Preparation for General Anaesthesia: Who Needs It?

Factors Associated with Peri-Operative Distress in Children

by

Caroline Haigh

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

Department of Psychology
School of Human Sciences
University of Surrey

July 2006

© Caroline Haigh 2006
Acknowledgements

I would like to thank my partner, family, fellow trainees and the academic and administrative staff of the Clinical Psychology department at the University of Surrey for personal and practical support over the three years of training, in particular those who have provided me with direct supervision or support for my research projects – Mick Finlay, James Murray, and Sue Thorpe.

Thanks must also go to my clinical placement supervisors, Anna Iwnicki, Zena Dowling, Carol Hagland, Penny Bebbington, Rebecca Scarth, Diana Chanfreau, Sarah Agnew, Ian Kneebone, Sam Peacock, Lesley Edwards, and Milly Sawyer.

I would also like to thank Lindsey Edwards and Daniela Hearst for the practical and intellectual support provided for my major research project, and thanks must also go to the anaesthetic department for supporting the research, and to the Operating Department Assistants at Great Ormond Street Hospital for completing the outcome measures without which there would be no project.
<table>
<thead>
<tr>
<th>Contents</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Section</td>
<td></td>
</tr>
<tr>
<td>Introduction to the academic section</td>
<td>1</td>
</tr>
<tr>
<td>AMH Essay</td>
<td>2</td>
</tr>
<tr>
<td>PLD Essay</td>
<td>32</td>
</tr>
<tr>
<td>CAF Essay</td>
<td>58</td>
</tr>
<tr>
<td>OP Essay</td>
<td>87</td>
</tr>
<tr>
<td>Introduction to the clinical section</td>
<td>120</td>
</tr>
<tr>
<td>AMH CR Summary</td>
<td>121</td>
</tr>
<tr>
<td>PLD CR Summary</td>
<td>127</td>
</tr>
<tr>
<td>CAF CR Summary</td>
<td>134</td>
</tr>
<tr>
<td>OP CR Summary</td>
<td>140</td>
</tr>
<tr>
<td>SP1 CR Summary</td>
<td>146</td>
</tr>
<tr>
<td>AMH placement summary</td>
<td>153</td>
</tr>
<tr>
<td>PLD placement summary</td>
<td>153</td>
</tr>
<tr>
<td>CAF placement summary</td>
<td>154</td>
</tr>
<tr>
<td>OP placement summary</td>
<td>154</td>
</tr>
<tr>
<td>SP1 placement summary</td>
<td>155</td>
</tr>
<tr>
<td>SP2 placement summary</td>
<td>155</td>
</tr>
<tr>
<td>Introduction to the research section</td>
<td>156</td>
</tr>
<tr>
<td>SRRP</td>
<td>157</td>
</tr>
<tr>
<td>MRP</td>
<td>190</td>
</tr>
<tr>
<td>Research logbook</td>
<td>321</td>
</tr>
</tbody>
</table>
INTRODUCTION TO THE ACADEMIC SECTION

The academic section of this portfolio comprises four essays written during the first and second years of the training course. They are organised within the section to reflect the order in which they were submitted. This order coincides with the order of the first four clinical placements, namely, adult mental health, people with learning disabilities, children and families, and, finally, older people. Each essay is preceded by a title page giving the title of the essay and the month and year it was submitted.
Critically Discuss The Evidence Base That People With Borderline Personality Disorder Can Be Treated Effectively By General Adult Mental Health Services. What Implications Might This Have For The Provision Of Services?
This essay will first address the issues of definition and epidemiology. Then the question of whether or not people with borderline personality disorder (BPD) can be treated effectively within a general adult mental health service (GAMHS) - both for problems comorbid to BPD, and for BPD specifically will be considered. Although pharmacological treatment often plays a large part in GAMHS, this will be mentioned only briefly; most emphasis will be on psychological interventions. Some conclusion will be drawn as to whether people with BPD can be treated effectively in GAMHS. Finally, implications for services – in terms of finance, organisation and staff resources will be considered.

To address the question of whether people with BPD can be treated effectively by GAMHS, one must first consider:

1) What is borderline personality disorder?
2) What is a general adult mental health service?

What is borderline personality disorder?

Definition and Diagnostic Criteria

The Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM–IV; APA, 1994) characterises personality disorder as:
An enduring pattern of inner experience and behavior that deviates markedly from the expectations of the individual’s culture, is pervasive and inflexible, has an onset in adolescence or early childhood, is stable over time, and leads to distress or impairment. (p.360)

The DSM-IV (APA, 1994) further organises the concept of personality disorder into three clusters. Cluster A; referred to as ‘odd-eccentric’; cluster B; referred to as ‘emotional-dramatic’; and cluster C; referred to as ‘anxious-fearful’. BPD falls within cluster B, along with antisocial, histrionic and narcissistic personality disorders. These other cluster B sub-types, however, are not the subject of this essay and will not be further discussed.

The DSM-IV (APA, 1994) sets out the diagnostic criteria for BPD as:

A pervasive pattern of instability of interpersonal relationships, self-image, and affects, and marked impulsivity beginning by early adulthood and present in a variety of contexts, as indicated by five (or more) of the following:

1. Frantic efforts to avoid real or imagined abandonment
2. A pattern of unstable & intense interpersonal relationships characterized by alternating between extremes of idealization and devaluation
3. Identity disturbance: markedly and persistent unstable self-image or sense of self
4. Impulsivity in at least two areas that are potentially self-damaging (e.g. spending, sex, substance abuse, reckless driving, binge eating)
5. Recurrent suicidal behaviour, gestures or threats, or self-mutilating behaviour

6. Affective instability due to a marked reactivity of mood (e.g., intense episodic dysphoria, irritability, or anxiety usually lasting a few hours and only rarely more than a few days)

7. Chronic feelings of emptiness

8. Inappropriate, intense anger or difficulty controlling anger (e.g., frequent displays of temper, constant anger, recurrent physical fights)

9. Transient, stress related paranoia or severe dissociative symptoms.

(p.654)

A number of criticisms of this diagnostic framework have been put forward. Kendell (2002) highlights that many of the diagnostic criteria are subjective, and could be affected by the society in which a person lives to such an extent that what would be considered normal in one country may well fit the criteria for personality disorder in another. Further, there is some disagreement as to whether or not BPD, and the other personality disorders, can be considered mental disorders. Kendell (2002) notes that as there is currently no commonly accepted definition of mental disorder, one cannot begin to consider whether or not personality disorder falls within those boundaries.

