their child’s psychological adjustment is consistent with the factor structure of the PSI/SF which contains both parent and child factors, and suggests that a large proportion of parenting stress is related to child psychological and behavioural difficulties and mother’s general anxiety and depression but that other factors such as more general stress may also be involved. There was a small correlation between mother and child psychological adjustment. Previous studies have found that how mothers rate their child’s psychological and behavioural difficulties is related to their own psychological adjustment (Fergusson, Lysnekey & Horwood, 1993; Smith, 2004; Smith & Jenkins, 1991). One reason proposed for this is that depressed mothers’ views of their child’s psychological and behaviour difficulties may be seen in a more negative light because of their own depression, meaning that they are likely to overestimate the child’s difficulties. This is called the ‘depression distortion
hypothesis’ (Richters & Pellegrini 1989; Thompson, Gustafson et al 1994; Thompson, Merrit, Keith, Murphy & Johndrow, 1993). However, the fact that there was only a small correlation between mother and child psychological adjustment suggests that this is not entirely the case and that there may be at least some accuracy in mothers’ reporting of their child’s psychological and behavioural difficulties. This is consistent with other studies which have found that mothers’ reports of their child’s behaviour are influenced by their child’s behaviour as well as by their own mood (Fergusson, Lynskey & Horwood, 1993; Walker, Ortiz-Valdes & Newborough, 1989).

4.2.6. PedsQL
Scores on both the mother-rated and child-rated PedsQL were consistent with those of the asthma standardisation sample, with a third of mothers and a third of the children rating the child’s quality of life within the range that may be considered at risk of an impaired quality of life. However, there was an imperfect relationship between mother-rated and child-rated child quality of life, with physical aspects being correlated with one another but psychosocial aspects not being correlated. One possible reason for this is that physical aspects of quality of life such as running, wheezing or using an inhaler may be easier for mothers to observe than internal, psychological aspects such as feeling scared, upset, or worried, difficulties in communication with others, and aspects relating to school where mothers are not present. This could have resulted in a higher concordance for physical aspects than psychosocial aspects of quality of life. These results differ from the PedsQL Asthma standardisation sample, where correlations were found between all parent-report and child-report measures. This suggests a second possible reason for the fact that only some variables were correlated, namely that the number of participants in this study was not large enough to find significant correlations for all variables.

Mother-rated child quality of life was correlated with all four of the other mother-rated measures. The correlation with the SDQ supports results from previous studies with adults and adolescents which have found that quality of life is related to psychological adjustment (Anderson, 1995; Hommel et al, 2002). The fact that mother-rated child quality of life was correlated with all four other measures also adds futher support to the idea that mothers’ ratings tended to be self-consistent. Interestingly,
mothers' perceptions of the physical functioning aspects of their child's quality of life were not correlated with their own anxiety, although they were correlated with their depression and parenting stress. This is surprising as previous studies have suggested that impairments in a child's functioning are related to both increased maternal depression and increased maternal anxiety (Quittner et al, 1998).

Child-rated child quality of life was not related to any of the other mother-rated variables. This indicates that children's perceptions of their quality of life are independent of maternal anxiety, depression and parenting stress and of how their mothers perceive their psychological and behavioural difficulties.

4.2.7. Maternal Illness Representations

On average, most mothers rated their child as having four to five asthma-related symptoms and an additional two unrelated symptoms, suggesting that for many of the children there were other difficulties as well as the asthma. Given that a number of the children in the sample may have been referred to the paediatrician because their asthma had other complicating factors, this finding is unsurprising. It also accords with research suggesting that children with asthma are more likely than children without asthma to suffer from other physical health difficulties such as eczema and allergies (British Thoracic Society Guidelines, 2004). As would be expected in terms of consistency, the more asthma symptoms mothers reported, the more of an effect these symptoms had on the child's physical functioning according to the mother (PedsQL mother-report). Mothers who reported higher numbers of symptoms in their child also reported more psychological and behavioural difficulties in their child.

There are several possible reasons for this. The first is that mothers who are predisposed to reporting more psychological and behavioural difficulties in their child also see more symptoms (i.e. it is due to biased mother reporting). The second is that having more asthma symptoms leads to more psychological and behavioural difficulties in the child. The third is that childhood psychological and behavioural problems may have an impact themselves and may result in poorly-controlled asthma (McQuaid, Kopel & Nassau, 2001; Weil et al, 1999). Previous research supporting these reasons suggests that a combination of the first and third, and possibly the second factor, seems most likely.
Most mothers thought their child’s asthma had a cyclical and changeable pattern but they were unsure whether it was a permanent or temporary condition. This is likely to reflect the fact that the prognosis of asthma is at times uncertain. Although the majority of children with asthma that has not resolved by age six continue to experience symptoms of asthma as adults, others find that their symptoms disappear in their late teens although they may reoccur when they are in their thirties (National Asthma Campaign, 2002). However, it may also reflect mothers’ confusion or lack of understanding about their child’s asthma.

The majority of mothers believed that their child’s asthma did not have major consequences on their child’s life. The Consequences subscale was correlated with both physical and psychosocial subscales of the PedsQL mother-report as well as maternal anxiety and mother’s feelings about their child’s asthma. This suggests that mothers’ beliefs about the consequences of their child’s asthma were related to their perceptions of how their child functioned in day-to-day life. The correlations between the Consequences subscale and the Emotional Representation subscale and maternal anxiety suggests either that perceiving their child’s asthma as having more serious consequences may contribute to more negative feelings about the asthma on the mother’s part or that feeling more anxious and upset both about the asthma and in general may result in mothers perceiving the asthma as having more serious consequences.

The majority of mothers thought that they had some personal control over their child’s asthma and that their child’s treatment would be effective in curing or controlling the asthma. Neither variable was related to mother anxiety or depression, mothers’ feelings about the child’s asthma, child psychological and behavioural difficulties or parenting stress. This indicates that mothers’ beliefs about their own self-efficacy or the efficacy of the treatment are irrelevant in terms of their own or their child’s mood or stress levels. This is interesting as it conflicts with the results found by Moss-Morris et al (2002).

The majority of mothers thought that they had a coherent representation or understanding of their child’s illness. These mothers tended to feel less depressed and
to hold other more positive beliefs about their child’s illness in terms of their own personal control, the treatment’s efficacy, the consequences of the asthma and how the asthma affected them emotionally, and tended to perceive the child’s asthma as being more predictable and stable. This suggests that perceiving oneself as having a good understanding of the illness is related to other more positive beliefs.

The results suggested that some mothers found their child’s asthma very distressing while others found it easier to cope with emotionally. The extent to which mothers found their child’s asthma emotionally distressing was related to their general anxiety and depression. This could indicate either that mothers’ overall anxiety and depression scores were significantly affected by the anxiety and depression they experienced in relation to their child’s asthma or that mothers who were in general more anxious and depressed also felt more anxious and depressed about their child’s asthma. The latter would seem to be a more plausible explanation.

The majority of mothers indicated that they thought their child’s asthma was due to hereditary factors or caused by pollution in the environment or a germ or virus. However, due to the fact that some mothers seemed to answer the subscale in terms of the original cause of the asthma and some in terms of the day-to-day causes of the child’s asthma episodes and asthma attacks, the scale was considered possibly invalid and not used any further in the analysis. The researcher was not aware of any previous studies using the IPQ-R that had encountered this difficulty. This may be due to the fact that whereas asthma often involves specific or clear exacerbatory factors, many of the chronic illnesses used in studies using the IPQ and IPQ-R (such as myocardial infarctions, multiple sclerosis and rheumatoid arthritis) do not (Hagger & Orbell, 2003). However, due to a lack of a comparison group in this study it was not possible to investigate this further. Nevertheless, it does suggest that more clarification of the ‘Cause’ subscale may be helpful for participants and consequently for researchers. It may be helpful to ask participants firstly which factors they believe cause their or their child’s asthma episodes and attacks, and secondly which factors they believe caused them or their child to develop asthma originally. For example, a study by Stein, McNicholas & Collis (2001) included a ‘cause of exacerbation’ scale as well as the
usual ‘Cause’ subscale in order to help participants differentiate between the original causes of their asthma and the things they believed exacerbated their asthma.

Overall, these results are interesting as they indicate a wide range of different correlations between variables and suggest several possible explanations for the results found. However, due to the nature of the study it was not possible to infer causality from any of the correlations found. Nevertheless, correlations between the IPQ-R subscales indicated a common trend for the way in which mothers organised their illness representations. Overall, those mothers who identified their children as having more asthma symptoms also identified strongly with other physical aspects of the illness such as the asthma being more chronic, more changeable and unpredictable, and having more severe consequences. They tended to find their child’s asthma more upsetting and anxiety-provoking, which may be a consequence of their negative beliefs about the asthma. These types of beliefs were to some extent related to higher levels of maternal anxiety and depression, higher levels of psychological and behavioural difficulties in their child, and higher levels of parenting stress, although not every belief was related to every outcome variable and corrections for Type 1 experiment-wise errors substantially reduced the number of correlations found.

One possible explanation for the correlations between the IPQ-R subscales and maternal anxiety and depression is that mother’s beliefs about their child’s illness simply reflect their more general affective disposition. However, Moss-Morris et al (2002) compared the IPQ-R with the Positive and Negative Affect Schedule (PANAS: Watson, Clark & Tellegen, 1988) which measures trait positive and negative affect and found only small to moderate correlations between them. Concordant with the results of the current study they found the highest correlations with the Emotional Representation subscale \( r = 0.54 \), which they concluded suggested that trait negative affect accounted for about 29% of the variance in emotional distress due to the illness.

Overall, correlations between the IPQ-R subscales differed somewhat from Moss-Morris et al’s (2002) study. This may have been partly because of the relatively small number of participants in this study compared to the number in Moss-Morris et al’s (2002) study, resulting in a smaller number of correlations being found. However, this
does not explain why this study found correlations between subscales which Moss-Morris et al's (2002) study did not. Therefore an alternative explanation may have been that Moss-Morris et al (2002) asked people about their own beliefs about their own illness whereas this study asked mothers about their beliefs about their child's illness. This suggests that people may hold different types of perceptions about others' illness compared to their own.

4.3. Overall Summary
Overall the study found no evidence that maternal illness beliefs moderate the relationship between paediatric asthma severity and maternal anxiety and depression, child psychological and behavioural difficulties, parenting stress and child quality of life. This could be taken as lending support to the view that asthma severity is of only marginal importance in terms of psychological adjustment to illness, and that there is no relationship, moderated or otherwise, between severity and psychological variables. However, there are several other possible explanations for the results found.

4.4. Why were the findings not in line with expectations?
The first possible reason is that the IPQ-R actually does not moderate between the variables. Since this study was testing out a new hypothesis it is feasible that the null hypothesis is true. However, there are several other possible reasons for the fact that maternal illness beliefs were not found to moderate between severity and psychological adjustment in mother and child.

4.4.1. There is a moderating relationship but this study did not find it (accepting the null hypothesis for this study but rejecting the null hypothesis in general)
It may be that maternal illness beliefs do moderate between paediatric asthma severity and psychological adjustment in mother and child but that for some reason this study did not find that relationship. There are two possible reasons for this. The first is due to the population used. As previously discussed, the sample used was taken from children and their mothers attending paediatric outpatient clinics and as such was likely to be biased towards children with severe and moderately-severe asthma and mothers with higher levels of concern or anxiety compared to the general population. This meant that the variance within the primary independent variable was relatively
small, meaning that there was a limited amount of variance to be 'shared' between the dependent variables. This may have biased correlations between the two types of variables downwards resulting in a lack of moderating effect being found. In addition, the response rate to the study was 48%, meaning that 52% of potential participants did not participate. The reasons for this were either the mother nor child attending the child’s appointment, the child being brought to the appointment by someone other than the mother, or the mother declining to participate. It may be that responders and non-responders differed in crucial ways and this may have affected the results. For example, mothers who did not attend their child’s appointment may have been more likely to believe that their child’s treatment would not be effective, leading to them not attending the appointment. However, due to a lack of information about those who did not participate it was not possible to explore this hypothesis.

The second possible reason is that the sample may not have been large enough to provide the power to detect a moderating relationship. As previously discussed, the study did not find the expected results for all measures – for example, only some of the mother-rated and child-rated child quality of life measures were correlated with each other, and the illness belief subscales were not as correlated with one another as might have been expected. It may be that the sample used was too small to detect correlations between these variables, and too small to detect a moderating effect of maternal illness beliefs. Finding a moderating relationship using a multiple regression approach is known to be difficult in psychology, particularly when the measures concerned contain non-trivial measurement errors (Busmeyer & Jones, 1983). Consequently, this study may not have found a moderating effect when one actually does exist. However, there is limited support for this hypothesis, as even if weak effects are considered as supporting illness beliefs as a moderating variable there is no compelling evidence of moderation in the current study.

In addition, the standard deviations of the IPQ-R subscales ranged from 0.51 to 0.85, which was below the standard deviation of one that would usually be expected from a five-point scale. This means that across the study mothers tended to have more similar beliefs to one another than would usually be expected. This could have affected the results as if the mothers in the study tended to hold very similar illness beliefs then
there would be less potential for differing illness beliefs to have any effect or to moderate between severity and psychosocial variables.

4.4.2. There is a different moderating variable

It is possible that there is a moderating variable between asthma severity and psychological adjustment, but that this moderator is not maternal illness beliefs. One possible moderator between severity and child psychological adjustment and quality of life could be the child’s own illness beliefs. The majority of studies using the IPQ and the IPQ-R have examined people’s illness representations about their own illness and the current study found differences from previous studies in correlations between the IPQ-R and other variables (Hagger & Orbell, 2003). It is therefore possible that beliefs held by a person who is not ill about a person who is ill may differ substantially in the effect they have than beliefs held by the person themselves.

4.4.3. The IPQ-R may not measure coherent or linear constructs

Although analysis of the IPQ-R has indicated that it displays good structural validity and good internal reliability (0.75 – 0.89), nevertheless it still may not measure entirely coherent constructs (Moss-Morris et al 2002). The IPQ-R assumes that illness beliefs are quantifiable along certain linear dimensions. For example, the “Identity” subscale assumes that a person’s illness “identity” relates purely to the number of symptoms they have, which does not allow for the possibility that a person with only one or two severe symptoms may identify themselves more with the illness than a person who has several mild symptoms. The “Emotional Representation” subscale assumes that a person’s feelings of anger about the illness are on the same dimension as their feelings of worry or depression about the illness. This does not allow for the fact that a person may feel very upset and depressed about the illness without feeling worried or vice versa, as if a person scored highly on only one or two questions they would not score highly overall for that subscale. In addition, Nerenz & Leventhal (1983) suggested that a person’s illness representations may be neither well-integrated nor complete – only some of the dimensions in the IPQ-R may be included in a person’s own illness representation, and those dimensions that a person has may either not be consistent with each other or not be independent of one another. For example, Nerenz & Leventhal (1983) suggest that beliefs about Timeline are implicit in several
of the other dimensions. The lack of independence of some illness representations has been supported by several studies (Hampson, Glasgow & Toobert, 1990; Heijmans & de Ridder, 1998). If this is the case, then one reason why no moderating relationship was found may be that the scores from the IPQ-R did not provide coherent enough data to result in illness beliefs being a moderator.

4.5. Critique

4.5.1. Limitations in Design
One possible design limitation was the fact that child behavioural and psychological adjustment was only assessed through mother-report. As previously discussed, asking mothers to report their child’s psychological and behavioural difficulties may have led to some biased responding, which may have resulted in stronger correlations between mother and child psychological adjustment than actually existed. For example, previous studies have found that findings regarding psychological and behavioural difficulties in children with paediatric asthma may vary according to whether mothers, teachers or health-professionals are responding (Klinnert et al, 2000). In order to account for this the researcher originally considered asking for a school report measure of child behavioural and psychological adjustment (SDQ teacher-report) in addition to the mother-report measure. However, it was considered that at least some of the schools contacted would be unlikely to respond, which may have reduced the number of children involved in the study. Nevertheless, this may be considered a design limitation and worth bearing in mind for future studies.

A second previously discussed limitation was that participants were recruited from paediatric outpatient clinics, which may have resulted in a reduced variance in severity and the concomitant difficulties this may have caused.

4.5.2. Changes to future design
This study focused on children aged five to eleven. However, the younger a child is, the more likely it is that their parents will be key in terms of caring for the child and monitoring and treating the child’s asthma. This may affect the extent to which their illness beliefs are important. Therefore, it would be useful to carry out this study with
mothers of children below the age of five, although as previously discussed it would not be possible to get self-report quality of life measures from children under five.

It may also be helpful to separate children into groups according to the length of time since diagnosis. The current study included children who had been diagnosed from six months to eleven years prior to the study. As previous studies have suggested that illness representations may change over time it may be helpful to examine whether there is any relationship between length of time since diagnosis and illness beliefs and whether this has any effect on the moderating relationship (Hagger & Orbell, 2003).

In order to ensure that the research was valid for the general asthma population and to increase severity variance it may also be helpful to carry out a study which involved recruiting patients from GP surgeries, thus trying to recruit a sample less biased towards children with severe or more complicated asthma or towards mothers who are more anxious about their child’s asthma.