**Epidemiology**

Epidemiological studies using the DSM-IV (APA, 1994) criteria have estimated the prevalence of BPD within the general population as between 2% (Widiger &
Weisman, 1991) and 5.4% (Ekselius, Tilfors, Furmark & Fredrikson, 2001); the prevalence of BPD within an adult population in touch with psychiatric services has been estimated as between 15% and 20% (Gunderson & Zanarini, 1987). This represents a significant proportion of adults using psychiatric services, and emphasises the importance of considering whether these individuals can be effectively treated within GAMHS.

**What is a general adult mental health service?**

This is a more difficult term to define. The Department of Health (DoH; 2002) sets out ten services that should be considered to constitute specialist adult mental health services. These are: Tertiary Eating Disorder Services; Neuropsychiatry; Forensic Services; Specialised Mental Health Services for Deaf People; Specialised Addiction Services; Specialist Psychological Therapies - Inpatient and Specialised Outpatient; Gender Identity Disorder; Perinatal Psychiatric Services; Complex and/or Treatment Resistant Disorders; Asperger's Syndrome.

It must be inferred that services not falling within the ten criteria should be judged as GAMHS. This would include community mental health teams (CMHT’s) and outpatient services offered not falling within the complex and/or treatment resistant or specialist psychological therapies brackets. The DoH (2002) specialised services definitions further describes the sorts of therapies that can be expected to be offered in GAMHS. Those cited specifically are: the psychoanalytic psychotherapies (including brief focussed psychodynamic psychotherapy, group analytic psychotherapy, individual or couple psychoanalytic psychotherapy, and analytically informed
supportive psychotherapy); the cognitive behavioural therapies (including cognitive
behavioural therapy, cognitive analytic therapy, dialectical behaviour therapy, schema
focussed therapy, and psychosocial interventions); and the systemic therapies
(including narrative therapy, solution focussed brief therapy, and social constructionist
therapy). Most of the therapeutic interventions suggested for BPD fall outside the
remit of specialised psychological therapies, and as such should be treated within
GAMHS. It could, however, be argued that BPD would fall within the complex
and/or treatment resistant disorders because of its pervasive and inflexible nature. The
DoH (2002) definition set mentions several disorders which should fall within this
bracket, including complex bipolar disorders and severe psychosis. No mention is
made of BPD, and therefore, it can be surmised that people BPD should be treated
within GAMHS. This, however, does not automatically infer that current GAMHS
can effectively treat these individuals.

So, can people with BPD be treated effectively within GAMHS? There seem to be
two main issues to be addressed in this question:

1) Can people with BPD be treated effectively in GAMHS for mental health
   problems comorbid to their BPD?

2) Can people with BPD be treated effectively in GAMHS for their BPD
   specifically?
Can people with BPD be treated effectively in GAMHS for mental health problems co-morbid to their BPD?

Prevalence of Comorbidity

Although there has been recent research interest in the impact of comorbid axis two disorders on treatment of axis one disorders, few of these studies address the specific personality disorders, preferring to look at personality disorders as a whole, or dividing them into cluster A, B, and C disorders. As a result, there is a paucity of research pertaining to BPD specifically—however it is an important issue to address, as the prevalence of BPD is much higher in the psychiatric population than in the non-psychiatric population. Studies of depression within a BPD population have reported comorbidity rates for depression ranging from 24% to 87% (Docherty, Fiester & Shea, 1986; Jonas and Pope, 1992—cited in Shea, Widiger & Klein, 1992). In a survey of 162 depressed patients receiving cognitive therapy, 12% were found to meet the DSM-IV (APA, 1994) diagnostic criteria for BPD (Kuyken, Kurzer, DeReubis, Beck & Brown, 2001). Similarly elevated co-occurrence of BPD has not been found for anxiety disorders, although elevated occurrence of other personality disorders has (Dreesen, Hoekstra & Arntz, 1997; Van Velzen, Emmelkamp & Scholing, 1997).

Treatment of Comorbid Axis One Disorders: Depression

There is some evidence to suggest that individuals with BPD respond less well to psychological treatment for depression than depressed individuals without diagnosis of BPD (Shea, Pilkonis, Beckham, Collins, Elkin, Sotsky, & Docherty, 1990; Shea,
Widiger and Klein, 1992). However, more recent research has suggested poor response to cognitive therapy in individuals with personality disorders, including BPD, may be due to the strength and type of maladaptive beliefs held (J.S. Beck, 1998; Kuyken et al., 2001), rather than personality disorder status. J.S. Beck (1998) suggests that the number of negative core beliefs held by individuals with a personality disorder is often higher than for a non-personality disordered individual. She also suggests that there may be more supportive evidence for negative beliefs held about the self, and that these beliefs are held more rigidly and strongly.

Kuyken et al. (2001) studied 162 depressed individuals accepted for treatment at the Centre for Cognitive Therapy in California. 12% of these were found to meet the DSM-IV (APA, 1994) criteria for BPD, whilst 59% were found to have a personality disorder. In addition to establishing DSM-IV (APA, 1994) axis one and axis two status, the Personality Beliefs Questionnaire (PBQ; A.T Beck & J.S. Beck, 1991 – cited in Kuyken et al, 2001) was administered to gauge the type and strength of participant’s maladaptive beliefs. The Beck Depression Inventory-II (BDI-II; Beck, Steer & Brown, 1996) was also administered. Therapy was delivered according to individual formulations and therapist judgement. Unless participants were presenting with co morbid personality disorders, standard cognitive therapy for depression was used for treatment. For participants presenting with comorbid personality disorders, focus on maladaptive behavioural strategies and core beliefs was increased. Post-treatment, there was no significant difference between the improvement scores for participants with or without a personality disorder. Equally, there was no significant difference in improvement between the different types of personality disorder. As there was no effect found for difference within the types of personality disorder, these
results can be considered applicable to BPD. Kuyken et al. (2001) state that this indicates that comorbid depression and personality disorder can be treated with altered forms of cognitive therapy to show improvements comparable to those found in a non-personality disordered depressed population.

Mennin and Heimberg (2000) point out that as cognitive therapy has become more widely used and researched, individual treatment guidelines for specific disorders have been developed to such an extent that a prescribed course of therapy can be followed, with suggestions as to what should be covered in each session. In research terms, this is a mixed blessing. Easily replicable treatment protocols allow readily replicable studies and good reliability. However, it could be argued that in more complex cases (e.g. depression comorbid with BPD) prescribed treatment protocols create misleading results. Kuyken et al. (2001) showed that adjustments to cognitive therapy for depression to allow for the individualised impact of personality disorders – as suggested by J.S. Beck (1998) – leads to more favourable outcomes than previously suggested. Kuyken et al. (2001) also point out that BPD participants in their study had more severe pre-treatment symptom severity, and more residual symptoms post-treatment, and emphasise the importance of monitoring improvement, rather than relying simply on categorical outcome scores.