4.5.3. Changes to measures

It may be useful to conduct a similar study using slightly different or additional measures. One possible useful addition would be including a measure of children’s own illness beliefs. Two previous studies have done this. The first, by Paterson, Moss-Morris & Butler (1999) modified the IPQ for use as a structured interview in order to examine the effect of children’s illness experiences on their illness representations (Paterson, Moss-Morris & Butler, 1999). The second used the IPQ-R in order to examine children’s representations of their asthma but adapted some of the questions in order to make them more understandable to children (Stein, McNicholas & Collis, 2001). As discussed, it is possible that while mothers’ illness beliefs may not moderate between asthma severity and psychological adjustment, children’s own illness beliefs may have some moderating effect, particularly in terms of the child’s own psychological adjustment and own perceptions of their quality of life.

As previously discussed, maternal reporting of child psychological and behavioural difficulties may be to some extent biased. Therefore including other measures of child psychological and behavioural difficulties such as the SDQ teacher-report form, the
SDQ self-report form for adolescents or the Children's Depression Inventory (CDI: Kovacs, 1992) could be useful in helping to differentiate children's actual psychological and behavioural difficulties from the effect of maternal perceptions of the child’s difficulties.

4.6. Future research and clinical implications

Some areas for future research have already been proposed throughout the discussion. However, one further area of particular relevance would be fathers’ illness beliefs and the impact that these might have as there is a much smaller evidence-base of studies using fathers (Cohen, 1999). A second area which may be useful would be to examine the effect of maternal illness beliefs over time, to investigate whether the relationship between illness beliefs and psychological adjustment changes over time and indeed whether there are some points in time when they do moderate between severity and psychological adjustment e.g. immediately after diagnosis compared to several years after diagnosis. A previous study using a longitudinal approach found that in adults with rheumatoid arthritis, illness beliefs about consequences interacted with illness severity to predict later depression. A belief in serious consequences combined with milder severity later on predicted lower levels of depression, and combined with higher severity later on predicted higher levels of depression. However, participants who believed that their illness would have less severe consequences and who later had mild severity symptoms also reported higher levels of depression (Schiaffino, Shawaryn & Blum, 1998). Therefore examining the potential moderating relationship of current maternal illness representations between asthma severity and future psychological adjustment could be another area of potential interest.

The results of this study suggest that there is some relationship between mothers’ illness beliefs and their rates of depression, anxiety and parenting stress, as well as mothers’ perceptions of their child’s psychological and behavioural problems and quality of life. However, this study is not able to indicate whether there is a causal relationship between the two factors, and if so, what direction it is in. Therefore before any firmer conclusions can be drawn further work within this area needs to be carried out. Again, longitudinal studies could investigate how mothers’ illness beliefs and how the psychosocial variables change over time from the point of diagnosis.
Treatment trials, for example by either working with mothers in terms of their illness beliefs (if these are biased or inaccurate) or addressing their anxiety and depression or their child's psychological and behavioural difficulties, could also be helpful in identifying causal relationships.

Although there was no clear unambiguous evidence for the moderating effect of maternal illness beliefs on the relationship between paediatric asthma severity and psychological adjustment in mother and child, it is known to be particularly difficult to find moderating relationships using a multiple regression approach, and prior to corrections for Type 1 experiment-wise errors IPQ-R Personal Control beliefs were found to moderate between severity and five other variables (Busmeyer & Jones, 1983). This suggests that mothers' personal control beliefs may be a particularly important area to focus on in further studies examining the moderating effect of maternal illness beliefs.

The results also suggest that, contrary to what has previously been found, having a child with asthma is not necessarily related to increased levels of parenting stress. This suggest that there may be other reasons for increased parenting stress in mothers of children with asthma and that these may need to be explored rather than assuming that the asthma is the cause.

The fact that children's ratings of their own quality of life were independent of mothers' ratings of their own or their child’s psychological adjustment is important to note as it indicates that other measures of psychological adjustment in the child or mother can not can be used as useful determinants of or as a substitute for assessing a child's quality of life. This has clinical implications in that it supports previous studies suggesting that when working with children with a chronic illness such as asthma it is important to ask the child directly about how the asthma affects them and their lives rather than just relying on mothers' reporting.

The correlations found suggest that maternal illness beliefs may be part of, but not the whole of, the clinical picture in terms of mother and child psychological adjustment and parenting stress. This suggests that when working with children with asthma and
their mothers, mothers' beliefs about their child's asthma should be considered. However, due to the nature of the study it was not possible to establish causation or what direction this was in. Therefore before clinical implications can be properly outlined, further work on these issues needs to be carried out. If in the future illness beliefs are found to be a moderating variable between asthma severity and psychological adjustment it could have important clinical implications in terms of identifying mother-child dyads who are at risk of developing difficulties because of the mother's illness beliefs and targeting these illness beliefs in order to reduce parenting difficulties and improve psychological adaptation. However, again, this is an area for future research.

4.7. Conclusions
Overall, this study has contributed to the knowledge-base about paediatric asthma and how this affects mothers and children. However, it seems to have raised more questions than it has answered. It is hoped that further work in this area will contribute further to this knowledge base and towards the understanding of the effects of having a child with asthma. In particular, it is hoped that future studies will address the issue of how to identify and support those mother and child dyads who may be at the highest risk of psychosocial difficulties.
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APPENDICES

A  Treatment Flowchart
B  G*Power Calculation
C  Severity
D  Demographic Information
E  Hospital Anxiety and Depression Scale (HADS)
F  Strengths and Difficulties Questionnaire (SDQ)
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   iv Peds QL Generic child-report 8-12
   v  PedsQL Asthma mother-report 5-7
   vi PedsQL Asthma child-report 5-7
   vii PedsQL Asthma mother-report 8-12
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L  Participant Consent Form
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O  Subscale Correlations (SDQ, PSI/SF, PedsQL)
P  Correlations between IPQ-R and PedsQL (mother-report and child-report)
Appendix A:

Treatment Flowchart

Summary of stepwise management in children aged 5-12 years

**STEP 5: Continuous or frequent use of oral steroids**

- Let daily steroid tablet in lowest dose providing adequate control.
- Maintain high dose inhaled steroid at 800pg/day*.
- Refer to respiratory paediatrician.

**STEP 4: Persistent poor control**

- Increase inhaled steroid up to 800pg/day*.

**STEP 3: Add-on therapy**

1. Add inhaled long-acting β2 agonist (LABA).
2. Assess control of asthma:
   - good response to LABA – continue LABA.
   - benefit from LABA but control still inadequate – continue LABA and increase inhaled steroid dose to 400pg/day** (if not already on this dose).
   - no response to LABA – stop LABA and increase inhaled steroid to 400pg/day**. If control still inadequate, institute trial of other therapies (e.g., leukotriene receptor antagonist or SR theophylline).

**STEP 2: Regular preventer therapy**

Add inhaled steroid 200-400µg/day*.

(Other preventer drug if inhaled steroid cannot be used).

200µg/day* is an appropriate starting dose for many patients.

Start at dose of inhaled steroid appropriate to severity of disease.

**STEP 1: Mild intermittent asthma**

Inhaled short-acting β2 agonist as required.

*BDP or equivalent
Appendix B:

**G*Power Calculation**

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<th>Calc Effectsize</th>
<th>Graph</th>
<th>Analysis</th>
</tr>
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<td>Delta 2.8478</td>
<td>(*) A priori</td>
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<td>Alpha</td>
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<td>Critical t(80)=1.9901</td>
<td>I prefer...</td>
</tr>
<tr>
<td>Power</td>
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<td>() Speed</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>(*) Accuracy</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Actual power 0.8033</td>
</tr>
</tbody>
</table>

Protocol

----------- T-TEST FOR CORRELATIONS, A PRIORI ANALYSIS, ACCURACY

MODE -----------

Effect size r=0.3, Alpha=0.05, Power=0.8, two-tailed
Total sample size=82, Critical t(80)=1.9901, Delta=2.8478

Effect size conventions: small = 0.10 medium = 0.30 large = .50
Alt X Exit | t-test for correlations

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<thead>
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<th>About</th>
<th>Calc Effectsize</th>
<th>Graph</th>
<th>Analysis</th>
</tr>
</thead>
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<tr>
<td></td>
<td>0.15 Lambda 10.2000</td>
<td></td>
<td>(*) A priori</td>
</tr>
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<td>() Speed</td>
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Protocol

----- F-TEST IN MULTIPLE REGRESSION, A PRIORI ANALYSIS, ACCURACY

MODE -----

Effect size f²=0.15, Alpha=0.05, Power=0.8, global
Total sample size=68, Critical F(2,65)=3.1381, Lambda=10.2000

Effect size conventions: small = 0.02 medium = 0.15 large = 0.35
Alt X Exit | F-test in multiple regression
Appendix C:

Severity

Centre Number:

Patient Identification Number:

PAEDIATRICIAN-RATED SEVERITY MEASURE

Please tick the box that corresponds to your assessment of the severity of the child’s asthma, based on the medication you prescribe to the child at their current appointment

☐  Mild
   Bronchodilator only

☐  Moderate
   Low dose inhaled steroid

☐  Moderately Severe
   Low dose inhaled steroid plus extra agents (LABA or LTA)

☐  Severe
   High dose inhaled steroids (>400mcg/day BDP / BUD or >200mcg/day FP) or extra agent(s) (LABA or LTA)
Appendix D:

Demographic Information

Centre Number:
Patient Identification Number:

PARENT AND CHILD INFORMATION

Please answer all questions

1. How old is your child? _________

2. Is your child (please tick)
   Male □
   Female □

3. How many years has your child had asthma? _________

4. Who is the main wage earner in your household? _______________________

Please complete the following questions for the main wage-earner in your household.
The questions refer to their current main job, or (if they are not working now) their last main job. Please tick one box only per question.