It seems reasonable to assume that therapists with a good level of skill in cognitive therapy would be available in GAMHS, and that they would be able to tailor cognitive therapy to individual client’s needs. It can be concluded, then, that people diagnosed with BPD can be effectively treated for depression in GAMHS.
Treatment of Comorbid Axis One Disorders: Anxiety

Dreesen and Arntz (1998) conducted a comprehensive review of published evidence addressing the impact of personality disorders on treatment outcome for anxiety disorders. Most notably within the review was considerable disagreement about the impact of a comorbid personality disorder on treatment outcome for anxiety disorders. Dreesen and Arntz (1998) point out that this could be due to different personality disorders affecting treatment outcome in different directions. Most of the studies reviewed discuss the impact of personality disorders as a whole. As the focus of this essay is BPD, only those studies discussing the impact of individual personality disorders will be mentioned.

Dreesen, Arntz, Luttels and Sallearts (1994 – cited in Dreesen & Arntz, 1998) studied 31 patients with panic disorder and comorbid personality disorders. Overall, they found no significant difference in treatment outcome for these patients when compared to a non-personality disordered control. When considering the individual personality disorders, they found that obsessive-compulsive personality disorder predicted negative treatment outcome, whereas BPD predicted a more positive treatment outcome. With regard to obsessive-compulsive disorder, Baer, Jenicke, Black, Treece, Rosenfeld & Greist (1992 – cited in Dreesen & Arntz, 1998) found that BPD, along with schizotypal and avoidant personality disorder, correlated with poorer treatment outcomes. However, in a study looking at 52 patients with obsessive-compulsive disorder, Dreesen, Hoekstra and Arntz (1997) found that BPD did not affect treatment outcome, either positively or negatively. Similarly, Van Velzen, Emmelkamp & Scholing (1997) found no significant effect of BPD on treatment
outcome for social phobia. Chambless, Renneberg, Goldstein and Gracely (1992) studied 165 patients diagnosed with agoraphobia. Over 90% of these were found to have a co-morbid personality disorder. On examination of treatment outcomes for individual personality disorders, Chambless et al. (1992) concluded none of the personality disorders predicted poor outcome, although paranoid traits predicted early drop out.

On the basis of the evidence, it would seem that BPD does not predict negative outcome in psychological treatment of anxiety disorders, with the possible exception of obsessive-compulsive disorder, where there are contradictory findings. Parallel to the warnings mentioned with regard to depression and BPD, it must be considered that there is a lack of published research addressing BPD and treatment outcome for anxiety disorders. Dreessen and Arntz (1998) point out that in many cases, individuals with an anxiety disorder and comorbid personality disorder often present with more severe pre-treatment symptomatology, and often have more residual symptoms, but that it is important to consider improvement criteria. They further suggest that many negative treatment outcomes alluded to in treating individuals with personality disorders could be due to interpersonal problems, rendering it difficult to establish a therapeutic relationship, and that many of these problems could be overcome by a skilled therapist.

Importantly, this evidence would seem to suggest that people with BPD and a comorbid axis one anxiety disorder can be treated effectively in GAMHS, and certainly should not be declined treatment on the basis of their personality disorder.
Can people with BPD be treated effectively in GAMHS for mental health problems comorbid to their BPD? The evidence suggests that the answer to this is yes, but that the therapist needs to be aware of the particular difficulties associated with treating people with BPD and make allowances and adjustments for this within the therapeutic framework.

**Can people with BPD be treated effectively in GAMHS for their BPD specifically?**

Adshead (2001) states "treatability is a confused and confusing concept in psychiatry" (p. 107). This certainly seems to be more the case for BPD than for other diagnoses. Davison (2002), discussing BPD, states "in no other branch of medicine does treatable equate with curable" (p. 3). It seems that Davison (2002) is alluding to the commonly held idea that BPD, as well as the other personality disorders, are such ingrained patterns of behaviour and cognition, that very little can be done to change them. However, if improvement can be achieved in level of functioning, level of distress, or in self-harm behaviours, is this not effective treatment?

There are two main approaches to the treatment of BPD – psychoanalytic approaches and cognitive approaches. More recently, there have been syntheses of these two approaches, most notably cognitive analytic therapy (CAT), and deviations, for example dialectical behaviour therapy (DBT). There have also been attempts at outlining treatment and management plans to allow people with BPD to be managed in a CMHT. Recently, The American Psychiatric Association (APA, 2001) have issued a set of guidelines for the treatment of patients with BPD. Many criticisms
have been levelled at these, most notably that the document is written with a level of confidence not supported by the quality and breadth of evidence used to support its recommendations (McGlashan, 2002; Paris, 2002; Sanderson, Swenson, & Bohus, 2002; Tyrer, 2002).

_Treatment Approaches: Psychoanalytic_

From a psychoanalytic perspective, BPD is not considered a discrete diagnostic entity, but rather as a level of psychic functioning, and is more often referred to as borderline personality organisation (BPO). Therefore, it is difficult to compare psychoanalytic treatment efficacy with that of other therapies, as the psychoanalytic understanding of BPO will encompass far more people than would the DSM-IV (APA, 1994) criteria.

Psychoanalytic approaches to treating borderline personality disorder have been shown to be efficacious (Roth & Fonagy, 1996). Before considering psychoanalytic approaches to treating borderline personality disorder, one must first consider which psychoanalytic psychotherapies the DoH (2002) considers should be available in GAMHS.

The psychoanalytic psychotherapies include:

- **Brief focused psychodynamic therapy**: 10 – 30 sessions
- **Group analytic psychotherapy**: usually long-term
- **Individual (or couple) psychoanalytic psychotherapy**: usually from one to several years
- **Analytically-informed supportive psychotherapy**

(DoH, 2002, p.11)
This expectation of what is available in GAMHS excludes many of the outcome studies for psychoanalytic treatment, which have often been carried out in specialised facilities. However, it should not be ignored that psychoanalytically oriented partial hospitalisation has been found to be superior to standard psychiatric care for people with BPD (Bateman & Fonagy, 1999, 2001).

Roth and Fonagy (1996) point out that there are very few controlled studies of psychotherapy for personality disorder in general, suggesting that there will be very few concentrating on BPD. Winston (2000) is of the opinion that there has yet to be published a satisfactory evaluation, although the treatment approach seems promising in light of what evidence has been published. Winston, Pollack, McCullough, Flegenheimer, Kestenbaum and Trujillo (1991) studied thirty-two patients with BPD treated with brief psychodynamic therapy (one hour a week for up to 40 sessions). Significant improvement was found for these patients, although it should be noted that there was no control group. Stevenson and Meares (1992) evaluated the effectiveness of psychoanalytic psychotherapy for thirty patients with BPD. Twice weekly appointments for 12 months were offered. Significant improvement was found after 12 months – moreover, 30% of these patients no longer met diagnostic criteria for BPD at the end of treatment. Outcome was maintained at 5-year follow-up. Meares, Stevenson and Comerford (1999) replicated this earlier study with the inclusion of a control group, and found that those treated improved significantly in comparison to the control group.
It seems psychoanalytical and psychodynamic therapies offered in GAMHS could be of benefit to people with BPD. Bateman and Fonagy (2000) urge caution in interpreting the generally positive results of preliminary investigations, pointing out that many more, and better quality, studies need to be produced in order to accept this treatment as efficacious.

_Treatment Approaches: Cognitive_

Cognitive therapy (CT) is a flexible, focused, often brief therapy, which is offered for a number of psychological difficulties. Aspects of cognitive therapy have been adapted for use in other therapies addressing BPD (e.g. CAT, DBT), but these will be addressed separately. Due to its flexible nature, CT is readily adaptable to a number of psychological difficulties of varying severities. It is generally agreed that CT as used in simpler presentations (e.g. anxiety) would be inappropriate for treating the far more complex presentation of BPD, but that CT at a deeper level may be beneficial (Layden, Newman, Freeman & Morse, 1993; J.S. Beck, 1998). This deeper level CT has come to be referred to as schema-focussed cognitive therapy, concentrating on identifying and modifying early maladaptive schemas thought to underlie BPD. J.S. Beck (1998) reports positive trends for this type of CT emerging from uncontrolled studies or single case reports. Winston (2000) states that although this treatment approach is promising, it is as yet untested by satisfactory publications. Therefore, based on published evidence, it cannot be concluded that schema-focused CT is an effective treatment for BPD.
Treatment Approaches: DBT

DBT is specifically mentioned as a service which should be available in GAMHS (DoH, 2002). DBT is a relatively new treatment approach developed by Marsha Linehan (1987), based on a biosocial understanding of BPD, suggesting that biological dysfunction in the emotion regulation system coupled with an invalidating early childhood environment lead to pervasive emotional dysregulation in later life. Aspects of cognitive-behavioural therapy (CBT) are present, as are Zen concepts of mindfulness. The dialectical aspect involves emphasising the limitations of thinking in a linear manner, substituting ‘both/and’ for ‘either/or’. DBT is an involved process for both therapists and patients, involving once weekly individual therapy sessions (45-60 minutes), once weekly skills training group (2-2 ½ hours), out of hours telephone contact, and a once weekly consultation group (therapists only).

Linehan, Armstrong, Suarez, Allmon and Heard (1991) report a randomised clinical trial of DBT for patients with BPD. 44 participants were randomly assigned either to DBT for one year, or to treatment as usual in the community. On reassessment, participants in the DBT group had fewer parasuicidal/suicidal behaviours, and of those that did occur, they were less medically severe for the DBT group. In addition, the DBT group had fewer inpatient days and a lower treatment drop-out. There was no significant reduction in depression, hopelessness, suicidal ideation or reason for living. These results seem promising, but a number of criticisms have been levelled at this study. Scheel (2002) points out that, of the 22 treatment as usual patients, only nine received ongoing psychological therapy during the year, and further suggests that the analysis should have allowed for widely different experiences of the treatment as
usual group. Very few good quality studies have evaluated DBT’s efficacy since Linehan at al. (1991). Koons, Robins, Lynch, Tweed, Gonzalez, Morse, Bishop, Butterfield and Bastian (2001) conducted a randomised controlled trial of DBT for veterans with BPD. In addition to the positive outcomes found by Linehan et al. (1991), Koons et al. (2001) found significant reductions in suicidal ideation, hopelessness, depression, and anger expression. Robins (2002) suggests that the additional positive findings of the Koons et al. (2001) study are due to the veterans having a higher baseline level of functioning than Linehan et al.’s (1991) sample.

Despite the relatively sparse evidence base for DBT, it is a popular treatment. Swenson (2000) describes the evidence base as

slim and impressive: slim when considered against its already substantial dissemination into clinical practice, and impressive when considered against the relative absence of published empirical exploration of any alternative treatment’ (p.87)

Linehan (2000) points out that a number of outcome studies for BPD are currently underway, and that publication should lead to a more convincing evidence base.

Although specifically mentioned by the DoH (2002) as being a part of GAMHS, it is evidently a challenge to offer DBT in already overloaded services. DBT is an intensive therapy, expensive in terms of training and provision, and draining on the therapists who practice it (Palmer, 2002). Therefore, whether it should be classified as GAMHS is questionable.
However, if DBT is considered to fall within GAMHS, is it efficacious for people with BPD? Swenson (2000) sums up the answer to this question rather well: '...the jury is still out on DBT, ...it remains “probably efficacious”' (p.87).

_Treatment Approaches: CAT_

As with DBT, CAT is specifically mentioned as a service which should be available in GAMHS (DoH, 2002). CAT is an integration of cognitive and psychoanalytic ideas, whereby patterns of behaviour (dilemmas, traps and snags) which prevent negative recurring life themes from being revised are tackled (Ryle, 1997). It was developed specifically for use in the NHS as a medium term therapeutic option. CAT was specifically adapted to treat people presenting with BPD (Ryle, 1997), as the original CAT structure was found not to be diverse enough to cope with the chaotic presentation of BPD.

Denman (2001) argues that CAT is a valid treatment for BPD because of the sound theoretical underpinnings, despite the paucity of outcome studies. Only one outcome study of CAT for BPD was traced. Ryle and Golynkina (2000) monitored 27 patients with BPD treated with CAT. At 18-month follow-up, fourteen of these patients showed improvements. Whewell (2001) highlights the need for a randomised controlled trial of this promising therapy for BPD.