5. Does (did) the main wage-earner work as an employee or are (were) they self-employed?
   Employee □
   Self-employed □
   Self-employed / freelance without employees □
   (go to question 8)

6. For employees: How many people work (worked) for the main wage-earner’s employer at the place where they work (worked)?
   For self-employed: How many people does (did) the main wage-earner employ?
   Go to question 8 when you have completed this question.
   1 to 24 □
   25 or more □
7. Does (did) the main wage-earner supervise any other employees?
(A supervisor or foreman is responsible for overseeing the work of other employees on a day-to-day basis)

Yes □

No □

8. Please tick one box to show which best describes the sort of work the main wage-earner does.
(If the main wage-earner is not working now, please tick a box to show what they did in their last job).

PLEASE TICK ONE BOX ONLY

Modern professional occupations
such as: teacher - nurse - physiotherapist - social worker - welfare officer - artist - musician - police officer (sergeant or above) - software designer

Clerical and intermediate occupations
such as: secretary - personal assistant - clerical worker - office clerk - call centre agent - nursing auxiliary - nursery nurse

Senior managers or administrators
(usually responsible for planning, organising and co-ordinating work and for finance)
such as: finance manager - chief executive

Technical and craft occupations
such as: motor mechanic - fitter - inspector - plumber - printer - tool maker - electrician - gardener - train driver

Semi-routine manual and service occupations
such as: postal worker - machine operative - security guard - caretaker - farm worker - catering assistant - receptionist - sales assistant

Routine manual and service occupations
such as: HGV driver - van driver - cleaner - porter - packer - sewing machinist - messenger - labourer - waiter / waitress - bar staff

Middle or junior managers
such as: office manager - retail manager - bank manager - restaurant manager - warehouse manager - publican

Traditional professional occupations
such as: accountant - solicitor - medical practitioner - scientist - civil / mechanical engineer
9. How would you describe your ethnic origins?

Choose one section from (a) to (e) and then tick the appropriate category to indicate your ethnic background.

(a) White

British □
Irish □
Any other White background, please write below

(b) Mixed

White and Black Caribbean □
White and Black African □
White and Asian □
Any other mixed background, please write below

(c) Asian or Asian British

Indian □
Pakistani □
Bangladeshi □
Any other Asian background, please write in below

(d) Black or Black British

Caribbean □
African □
Any other Black background, please write in below

(e) Chinese or Other ethnic group

Chinese □
Any other ethnic group, please write below
### Appendix E:

**Hospital Anxiety and Depression Scale (HADS)**

**HAD Scale**

This questionnaire is designed to help us know how you feel. Read each item and underline the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought out response.

<table>
<thead>
<tr>
<th></th>
<th>Question</th>
<th>Most of the time</th>
<th>A lot of the time</th>
<th>Time to time / occasionally</th>
<th>Not at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel tense or wound up</td>
<td>Most of the time</td>
<td>A lot of the time</td>
<td>Time to time / occasionally</td>
<td>Not at all</td>
</tr>
<tr>
<td>2</td>
<td>I still enjoy the things I used to enjoy</td>
<td>Definitely as much</td>
<td>Not quite so much</td>
<td>Only a little</td>
<td>Hardly at all</td>
</tr>
<tr>
<td>3</td>
<td>I get a sort of frightened feeling as if something awful is about to happen</td>
<td>Very definitely and quite badly</td>
<td>Yes, but not too badly</td>
<td>A little, but it doesn't worry me</td>
<td>Not at all</td>
</tr>
<tr>
<td>4</td>
<td>I can laugh and see the funny side of things</td>
<td>A much as I always could</td>
<td>Not quite so much now</td>
<td>Definitely not so much now</td>
<td>Not at all</td>
</tr>
<tr>
<td>5</td>
<td>Worrying thoughts go through my mind</td>
<td>A great deal of the time</td>
<td>A lot of the time</td>
<td>From time to time but not too often</td>
<td>Only occasionally</td>
</tr>
<tr>
<td>6</td>
<td>I feel cheerful</td>
<td>Not at all</td>
<td>Not often</td>
<td>Sometimes</td>
<td>Most of the time</td>
</tr>
<tr>
<td>7</td>
<td>I can sit at ease and feel relaxed</td>
<td>Definitely</td>
<td>Usually</td>
<td>Not often</td>
<td>Not at all</td>
</tr>
<tr>
<td>8</td>
<td>I feel as if I am slowed down</td>
<td>Nearly all the time</td>
<td>Very often</td>
<td>Sometimes</td>
<td>Not at all</td>
</tr>
<tr>
<td>9</td>
<td>I get a sort of frightened feeling like 'butterflies' in the stomach</td>
<td>Not at all</td>
<td>Occasionally</td>
<td>Quite often</td>
<td>Very often</td>
</tr>
<tr>
<td>10</td>
<td>I have lost interest in my appearance</td>
<td>Definitely</td>
<td>I don’t take so much care as I should</td>
<td>I may not take quite as much care</td>
<td>I take just as much care as ever</td>
</tr>
<tr>
<td>11</td>
<td>I feel restless as if I have to be on the move</td>
<td>Very much indeed</td>
<td>Quite a lot</td>
<td>Not very much</td>
<td>Not at all</td>
</tr>
<tr>
<td>12</td>
<td>I look forward with enjoyment to things</td>
<td>As much as I ever did</td>
<td>Rather less than I used to</td>
<td>Definitely less than I used to</td>
<td>Hardly at all</td>
</tr>
<tr>
<td>13</td>
<td>I get sudden feelings of panic</td>
<td>Very often indeed</td>
<td>Quite often</td>
<td>Not very often</td>
<td>Not at all</td>
</tr>
<tr>
<td>14</td>
<td>I can enjoy a good book or radio or TV programme</td>
<td>Often</td>
<td>Sometimes</td>
<td>Not often</td>
<td>Very seldom</td>
</tr>
</tbody>
</table>

**TOT ALS**
Appendix F:
Strengths and Difficulties Questionnaire (SDQ)

Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months or this school year.

<table>
<thead>
<tr>
<th>Item</th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people's feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Restless, overactive, cannot stay still for long</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Often complains of headaches, stomach-aches or sickness</td>
<td></td>
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<tr>
<td>Shares readily with other children (treats, toys, pencils etc.)</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Often has temper tantrums or hot tempers</td>
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<tr>
<td>Rather solitary, tends to play alone</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generally obedient, usually does what adults request</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many worries, often seems worried</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Helpful if someone is hurt, upset or feeling ill</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Constantly fidgeting or squirming</td>
<td></td>
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<tr>
<td>Has at least one good friend</td>
<td></td>
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<tr>
<td>Often fights with other children or bullies them</td>
<td></td>
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<tr>
<td>Often unhappy, down-hearted or tearful</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Generally liked by other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Easily distracted, concentration wanders</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Nervous or clingy in new situations, easily loses confidence</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Kind to younger children</td>
<td></td>
<td></td>
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<tr>
<td>Often lies or cheats</td>
<td></td>
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<tr>
<td>Picked on or bullied by other children</td>
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<tr>
<td>Often volunteers to help others (parents, teachers, other children)</td>
<td></td>
<td></td>
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<tr>
<td>Thinks things out before acting</td>
<td></td>
<td></td>
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<tr>
<td>Steals from home, school or elsewhere</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gets on better with adults than with other children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Many fears, easily scared</td>
<td></td>
<td></td>
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<tr>
<td>Sees tasks through to the end, good attention span</td>
<td></td>
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</tbody>
</table>
Appendix G:

Parenting Stress Index – Short Form (PSI/SF)