To summarise, there is not sufficient evidence to conclude that CAT is an efficacious treatment for BPD, although preliminary studies suggest that it may be helpful.
Treatment Approaches: Management in CMHT’s

Currently, by far the most commonly used management strategy for people with BPD is CMHT management and the care plan approach (CPA). However, whilst there is no evidence to suggest that this approach is less effective than any other, there is little or no evidence to suggest that it is effective in treating people with BPD (Tyrer, Coid, Simmonds, Joseph & Marriott, 2002). It is as important to reassess current practice as it is to evaluate new treatment approaches, and yet there do not seem to be any published studies addressing the efficacy of CMHT management for people with BPD, despite their making up such a large part of GAMHS.

Some studies have attempted to address the issue of whether CMHT staff feel able to manage people with BPD. Nehls (2000) interviewed CMHT staff and found that they often feel under-supported and under-trained in how to establish a relationship with and effectively manage people with BPD. Similarly, Dunn and Parry (1997) state, with reference to people with BPD, ‘the staff are often stressed and deskilled; the psychiatrist is frustrated and irritated’ (p.19). This negative feeling and ambiguity among CMHT staff cannot be the optimum environment for effective treatment of BPD. Davison (2002), however, maintains that CPA provides appropriate treatment and management for people with BPD if the staff involved are aware of and sensitive to the specific treatment needs and obstacles to engagement of the BPD population.
To conclude, there does not seem to be evidence that people with BPD can be treated effectively within CMHT’s, although arguments have been put forward that, with training, CPA should be adequate.

Can people with BPD be treated effectively in GAMHS for their BPD specifically? Certainly many of the treatments recommended by various authors for treatment of BPD can be delivered within general GAMHS. However, based on the sparse research indications, the only sensible answer to this question is ‘probably’.

Despite many unanswered questions, recent developments give grounds for optimism. It is now difficult to sustain the view that all borderline patients are untreated. (Winston, 2000; p.215).

**Implications for the provision of services**

Services must be aware of the sparse evidence base for many of the therapies recommended for BPD, and weigh this up with their widespread usage and promise of helping to deal with what is considered a problematic population. It seems to be the responsibility of services offering psychological therapies for BPD to engage in audit and evaluation of these therapies, and to make this data available for wider dissemination, to begin to address the dearth of outcome studies in the literature.

If services use strategies such as BPD and CAT in the treatment of BPD, despite lack of outcome research, it should be a priority that adequate training and support is available, which will have a considerable impact on training budget and staff time.
Kerr (1999) maintains that CAT can only be efficacious in a team environment when the context and team are prepared to accommodate and deal with issues arising, and that to achieve this, every member of a team should have received some training. Palmer (2002) makes a similar observation with regard to DBT, emphasising that DBT is a team treatment, and anyone wishing to practice it will need to undergo training as part of a team. It seems that significant investment is required in order to offer CAT or DBT in the manner suggested by their originators.

Davison (2002) suggests it might be useful for services to help clinicians who care manage to overtly access the skills they have in managing people with personality disorder. She maintains that most clinicians have considerable experience of managing people with BPD, although it may not be overt. This would reduce the 'deskilled' feeling discussed by Dunn and Parry (1997), and perhaps create a more accepting environment for the client.

Cost-Effectiveness

So far, efficacy has been discussed in terms of symptom relief – an improvement for the patient. However, in an economic environment, cost-offset needs to be considered. The fact that people with BPD incur higher costs associated with suicide attempts, casualty attendance and psychiatric hospitalisation (Lazar & Gabbard, 1997) cannot be ignored.

No studies were traced addressing the economic impact of BPD specifically on the UK health system; but, since BPD is associated with a higher incidence of self-harm
behaviours than many of the other personality disorders, it can be assumed that BPD represents at least an equal portion of costs.

Rendu, Moran, Patel, Knapp and Mann (2002) conducted a prospective study of 303 general practice attenders; 24% of these had a personality disorder. Rendu et al. (2002) found the mean cost of general practice treatment over one year for those with a personality disorder was £3094, whilst for those without, it was £1633. Chiles, Lambert and Hatch (1999) conducted a meta-analysis of the impact of psychological interventions on offsetting medical costs. They concluded that savings of approximately 20% were achieved after psychological interventions, even when therapeutic costs were considered. Chiesa, Fonagy, Drahorad and Harrison-Hall (2002) found a reduction in health service costs of €3440 after treatment in GAMHS.

This magnitude of cost reduction cannot be ignored, and should be borne in mind by services when considering policy and staff treatment needs with regard to people with BPD.

In summary, it seems there is evidence to support the idea that people with BPD can be treated effectively for axis one disorders in GAMHS. The evidence is less conclusive if treatment specifically for BPD is considered. Although reliable evidence for the efficacy of treatments targeting BPD is sparse, what evidence there is suggests positive outcomes. Although it cannot be concluded that people with BPD can be treated effectively in GAMHS, there is also no evidence suggesting that they cannot.
REFERENCES


Submitted October 2003

Describe and Discuss Some of the Issues Involved in Assessing consent in People With Learning Disabilities
Consent, informed consent and valid consent, whilst very closely related, could be argued to be semantically distinct concepts. Henceforth, where ‘consent’ is written, it should be taken to mean valid and informed consent; concepts which will be discussed further in the body of the essay. This essay will first address the question of what consent is and why it is important that consent be assessed in people with learning disabilities (LD). Then the question of how capacity to consent can be assessed will be considered. Some of the issues surrounding what should happen if a person is judged unable to consent will be discussed.

Consent in people with LD is a complex and thought provoking issue, needing input from disciplines such as clinical psychology, medicine, sociology and law. This essay will attempt to discuss the implications for clinical psychologists, but the question posed by the title cannot be addressed without consideration of perspectives from these other disciplines. Although published literature addressing societal diversity in consent issues for people with LD is sparse, some attempt will be made to consider these issues. Finally, some conclusion will be drawn as to what the issues involved in addressing consent in people with LD are, the clinical implications of these, and whether there are any steps health and social care professionals can take to address or remediate these issues.

What is consent?

Before beginning to address the issues involved in assessing consent in people with LD, one must first reach an operational definition of consent. The Oxford English Dictionary (1989) defines consent as to agree or give permission. In the health and
social care arena, however, this definition is far from appropriate, since agreement can be reached or permission given without understanding the implications, or as a result of coercion or an overly compliant disposition. The consideration of understanding, coercion and compliance are relevant when considering consent from vulnerable adults, and particularly so when considering adults with a LD (Arscott, 1997).