<table>
<thead>
<tr>
<th></th>
<th>SA = Strongly Agree</th>
<th>A = Agree</th>
<th>NS = Not Sure</th>
<th>D = Disagree</th>
<th>SD = Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I often have the feeling that I cannot handle things very well.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2. I find myself giving up more of my life to meet my children's needs than I ever expected.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>3. I feel trapped by my responsibilities as a parent.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>4. Since having this child, I have been unable to do new and different things.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Since having a child, I feel that I am almost never able to do things that I like to do.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>6. I am unhappy with the last purchase of clothing I made for myself.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. There are quite a few things that bother me about my life.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Having a child has caused more problems than I expected in my relationship with my spouse (or male/female friend).</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>9. I feel alone and without friends.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. When I go to a party, I usually expect not to enjoy myself.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. I am not as interested in people as I used to be.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. I don't enjoy things as I used to.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13. My child rarely does things for me that make me feel good.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14. Sometimes I feel my child doesn't like me and doesn't want to be close to me.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15. My child smiles at me much less than I expected.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16. When I do things for my child, I get the feeling that my efforts are not appreciated very much.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17. When playing, my child doesn't often giggle or laugh.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18. My child doesn't seem to learn as quickly as most children.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19. My child doesn't seem to smile as much as most children.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20. My child is not able to do as much as I expected.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21. It takes a long time and it is very hard for my child to get used to new things.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>22. I feel that I am:</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>23. I expected to have closer and warmer feelings for my child than I do and this bothers me.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>24. Sometimes my child does things that bother me just to be mean.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>25. My child seems to cry or fuss more often than most children.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>26. My child generally wakes up in a bad mood.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>27. I feel that my child is very moody and easily upset.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>28. My child does a few things which bother me a great deal.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>29. My child reacts very strongly when something happens that my child doesn't like.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>30. My child gets upset easily over the smallest thing.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31. My child's sleeping or eating schedule was much harder to establish than I expected.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>32. I have found that getting my child to do something or stop doing something is:</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>33. Think carefully and count the number of things which your child does that bother you.</td>
<td>10+ 8-9 6-7 4-5 1-3</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>34. There are some things my child does that really bother me a lot.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>35. My child turned out to be more of a problem than I had expected.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>36. My child makes more demands on me than most children.</td>
<td>SA A NS D SD</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix I:

Illness Perception Questionnaire - Revised (IPQ-R)

YOUR VIEWS ABOUT YOUR CHILD'S ASTHMA

Listed below are a number of symptoms that your child may or may not have experienced since their asthma. Please indicate by circling Yes or No, whether your child has experienced any of these symptoms since their asthma, and whether you believe that these symptoms are related to their asthma.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>My child has experienced this symptom since his/her asthma</th>
<th>This symptom is related to my child's asthma</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sore Throat</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Nausea</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Stiff Joints</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sore Eyes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Wheeziness</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Headaches</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Upset Stomach</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sleep Difficulties</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Loss of Strength</td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>
We are interested in your own personal views of how you now see your child’s current asthma.
Please indicate how much you agree or disagree with the following statements about your child’s asthma by ticking the appropriate box.

<table>
<thead>
<tr>
<th>Views About Your Child’s asthma</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>My child’s asthma will last a short time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma is likely to be permanent rather than temporary</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child’s asthma will last for a long time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma will pass quickly</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I expect my child to have this asthma for the rest of his/her life</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child’s asthma is a serious condition</td>
<td></td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child’s asthma has major consequences on his/her life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma does not have much effect on his/her life</td>
<td></td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>My child’s asthma strongly affects the way others see him/her</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>My child’s asthma has serious financial consequences</td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma causes difficulties for those who are close to him/her</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>There is a lot which I can do to control my child’s symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What I do can determine whether my child’s asthma gets better or worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The course of my child’s asthma depends on me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nothing I do will affect my child’s asthma</td>
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<tr>
<td>I have the power to influence my child’s asthma</td>
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<tr>
<td>My actions will have no affect on the outcome of my child’s asthma</td>
<td></td>
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<tr>
<td>My child’s asthma will improve in time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There is very little that can be done to improve my child’s asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Views About Your Child's asthma</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither Agree nor Disagree</td>
<td>Agree</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>---------------------------------</td>
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</tr>
<tr>
<td>My child’s treatment will be effective in curing my his/her asthma</td>
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</tr>
<tr>
<td>The negative effects of my child’s asthma can be prevented (avoided) by his/her treatment</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child’s treatment can control my child’s asthma</td>
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<td></td>
</tr>
<tr>
<td>There is nothing which can help my child’s condition</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>The symptoms of my child’s condition are puzzling to me</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>My child’s asthma is a mystery to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I don’t understand my child’s asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma doesn’t make any sense to me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have a clear picture or understanding of my child’s condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The symptoms of my child’s asthma change a great deal from day to day</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s symptoms come and go in cycles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma is very unpredictable</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child goes through cycles in which his/her asthma gets better and worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get depressed when I think about my child’s asthma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>When I think about my child’s asthma I get upset</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma makes me feel angry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma does not worry me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child having this asthma makes me feel anxious</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s asthma makes me feel afraid</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CAUSES OF MY CHILD’S ASTHMA

We are interested in what you consider may have been the cause of your child’s asthma. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your child’s asthma rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your child’s asthma. Please indicate how much you agree or disagree that they were causes for your child by ticking the appropriate box.

<table>
<thead>
<tr>
<th>Possible Causes</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress or worry</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hereditary - it runs in my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A germ or virus</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet or eating habits</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chance or bad luck</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Poor medical care in my child’s past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pollution in the environment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s mental attitude e.g. thinking about life negatively</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family problems or worries</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overwork (in or out of school)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s emotional state e.g. feeling down, lonely, anxious, empty</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child getting older</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My drinking alcohol</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My smoking</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accident or injury</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My personality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My child’s personality</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Altered immunity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

In the table below, please list in rank-order the three most important factors that you now believe caused YOUR CHILD’S asthama. You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for my child’s asthama:

1. ____________________________________________

2. ____________________________________________

3. ____________________________________________
Dear Ms Freeman,

Title: The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother & child
LREC: 03.0111

This is to confirm that this research project has successfully completed the quality assurance procedure in accordance with Research Governance.

The NHS Trust Research & Development Committee have therefore approved the start of the research project. A copy of the start form with a synopsis of the research details is enclosed, could you please complete the correct commencement date and return to me at the address above.

We wish you every success with the project.

Yours Sincerely,

Professor
Director of Research & Development
Dear Ms Freeman

The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child.

Thank you for your letter dated the 12th June 2003 concerning the above study. We are now happy to give final approval for this project to proceed.

Yours sincerely

Dr
Vice Chair/ Clinical Secretary
Local Research Ethics Committee
Our Ref:
15 July 2003

Ms Elizabeth Freeman
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford
Surrey GU2 7XH

Dear Ms Freeman

Re: The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child

Thank you for coming to our meeting on Monday July 14th 2003.

There were a number of concerns that the committee had about your protocol but as it would be difficult to have different wording for different centres we are happy to indicate that we have no objection on ethical grounds for your study to proceed. I do, however, point out that the ... Committees are separate, though in future they may combine, and the Consent Form should reflect this.

We would be most interested to have a progress report in one year as to how your study is proceeding.

With best wishes for a successful outcome.

Yours sincerely,

Dr...
Chairman - Local Research Ethics Committee
General Hospital
Dear Ms Freeman

The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child (ACE/2003/59/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/2003/59/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: 21 July 2003
Date of expiry of approval by the Advisory Committee on Ethics: 20 July 2008

Please inform me when the research has been completed.

Yours sincerely

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

22 August 2003

Dear Ms Freeman

Re: The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child.

In accordance with Research Governance requirements, your project has now been reviewed and approved by the R&D Directorate on behalf of the Trust. Trust approval is given on the understanding that the following information, where appropriate, is provided:

- Actual start date of the project within the Trust together with an indication of the duration of the project.
- Quarterly updates on the project including numbers of patients recruited.
- NHS Programme Identification Number.
- The International Trial Reference Number of the project.
- The Funding Reference, i.e. name(s) of funder(s), grant(s) code(s) and amount(s).
- An indication of your assessment of what the service support costs should be.

Kindly note that research studies may not commence on Trust staff and/or patients without the prior written approvals of both the Trust and Ethics Committee.

Where appropriate, honorary contracts must be obtained. Please contact Mr Michael Humphies, Human Resources Department, St Helier Hospital for further details in respect of honorary contracts.

Yours sincerely

Dr.
Director of Research & Development
18 July 2003

Ms E Freeman
51 Leatherhead Road
Ashtead
Surrey
KT21 2TP

Dear Ms Freeman

Re: The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child

Thank you for submitting this protocol, which we reviewed at our meeting on 18 June 2003.

This is to confirm our agreement that you will send us a letter from a statistician giving approval for your planned statistics methodology (which should also be sent to R & D to facilitate their approval process). After our discussion about your project on the phone, I am now happy to give full approval on behalf of the Committee to this project.

LREC approval is given on the understanding that:

i) the study is commenced within the next 12 months. Should the start of the study be delayed beyond this time, a re-application to the Committee will be required.

ii) any change or amendment to the protocol will be reported to the Committee.

iii) the Committee should be sent one copy of any publication arising from your study, or a brief report after completion if there is to be no publication. If the study lasts for more than a year, a brief annual report should be provided.