It is commonly understood that consent should be considered along three dimensions: information, voluntariness, and capacity (Arscott, 1997; Department of Health, 2001; Hart, 2001; Hillery, Tomkin, McAuley, Keane & Staines, 1998; Matthews, 2003). The precise parameters for each of these three dimensions are vague, and have particular pertinence when considering people with LD. A fourth dimension specific to assessing consent in people with LD is the ability of the person to communicate decisions.

**Information**

The Department of Health (DoH; 2001) states that for consent to be valid, the person must be ‘provided with enough information to be able to make the decision’ (p.3). This raises the question of what is ‘enough’ information? The DoH (2001) states that information should be given about the benefits and risks of proposed treatment, what it will involve, what the implications of not having the treatment are, what alternatives are available and what the practical effects of having/not having the treatment will be. For medical procedures, such as medication, phlebotomy, or surgery, guidelines exist with regard to giving information, such as the British Medical Association’s (BMA) Consent Tool Kit (2001) and the DoH’s (2002) Reference Guide to Consent for
Examination or Treatment. However, just how much information is appropriate to give is not made clear.

With regard to psychological intervention, the British Psychological Society (BPS), in its Professional Practice Guidelines (BPS, 1995), sets out an inclusive list of information that a clinical psychologist should provide to the client to ensure consent is informed. The volume and complexity of this information may be difficult for most people with LD to understand.

This raises the question of how much information should be given to people with LD. That this is necessary is demonstrated in a study by Strydom, Forster, Wilkie, Edwards & Hall (2001), who, in a review of people with LD taking psychiatric medication, found that only 52% could read the label, and perhaps most alarmingly, that only 65% knew why they were taking their medication.

*Voluntariness*

The DoH (2001) states that for a person’s consent to be valid, ‘the person must be acting voluntarily (not under pressure or duress from anyone)’ (p.3). This is a complicated issue, and particularly difficult to assess. It could be argued that nobody ever acts purely without pressure – be it from family members, society, medical professionals, or significant people in a person’s life. In our multicultural society, it is of particular importance to understand cultural pressures which may impinge on an individual’s ability to act voluntarily, for example, there may be a perceived need to marry in order to be socially acceptable. In a case study of a Muslim Bangladeshi
woman with significant LD in an arranged marriage, Hepper (1999) highlights cultural pressures including the need for the oldest daughter to be married before her younger sisters, marriage as a transfer of burden of care, and marriage as a step towards normality for the young woman. The issues of acquiescence and compliance are particularly relevant for people with LD, as these are traits often praised by carers (Harris, 2003). Malhotra and Mellan (1996) identify this as a particular consideration for women from cultural backgrounds which value submissiveness in women.

Often, people with LD have little opportunity to exercise voluntary choice in day-to-day activities (Arscott, Dagnan & Stenfert Kroese, 1999; Harris, 2003), and this could result in a lack of decision-making skill, evidence evaluation skills, or understanding of the effect of decisions (Stalker & Harris, 1998; Harris 2003). This is often a particular difficulty for people living with their parents (Jenkinson, 1993), due to a lack of risk-taking opportunities (Sutcliffe, 1990). The theory of learned helplessness has been discussed with regard to people with LD and ability to consent (Stalker & Harris, 1998). Seligman (1992) states that three factors operate in learned helplessness: an environment in which some important outcome is beyond control, the response of giving up, and the expectation that no voluntary action can control the outcome. It is not difficult to envision situations where this could happen. For example, in a residential home, a person may want to visit their boyfriend or girlfriend, who lives in another home, but has no means of personal transport, and where the home is too short staffed to spare a team member as escort. Another situation could be if a client is dissatisfied with their day service, but lacks the expressive language to make this known and is unaware of other options — or even that there are other options open to them. In these situations, there is little that the
client can do to influence the outcome, and pursuant to Seligman's (1992) theory, a state of learned helplessness could develop, resulting in a lack of understanding of the concept of voluntary decision making or action. Hart (2001), assessing medical treatment consent, found that few people with a LD understood that they had the choice to accept or refuse treatment; most thought the treatment would go ahead no matter what.

Finlay and Lyons (2002) point out that people with LD are more likely to give an affirmative answer to questions put to them than are the general population. Other authors have drawn attention to the power imbalance that exists for many people with LD in dealings with health and social care professionals, and the impact this will have on any decision they are called upon to make (Arscott, 1997; Arscott, Dagnan & Stenfert Kroese, 1998; Treece, Gregory, Ayres & Mendes, 1999; Hart, 2001). Perceived gender or cultural power differentials can also affect this. Given the information presented above, how voluntary could a consent decision made by a person with LD be?

**Capacity**

The DoH (2001) states that for consent to be valid 'the person must be capable of taking that particular decision'. However, there is no operationalised definition of what this capacity comprises (Arscott, Dagnan & Stenfert-Kroese, 1999; Chahal & Morris, 2000a and 2000b; Raymont, 2002). The Law Commission (1991) states that in order to have capacity, a person needs to have an 'understanding in broad terms of the nature and likely effects of what is to take place' (p.29). In a more recent review
of the legal position, Chahal and Morris (2000a) conclude that in order for a person to be deemed capable of consenting, that person must be able to firstly comprehend and retain the information presented, secondly, be able to believe that information, and thirdly, be able to weigh that information in the balance to arrive at a choice. Murphy and Clare (1995) make the point that most situations where consent is assessed in people with LD, the criteria are set very high, perhaps causing a situation where more people are deemed incapable of giving consent than the true number would be if a different and more sensitive form of assessment were used. It can therefore be seen that capacity is an aspect of consent which is closely linked to both the issues of information and voluntariness. Whether capacity to consent can be assessed, and indeed whether it should be assessed, will be discussed later in this essay.

Communication

There is a widespread misunderstanding that valid consent can only be communicated by physically signing a statement (Fovargue, Keywood & Flynn, 2000; Hart, 2001). This misunderstanding has led to situations where people's mothers or husbands have signed consent forms on their behalf, as the clients involved could not write (Hart, 2001).

The DoH's (2001) guidance on seeking consent from people with LD makes it clear that, legally, it makes no difference whether people sign a form to indicate their consent, or whether they consent verbally, or even non-verbally.
It is clear that a client’s consent can be communicated in any way, and it is the responsibility of health and social care professionals to ensure that every opportunity for the client to communicate that consent is made available. The provision of non-familial interpreters for people who do not have English as a first language should be considered as vital in facilitating communication, especially as there may be familial pressures to act in a way that does not coincide with the client’s wishes (Nadirshaw, 1997).

**Why is it important to assess consent in people with LD?**

Perhaps the most important reason to assess capacity to consent in people with LD is to maximise rights to both liberty and personal freedom and to protection from torture, inhuman, or degrading treatment as laid out in the Human Rights Act (Lord Chancellor’s Department, 1998). The Human Rights Act became law in Britain on 2nd October 2000 (British Institute of Learning Disabilities, 2001). It is significant that this coincided with continuing efforts by providers of services for people with LD to move residents out of long stay institutional settings and into more integrated, community residential placements. As people with LD move into the community, their lives become more normal, and the number of occasions on which they are required to make decisions increases (Adshead, Sellars, Males, Haywood & Ross, 2001). This indicates that it is important to consider consent in terms other than for medical treatment. People with LD should be able to exercise choice over where and with whom they live, who provides their care, what they eat, and many other aspects of their lives. As services move towards allowing people with LD more autonomy, it will be increasingly important to consider issues of consent. However, in the context
of normality, one could question the normality of having capacity assessed for every significant decision made (Gelsthorpe, 1995; Wong, 1997).

‘Seeking consent is part of a respectful relationship with people with learning disabilities...’ (DoH, 2001, p.3).

It is also the law.

Achieving the balance between protection of freedom of choice and freedom from degrading treatment is very important. The current legal position is that no adult is considered incapable of giving consent unless proved so (Chahal & Morris, 2000a and 2000b). Therefore, there is an assumption of capacity in all cases. It should be remembered that, although most research and discussion focuses on assessment of capacity to consent, there is also the issue of capacity to withhold or to withdraw consent, an issue which is often overlooked. Hart (2001) reports a situation where a person with LD was assessed as able to consent, but whose subsequent attempts to withdraw that consent were ignored.

A further reason to assess capacity to consent in people with LD is to protect the professionals involved in that person’s care. The clinician must have freedom to make appropriate decisions, confident of remaining ‘not only within the limits of good practice but also having the protection of the law’ (Hillery et al, 1998, p.117). This is especially true where a person is withholding consent for a procedure – because if that person were in fact incapable of giving consent, the professionals would be guilty of neglect if the procedure were not carried out. Equally, the professionals would be
guilty of assault if the person was capable of giving consent and yet the procedure was carried out against the person’s wishes.

Particularly pertinent to assessing capacity to consent in people with LD is the issue of differential ability. Within the general population, one can assume, to some extent, that a basic level of understanding exists. However, this is not the case for people with LD; ability within the learning-disabled population can vary from only slightly below that of the general population to an extremely impaired individual who perhaps does not have the capacity for expressive language. Within such a wide range of ability, no sweeping decisions or generalisations can be made, and as such, individualised assessments of capacity to consent are imperative.

How can consent be assessed in people with LD?

It could be argued that the assessment of consent in people with LD focuses almost exclusively on the assessment of capacity — the domains of voluntariness and accessibility of information have little attention paid to them. Perhaps one reason for this could be that these other dimensions of capacity vary so greatly among people with LD. For example, written information would be accessible to some people with LD, but not others. With regard to voluntariness, as discussed earlier, there are so many lifestyle variables, including cultural, religious, gender, and age-related norms and place of residence, affecting ability to exercise choice that any assessment of this dimension would need to be so far reaching as to be impractical. This discussion of how consent can be assessed in people with LD, then, will focus on how capacity can be assessed.
The DoH (2001) highlights the fact that assessment of capacity can be affected by organisation pressures such as time or availability of particular professionals. However, it is made clear that it is vital that people are given every opportunity to exercise consent, and that it is a professional responsibility to ensure that people are assisted to maximise their consent.

A central concept in assessing capacity to consent in people with LD is the fact that it is not a static trait. A person may be able to consent to some things, but not others. Additionally, a person may be able to give valid consent at one point in time, but not at another. The role of strong emotions has been discussed as playing a role in this. Schwehr (2002) suggests that pain, shock, fatigue and fear are particular emotional states that can temporarily affect an individual’s capacity to consent. Someone experiencing a high level of fear, perhaps due to a phobia, may refuse to consent to a procedure on the basis of that fear alone, and not on the basis of any rational decision making process, despite having the ability to make such a decision (Moorhead & Turkington, 2002). A High Court ruled (Re MB, 1997) that a person had been rendered incapable of consent to a blood test due to a needle phobia, and that the physicians involved had acted appropriately by sedating that person in order to take blood. This is an area which needs much attention in people with LD, due to their often restricted life experiences (Arscott, Dagnan & Stenfert Kroese, 1999; Harris, 2003; Lancioni, O’Reilly, & Emerson, 1996), and the possible fear that could be engendered when faced with unusual and potentially threatening situations, such as a first visit to hospital for treatment.
Arscott (1997) and Wong, Clare, Gunn and Holland (1999) outline three approaches which have been used to determine an individual’s capacity to consent: diagnostic, outcome and functional. The diagnostic approach assumes capacity, or otherwise, on the basis of an individual’s diagnostic status. This approach is simple and easy to apply, but pays little attention to the spectrum of abilities and the differential requirements for consent in diverse situations. One situation where this approach is applied is in relation to sexual activity. The 1956 Sexual Offences Act states that it is illegal to engage in sexual activities with a ‘mental defective’ (a person whose IQ is under 55), as that person is deemed incapable of consenting to sex due to their LD. Obviously, this legislation is meant to protect the vulnerable adult, but can cause difficulties in borderline cases.

The outcome approach suggests that capacity to consent should be based on the severity of the outcome of the decision, and how reasonable health professionals think that decision is. Drane (1984) proposed a sliding scale model with which to apply this approach. In this model, the severity of the issue to which the individual is consenting is assessed, and allocated to one of three standards – least restrictive, intermediate, or most restrictive. The least restrictive standard requires the individual to be aware of the situation, but not to meet any standard of understanding. This would apply to routine decisions that pose little or no risk, such as having a blood test. The intermediate standard requires the individual to be aware of risks and benefits involved in the options available, and to be able to make a choice based on these. This standard would apply to non-routine decisions such as surgery where the procedure is invasive, and may be dangerous or ineffective. The most restrictive standard requires the individual to give thoughtful reasons for their decision based on
their personal values and available evidence. This standard would apply to life-threatening or irreversible decisions. As personal values are central to this approach, a good understanding of the client’s background is needed. This could be more difficult where the cultural upbringing of the client and the professional differ. Nadirshaw (1997) points out that it is important for services to understand and become more responsive to diverse cultural and religious needs. This is particularly important where professionals are involved in assessing consent issues for clients.

The outcome approach errs on the side of protecting the client, but is perhaps a little patriarchal, allowing the subjective judgements of health professionals to impose their personal judgements on the client. It is clear that this approach is used frequently in practice, even though it may contravene an individual’s right to self determination.