The following documentation was reviewed:

Protocol
Invitation to participate in a clinical research study
Consent Form
Notification to GP of patient’s participation in a research project
Appendix K:

Participant Information Sheet and Covering Letter

Dear

INVITATION TO PARTICIPATE IN A CLINICAL RESEARCH STUDY

Title of Project:

The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child

Name of Researcher: Beth Freeman

As you know, your child is currently being seen in the paediatric asthma clinic. As part of continuing efforts to improve the support offered to parents of children with asthma, we are carrying out a study to investigate the potential relationships between illness beliefs, child asthma severity and psychological adjustment. I would like to ask if you and your child would be willing to take part in this study, to help us do this.

I enclose an information sheet, which explains more about the study, and a consent form for you to sign if you are happy for you and your child to take part. I would be grateful if you would bring the signed consent form to your child’s next appointment at the asthma clinic if you are happy to take part.

Yours sincerely

Beth Freeman
Trainee Clinical Psychologist

Dr.
Consultant Paediatrician
PATIENT INFORMATION SHEET
(1st May 2003: Version 1)

Title of Project:
The potential moderating effects of maternal illness beliefs between
asthma severity and psychological adjustment in mother and child

Name of Researcher: Beth Freeman

You and your child are invited to take part in this research study. Before you decide, it
is important for you to understand why the research is being done and what it will
involve. Please take time to read the following information carefully and discuss it
with friends, family and your child’s consultant if you wish. Please contact me if there
is anything that is not clear or you would like more information. Take time to decide
whether or not you wish to take part before signing the consent form.

(Consumers of Ethics in Research (CERES) publish a leaflet called Medical Research
and You. This leaflet gives more information about medical research and looks at
some questions that you may want to ask. A copy can be obtained from CERES, PO
Box 1365, London N16 0BW).

What is the purpose of this study?

Studies have shown that in many cases, the severity of a child’s asthma is not related
to psychological adjustment in their mother or the child themselves. However, recent
research has suggested that beliefs about illness may affect this relationship. The aim
of this study is to investigate the potential relationship between illness beliefs, child
asthma severity and psychological adjustment. If such an effect can be demonstrated,
then this will help provide possible improvements in support for parents of children
with asthma.

Why have I been chosen?

Your child is being seen in the paediatric asthma clinic. All children aged 5-11 who
are being seen in this clinic and their parents are being asked to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do not take part, it will have
no impact on the treatment you or your child will be offered. If you decide to take part,
you are still free to withdraw at any time and without giving a reason. A decision to
withdraw at any time, or a decision not to take part, will not affect the standard of care
you or your child receive.

What will happen to me if I take part?

You will be asked to read and sign a consent form and to hand this in to reception at
your child’s next appointment at the asthma clinic. If you agree to take part, it would
help the researcher if you could arrive 15-30 minutes early for your appointment so that you have time to complete the questionnaires. If you agree to take part, the researcher will approach you while you are waiting for your appointment. They will ask you to complete a front sheet stating your child’s age, gender and ethnic origin. You will also be asked to complete five simple questionnaires relating to your feelings and beliefs about your child’s asthma, how your child’s asthma affects his or her life, and how this affects you as a parent. It should take no longer than ½ an hour to complete the forms. Your child will also be asked to complete a simple form about their asthma and how it affects their life. Once completed, you can return the questionnaires to the researcher in the envelope provided. Alternatively you can return them by post in a pre-paid envelope.

What are the possible advantages and risks of taking part?

There are no known risks in taking part in this study. It is possible though that you might find filling in the questionnaires leads you to think about your child’s asthma and your thoughts and feelings about this. As such, it is possible that completing the questionnaires may cause you some uneasy feelings. If this is the case, then you are encouraged to discuss this with your child’s consultant or asthma nurse at your child’s appointment.

What are the possible benefits of taking part?

The information we get from this study may help us to support future parents of children with asthma better.

What if new information becomes available?

Sometimes during the course of a research project, new information becomes available about the topic that is being studied. If this happens, the researcher will tell you about it and discuss with you whether you wish to continue in the study. If you decide to withdraw, this will not affect your or your child’s care. If you decide to continue in the study, then you will be asked to sign an updated consent form.

On reviewing new information, the researcher might consider it in your best interests to withdraw you from the study. She will explain the reasons and arrange for your care to continue.

What if something goes wrong?

During research trials, there can be problems due to the methods used or due to the way in which you are treated by members of staff. It is highly unlikely that the methods being used in this study will have any harmful effects. However, if you were to be harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone’s negligence, then you may have grounds for legal action. Regardless of this, if you wish to complain about any aspect of the way that you have been approached or treated during the course of this study, the normal NHS complaints mechanism will be available to you.
Will my taking part in the study be kept confidential?

All information collected about you and your child during the course of the research will be kept entirely confidential. The consent forms will be separate from the questionnaires and held in a locked filing cabinet, so that the questionnaires themselves remain completely anonymous. However, you will be asked if it is acceptable for the researcher to notify your and your child’s GP’s that you are taking part in the study. Your consultant will be aware that you are taking part as we will ask them to indicate the severity of your child’s asthma.

What will happen to the results of the research study?

The results of the study will be written up and submitted as a Major research Project as part of a PsychD in Clinical Psychology. It is also anticipated that the results will be submitted for publication in peer-reviewed journals. You will not be identified in any report or publication. If you should wish, then you will be sent a brief summary of the findings at the end of the study (August 2004).

Who is organising and funding the research?

The research is being organised and carried out by a Trainee Clinical Psychologist (Beth Freeman). The research is being supervised by Dr. , Head of Psychology at the University of Surrey, and Dr. , Consultant Clinical Psychologist.

Who has reviewed the study

This study has been reviewed and approved by the Local Research Ethics Committee, the Local Research Ethics Committee, the Local Research Ethics Committee, and by the University of Surrey’s Advisory Committee on Ethics.

Contact for further information

For further information about the study, please contact: Beth Freeman, Trainee Clinical Psychologist via Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH, telephone number

This copy of the Information Sheet is yours to keep. If you agree to take part, then you will be asked to sign a Consent Form and you will be given a copy of that form.

With many thanks for your time.

Yours sincerely

Beth Freeman
Trainee Clinical Psychologist

Consultant Paediatrician
Appendix L:

Participant Consent Form

Centre Number:
Patient Identification Number:

CONSENT FORM

Title of Project:
The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child

Name of Researcher: Beth Freeman

1. I confirm that I have read and understood the Information Sheet dated 1st May 2003 (Version 1) for the above study, and have had the opportunity to ask questions.

2. I understand that my participation and my child’s participation is voluntary and that we are both free to withdraw at any time, without giving any reason and without our medical care or legal rights being affected.

3. I agree to my child’s GP being informed of my participation in this study.

4. I agree to my GP being informed of my participation in this study (if different from child’s GP).

5. I agree for myself and my child to take part in the above study.

Name of patient Name of patient’s mother Date Signature of patient’s mother

Name of researcher Date Signature
Appendix M:

GP Information Letter

Dear

NOTIFICATION TO GP OF PATIENT’S PARTICIPATION IN A RESEARCH PROJECT

Patient’s Name: ____________________ ___

Title of Project: The potential moderating effects of maternal illness beliefs between asthma severity and psychological adjustment in mother and child

Name of Researcher: Beth Freeman

As you will know, this patient suffers from asthma. I am writing to let you know that we have asked this patient and his/her mother to take part in a research study examining the potential moderating effect of maternal illness beliefs between the child’s asthma severity and psychological adjustment in mother and child. Your patient will be asked to complete a questionnaire about how his or her asthma affects his or her life. Your patient’s mother will be asked to complete five questionnaires, relating to her feelings and beliefs about her child’s asthma, how her child’s asthma affects him or her life, and how this affects your patient.

If you are not the patient’s mother’s GP, please could you contact me at the Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH, telephone number . I will then contact the patient’s mother’s GP to inform them of their patient’s potential involvement in this study.

It is not anticipated that there will be any side effects from this investigation, but your patient and your patient’s mother will be advised to talk the child’s asthma consultant or asthma nurse if either of them finds the questionnaires in any way distressing. If you would like more information on this research (or would like details of the outcome of the study), please contact me at the Department of Psychology, University of Surrey, Guildford, Surrey GU2 7XH, telephone number

Yours sincerely

Beth Freeman
Trainee Clinical Psychologist

Consultant Paediatrician
## Appendix N:

### Reliability, Skew & Kurtosis Data

Table 25: Cronbach Alpha coefficients for the HADS, SDQ, PSI/SF, IPQ, and PedsQL measures.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Scale</th>
<th>Alpha Coefficient</th>
<th>Skew</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS</td>
<td>Anxiety</td>
<td>0.82</td>
<td>0.47</td>
<td>-0.52</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>0.81</td>
<td>0.86</td>
<td>-0.01</td>
</tr>
<tr>
<td>SDQ</td>
<td>Total</td>
<td>0.84</td>
<td>0.65</td>
<td>-0.06</td>
</tr>
<tr>
<td>PSI/SF</td>
<td>Total</td>
<td>0.95</td>
<td>0.64</td>
<td>0.37</td>
</tr>
<tr>
<td>IPQ</td>
<td>Identity (symptoms)</td>
<td>0.75</td>
<td>0.96</td>
<td>1.32</td>
</tr>
<tr>
<td></td>
<td>Timeline (acute/chronic)</td>
<td>0.74</td>
<td>-0.02</td>
<td>-0.16</td>
</tr>
<tr>
<td></td>
<td>Timeline Cyclical Control</td>
<td>0.82</td>
<td>-0.32</td>
<td>-0.46</td>
</tr>
<tr>
<td></td>
<td>Consequences</td>
<td>0.74</td>
<td>0.30</td>
<td>-0.58</td>
</tr>
<tr>
<td></td>
<td>Personal Control</td>
<td>0.83</td>
<td>-0.02</td>
<td>-0.10</td>
</tr>
<tr>
<td></td>
<td>Treatment Control</td>
<td>0.67</td>
<td>0.01</td>
<td>0.52</td>
</tr>
<tr>
<td></td>
<td>Illness Coherence</td>
<td>0.61</td>
<td>-0.70</td>
<td>0.50</td>
</tr>
<tr>
<td></td>
<td>Emotional Representation</td>
<td>0.91</td>
<td>0.13</td>
<td>-0.49</td>
</tr>
<tr>
<td>PedsQL Mother-report</td>
<td>Physical</td>
<td>0.84</td>
<td>-0.62</td>
<td>0.07</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
<td></td>
<td>-0.38</td>
<td>-0.69</td>
</tr>
<tr>
<td>PedsQL Generic-report</td>
<td>Physical</td>
<td>0.90</td>
<td>-1.04</td>
<td>1.27</td>
</tr>
<tr>
<td></td>
<td>Psychosocial</td>
<td></td>
<td>-0.47</td>
<td>-0.54</td>
</tr>
<tr>
<td>PedsQL Asthma Mother-report</td>
<td>Asthma</td>
<td>0.88</td>
<td>0.12</td>
<td>-0.43</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>0.86</td>
<td>-0.53</td>
<td>-0.86</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>0.89</td>
<td>-1.42</td>
<td>1.54</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>0.90</td>
<td>-0.63</td>
<td>-0.49</td>
</tr>
<tr>
<td>PedsQL Asthma Child-report</td>
<td>Asthma</td>
<td>0.70</td>
<td>-0.10</td>
<td>-0.63</td>
</tr>
<tr>
<td></td>
<td>Treatment</td>
<td>0.65</td>
<td>-0.70</td>
<td>0.62</td>
</tr>
<tr>
<td></td>
<td>Worry</td>
<td>0.73</td>
<td>-1.29</td>
<td>1.22</td>
</tr>
<tr>
<td></td>
<td>Communication</td>
<td>0.65</td>
<td>-0.47</td>
<td>-0.45</td>
</tr>
</tbody>
</table>
Appendix O:

Subscale Correlations (SDQ, PSI/SF, PedsQL)

Table 26: Correlations between subscales on the PSI/SF

<table>
<thead>
<tr>
<th>Parent/Child</th>
<th>Parental Distress</th>
<th>Parent/Child Dysfunctional Interaction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dysfunction</td>
<td>0.61**</td>
<td></td>
</tr>
<tr>
<td>Difficult</td>
<td>0.60**</td>
<td>0.71**</td>
</tr>
</tbody>
</table>

** p<0.01

Table 27: Correlations between subscales on the SDQ

<table>
<thead>
<tr>
<th>Conduct Problems</th>
<th>Emotional Symptoms</th>
<th>Conduct Problems</th>
<th>Hyperactivity</th>
<th>Peer Problems</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct Problems</td>
<td>0.40**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>0.35**</td>
<td>0.60**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Peer Problems</td>
<td>0.47**</td>
<td>0.38**</td>
<td>0.26*</td>
<td></td>
</tr>
<tr>
<td>Prosocial Behaviour</td>
<td>-0.01</td>
<td>-0.35**</td>
<td>-0.42**</td>
<td>0.02</td>
</tr>
</tbody>
</table>

* p<0.05 ** p<0.01

Table 28: Correlations between subscales on the PedsQL Generic Mother-report

<table>
<thead>
<tr>
<th>Emotional</th>
<th>Physical</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>0.45**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>0.58**</td>
<td>0.52**</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>0.62**</td>
<td>0.38**</td>
<td>0.56**</td>
</tr>
</tbody>
</table>

** p<0.01

Table 29: Correlations between subscales on the PedsQL Asthma Mother-report

<table>
<thead>
<tr>
<th>Asthma</th>
<th>Treatment</th>
<th>Worry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>0.54**</td>
<td></td>
</tr>
<tr>
<td>Worry</td>
<td>0.44**</td>
<td>0.48**</td>
</tr>
<tr>
<td>Communication</td>
<td>0.19</td>
<td>0.37**</td>
</tr>
</tbody>
</table>

** p<0.01
### Table 30: Correlations between subscales on the PedsQL Generic Child-report.

<table>
<thead>
<tr>
<th></th>
<th>Physical</th>
<th>Emotional</th>
<th>Social</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional</td>
<td>0.44**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social</td>
<td>0.49**</td>
<td>0.56**</td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>0.37**</td>
<td>0.44**</td>
<td>0.44**</td>
</tr>
</tbody>
</table>

** p<0.01

### Table 31: Correlations between subscales on the PedsQL Asthma Child-report.

<table>
<thead>
<tr>
<th></th>
<th>Asthma</th>
<th>Treatment</th>
<th>Worry</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>0.55**</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Worry</td>
<td>0.57**</td>
<td>0.31**</td>
<td></td>
</tr>
<tr>
<td>Communication</td>
<td>0.31**</td>
<td>0.38**</td>
<td>0.21</td>
</tr>
</tbody>
</table>

** p<0.01
### Appendix P:

**Correlations between IPQ-R and PedsQL (mother-report and child-report)**

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline</th>
<th>Timeline Cylindrical</th>
<th>Consequences</th>
<th>Personal Control</th>
<th>Treatment Cure Control</th>
<th>Illness Coherence</th>
<th>Emotional Representation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mother-report</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generic</td>
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<td></td>
</tr>
<tr>
<td>Physical</td>
<td>-0.12</td>
<td>-0.05</td>
<td>-0.21</td>
<td>-0.28</td>
<td>0.31</td>
<td>0.18</td>
<td>0.26</td>
<td>-0.24</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>-0.27</td>
<td>-0.22</td>
<td>-0.31</td>
<td>-0.48*</td>
<td>0.24</td>
<td>0.17</td>
<td>0.30</td>
<td>-0.25</td>
</tr>
<tr>
<td><strong>Asthma</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>-0.42*</td>
<td>-0.15</td>
<td>-0.34*</td>
<td>-0.40*</td>
<td>0.20</td>
<td>0.13</td>
<td>0.15</td>
<td>-0.26</td>
</tr>
<tr>
<td>Treatment</td>
<td>-0.40*</td>
<td>-0.09</td>
<td>-0.28</td>
<td>-0.34*</td>
<td>0.09</td>
<td>0.11</td>
<td>0.24</td>
<td>-0.26</td>
</tr>
<tr>
<td>Worry</td>
<td>-0.27</td>
<td>-0.09</td>
<td>-0.15</td>
<td>-0.23</td>
<td>0.11</td>
<td>0.00</td>
<td>0.14</td>
<td>-0.27</td>
</tr>
<tr>
<td>Communication</td>
<td>-0.17</td>
<td>-0.06</td>
<td>0.03</td>
<td>0.01</td>
<td>0.20</td>
<td>0.08</td>
<td>0.14</td>
<td>-0.06</td>
</tr>
<tr>
<td><strong>Child-report</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generic</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical</td>
<td>-0.06</td>
<td>0.11</td>
<td>-0.05</td>
<td>0.12</td>
<td>0.17</td>
<td>0.01</td>
<td>0.04</td>
<td>0.05</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>0.03</td>
<td>-0.08</td>
<td>0.05</td>
<td>-0.01</td>
<td>0.09</td>
<td>0.03</td>
<td>-0.03</td>
<td>0.06</td>
</tr>
<tr>
<td><strong>Asthma</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asthma</td>
<td>-0.14</td>
<td>-0.10</td>
<td>-0.13</td>
<td>-0.25</td>
<td>0.10</td>
<td>-0.16</td>
<td>-0.00</td>
<td>-0.04</td>
</tr>
<tr>
<td>Treatment</td>
<td>-0.12</td>
<td>-0.03</td>
<td>-0.04</td>
<td>-0.10</td>
<td>0.18</td>
<td>0.03</td>
<td>0.11</td>
<td>-0.07</td>
</tr>
<tr>
<td>Worry</td>
<td>-0.22</td>
<td>-0.23</td>
<td>-0.09</td>
<td>-0.24</td>
<td>-0.01</td>
<td>-0.11</td>
<td>-0.04</td>
<td>-0.05</td>
</tr>
<tr>
<td>Communication</td>
<td>0.17</td>
<td>-0.10</td>
<td>-0.11</td>
<td>0.11</td>
<td>0.17</td>
<td>-0.08</td>
<td>0.13</td>
<td>-0.07</td>
</tr>
</tbody>
</table>

*significant correlations, corrected for Type 1 experiment-wise errors using Holm’s (1979) correction criteria*
LOG OF RESEARCH EXPERIENCE
<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct a literature search</td>
<td>Used PsychInfo computerised literature database, Medline Database and Google to conduct several literature searches to inform clinical practice and assist with research and essays. SRRP – National Service Framework, line management, teams, working together, community mental health teams QRP – mental illness, mental health problems, attitudes, opinions, beliefs, knowledge, men, gender MRP – Illness perceptions, asthma, depression, anxiety, behavioural difficulties, parenting stress, quality of life, children, mothers</td>
<td>Winter 2001 – Spring 2002 Spring 2003</td>
</tr>
<tr>
<td>Critically review the literature</td>
<td>For all literature searches I looked for recent, up to date literature and tried to find reviews and meta-analyses where available. SRRP – Critically reviewed literature for SRRP QRP – Critically reviewed literature for Qualitative Research Project MRP – Critically reviewed literature for MRP Presentations – Critically reviewed literature for presentations on; Offenders with Learning Disabilities; Race and Ethnicity - are they important in the incidence and treatment of mental health difficulties in older people?: PTSD and Chronic Pain.</td>
<td>Winter 2001 Spring 2003 Spring 2003 Summer 2002 Summer 2003 Spring 2004</td>
</tr>
<tr>
<td>Research Skill/Experience</td>
<td>Description of how research skill/experience acquired</td>
<td>Date research skill/experience acquired</td>
</tr>
<tr>
<td>---------------------------</td>
<td>--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------</td>
</tr>
</tbody>
</table>
| Formulate a specific research question | SRRP - After discussion with placement supervisor and CMHT team manager decided to do an audit to look at to what extent CMHT staff were aware of and understood the recent integration of Health and Social Services and the creation of a single line-management structure within their CMHTs and how they felt about it, in order to inform service heads.  
MRP – The research question was formulated in discussion with the field supervisor and through examinations of the literature. The primary research question whether the relationships between paediatric asthma severity and psychosocial variables (maternal anxiety and depression, maternal parenting stress, child psychological and behavioural difficulties, child quality of life) were moderated by maternal illness beliefs, with secondary questions about the relationships between paediatric asthma severity, maternal illness beliefs and a the psychosocial variables. | Winter 2001  
Spring 2003 |
| Write a brief research proposal | SRRP – Prepared a brief research proposal to investigate CMHT staff members’ knowledge, understanding and opinions of the recent integration of Health and Social Services and the creation of a single line-management structure within their CMHTs  
MRP – Prepared a brief research proposal to investigate attitudes towards social roles of people with psychosis. Due to difficulties in finding appropriate measures and accessing an appropriate client group this proposal was not carried forward.  
MRP – Prepared a brief research proposal to investigate whether maternal illness beliefs moderate the relationship between paediatric asthma severity and psychosocial variables. | Winter 2001  
Winter 2003  
Spring 2003 |
<p>| Write a detailed proposal/protocol | MRP – Prepared detailed research protocols for three Local Regional Ethics Committees and the University of Surrey Ethics Committee, detailing the proposed major research idea. Proposal approved at all ethic committees. | Spring 2003 |</p>
<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>SRRP – CMHT team manager agreed to collaborate on the questionnaire design in order to ensure that the questionnaire reflected the needs of the service. Placement supervisor and a course team member agreed to act as supervisors for the research. QRP – Undertaken collaboratively with three other trainees and data was shared. MRP – Research topic was developed in conjunction with a clinical psychologist working in paediatric psychology who then agreed to act as a field supervisor. University supervisor with an interest in health psychology was approached and agreed to act as university supervisor. Staff at the three clinic sites collaborated with the research by providing patient contact details, access to patients and completing severity measures.</td>
<td>Winter 2001 Spring 2003 Spring 2003</td>
</tr>
<tr>
<td>Write a participant information sheet and consent form</td>
<td>SRRP – Covering letter for questionnaires written MRP - Information sheets and consent form for participants written. Contact details for the researcher were provided and potential participants were reassured of the confidentiality of the study.</td>
<td>Spring 2002 Spring 2003</td>
</tr>
<tr>
<td>Judge ethical issues in research and amend plans accordingly</td>
<td>SRRP – Questionnaires were returned anonymously MRP – Mother- and child-report measures were carefully selected for those that were unlikely to cause significant distress. Participants were reassured of the confidentiality of the study and data was kept secure. Information about the researcher’s contact details was given and participants were free to withdraw at any time. If participants preferred, they could take the measures home and fill them in private, returning them in a stamped addressed envelope. The GPs of children and mothers of children who participated were informed of their participation.</td>
<td>Spring 2002 Spring 2004 – Summer 2004</td>
</tr>
<tr>
<td>Research Skill/Experience</td>
<td>Description of how research skill/experience acquired</td>
<td>Date research skill/experience acquired</td>
</tr>
<tr>
<td>---------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------------------------------</td>
</tr>
</tbody>
</table>
| Obtain approval from a research ethics committee | SRRP – Contacted the trust Research and Development Department who said that they considered the project as a small-scale audit and that therefore I did not need to obtain ethical approval or submit the proposal to the Ethics or R&D committees. Contacted the audit department who sent me some information but said that I did not need to submit the audit to them.  
MRP – Ethical approval obtained from three Local Research Ethics Committees and the University of Surrey Ethics Committee. | January 2002 |
| Collect data from research participants | SRRP – All staff members in the four CMHTs were sent postal questionnaires, to be returned to the researcher anonymously in stamped addressed envelopes  
QRP – A man known to the researcher was interviewed (the sample excluded close friends or family members)  
MRP – All mothers with children aged 5-11 diagnosed with asthma who were attending a paediatric outpatient appointment in the data collection period were invited to participate. Questionnaires were given to mothers and their children at the child’s clinic appointment and the paediatrician was asked to rate the child’s asthma severity after the appointment. If mothers preferred they could take the questionnaire home and return it in a stamped addressed envelope. On receipt the questionnaires were numbered and stored separately from the consent forms. | June 2003, July 2003, July 2003 |
| Set up a data file | SRRP and MRP – data files set up using SPSS for all variables being investigated. These formed the basis for analysis and hypothesis testing. | Spring 2002, Spring 2003 |
| Analyse quantitative data | SRRP – analysed using Frequencies and a Wilcoxon signed ranks test.  
MRP – analysed using Frequencies, Pearson’s correlations, Chi-square, ANOVAs and multiple regressions, using Cronbach’s alpha coefficients to check for reliability and skew and kurtosis data to check for normal distribution. | Autumn 2003 – Spring 2004, Spring 2003, Summer 2004 |
<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Analyse qualitative data</td>
<td>QRP – interviews were transcribed and analysed using Interpretative Phenomenological Analysis (IPA). As this was a group project, within the group each person interviewed one person and transcribed their own interview and identified key themes. The group then met to discuss the themes to identify patterns, clusters and links.</td>
<td>Spring 2003</td>
</tr>
<tr>
<td>Summarise results in figures/graphs</td>
<td>All data for the SRRP and MRP was more appropriately summarised in tables or prose highlighting trends, themes or key results.</td>
<td>Spring 2003, Summer 2004</td>
</tr>
<tr>
<td>Interpret results from data analysis</td>
<td>Results from SRRP, QRP and MRP interpreted in the context of the original research questions. For the MRP, reasons why the findings were not in line with expectations were discussed. For both the SRRP and MRP, limitations were acknowledged and clinical implications and areas of further research were discussed.</td>
<td>Spring 2003, Summer 2004</td>
</tr>
<tr>
<td>Produce a written report on a research project</td>
<td>SRRP, QRP and MRP all written up for portfolio. Feedback on draft of MRP from supervisors before final report written up.</td>
<td>June 2002, May 2003, July 2004</td>
</tr>
<tr>
<td>Defend research project at an oral examination</td>
<td>Viva</td>
<td>10th September 2004</td>
</tr>
<tr>
<td>Research Skill/Experience acquired</td>
<td>Description of how research skill/experience acquired</td>
<td>Date research skill/experience acquired</td>
</tr>
<tr>
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<td>-----------------------------------------------------</td>
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