The functional approach is the approach most frequently applied in English law (The Law Commission, 1991). It is based on establishing an individual’s functional abilities, capacities and behaviours in relation to the demands of a particular decision and a particular situation. This is the approach where the individual’s ability to understand and retain relevant information, be able to weigh that information to come to a decision, and to be able to communicate that decision is assessed. Some of the issues involved in assessing these areas have already been discussed.

The question that remains, however, is how these dimensions could be best assessed. There are a number of assessment measures that have been developed to attempt to assess the capacity to give informed consent in vulnerable adults. These include The Knowledge and Understanding Test (Annas & Densberger, 1984; in Arscott, 1997),
The Competence Interview (Searight, 1992; in Arscott, 1997), The Consent Screening Interview (Lindsey, 1994), and the MacArthur Competence Assessment Tool (Grisso, Appelbaum & Hill-Fotouhi, 1997). However, these assessment schedules have all been developed for use with vulnerable adults generally, not for adults with a LD. There is clearly a need for such an assessment schedule to be generated for use with people with LD. There has been some progress in this area. Morris, Niederbuhl and Mahr (1993; in Arscott, 1997) developed an assessment which required people with LD to consider vignettes, and a series of questions were asked to assess the individual’s capacity to consent in each of the situations. Arscott et al (1999) have attempted to adapt this framework for use in practice rather than research, but further developments are still needed.

It is important to realise that not everyone is familiar with the ‘sit-down’, one-to-one assessment process, due to their life experiences. Hatton (1998), points out that the concept of LD is socially constructed, and so societal factors such as cultural and linguistic diversity must be taken into account when it is assessed. He further highlights that exposure to mainstream educational environments will differ according to age, cultural background, family values, and service availability, and that this may influence test performance, causing people to perform below their actual level of ability. This could have profound implications on decisions about these people’s ability to consent.

Deciding whether or not a person has capacity to consent in a particular situation has far reaching consequences for that person. Hillery et al (1998) ask whether individual clinicians would be happy to use standardised assessments to make a significant
decision. There is also the question of whether a standardised questionnaire or interview schedule would be applicable to all situations in which a person could be required to consent, rather than just within the medical arena. It also raises the difficult questions of borderline cases, and labelling. A label, once attached to a person, can stay with them for a long time (Haghighat, 2001) especially when it is based on the outcome of a standardised assessment. A conclusion of incapacity to consent to a decision at one point may well prejudice future assessments of that capacity.

Arscott et al (1999) state that any schedule for assessing capacity would need to allow for deficits in verbal ability, memory, problem solving, comprehension and inferential reasoning that people with a LD often experience. They also point out that any such schedule would need to make allowances for the tendency towards acquiescence and suggestibility that is often a trait of people with LD. Assessment packages would also need to be sensitive to cultural differences in what is appropriate to discuss with the client. One important consideration is the acceptability of talking openly about consent issues, particularly where sexual activity is concerned. Malhotra and Mellan (1996) note that most sexual consent packages adopt a feminist perspective, and this may not be acceptable to people from a culture where submissiveness is valued in women. Hepper (1999) further points out that in some cultures, discussion of sexuality and sexual issues is taboo, and viewed as shameful.

Although there are obvious risks in developing a measure to assess capacity to consent, it could be argued that there is a growing need for a universally accepted and
legally correct protocol as more and more clinicians, including clinical psychologists, are called upon to make decisions about the capacity of clients.

What if a person is assessed as unable to consent?

What should happen when a person is assessed as unable to consent has been the subject of much recent debate (Booth, 2002; Kramer, 2002; Matthews, 2003; Murphy, 2001). The DoH (2001) reinforces the legal fact that no one can give consent on behalf of adults who are not capable of giving consent for themselves, and states that the professional can only proceed with the treatment or care if it is in the person’s best interests. Adshead et al (2001) recognise that, although practitioners may feel they are contravening Article 5 (the right to liberty and personal freedom) of The Human Rights Act (Lord Chancellors Department, 1998) by acting without consent, Article 3 states that people have the right to freedom from torture, inhuman or degrading treatment; and what could be more inhuman than refusing to treat someone or failing to act in their best interests? Chahal and Morris (2000b) emphasise that the legal position needs to be clarified with regard to what exactly best interests are, but note that the concept of best interests stretches further than physical well-being into areas such as place of residence and access to family. Best interests would also need to acknowledge and provide for cultural or religious needs. This is echoed by the DoH (2001), who state that

Other factors, such as their general well-being, their relationships with those close to them, and their spiritual and religious welfare, should all be taken into account. (p.11)
Again, this is a far reaching definition, extending well beyond the arena of medical treatment that has received such a great deal of attention. There is clearly a need for more research and discussion to draw up guidelines on which a judgement can be made regarding best interests in a non-medical treatment situation.

Conclusions and Implications

A number of issues have been identified in this essay. Perhaps the most imperative is that guidance from government similar to The Adults With Incapacity (Scotland) Act (Her Majesty’s Stationary Office, 2000) is needed to protect both professionals and clients in situations where consent cannot be given due to lack of capacity. Guidance is also needed on how to and who should assess capacity to consent in non-healthcare decisions. An important aspect of any legislation would be to achieve the delicate balance between protecting an individual who is unable to consent whilst protecting their right to exercise choice where they can (Chahal & Morris, 2000b). The role here is perhaps primarily for the legal profession, but consultation from the professionals and family carers who would be affected by such legislation would be an integral part of making such legislation useful, useable, and acceptable.

Perhaps the most important and overarching issue is the fact that assessment of consent in people with LD is not the domain of a single professional grouping. In healthcare treatment decisions, current guidance, vague though it is, states that it is the professional conducting treatment that should confirm consent can be given, or not, and if not, to act in the client’s best interests. However, it is clear that there are
situations other than healthcare decisions that require consent. These include sexual relationships, where to live, who to spend time with, and even whether or not to have a haircut (Stalker & Harris, 1998). It is clear that every health and social care professional, every care worker and every family member and friend has a role to play in assisting with and assessing consent in these non-healthcare decisions.

Another issue is that of information giving. Evidently, information needs to be given in a variety of different mediums, (verbal, written, pictorial) and in a variety of different languages to enable people to make an informed choice. However, the standard information used within the general population, and the way it is delivered is not adequate for at least some people with LD (Strydom et al, 2001). In practice, this means that more investment – in terms of both money and time – is needed to help people with LD access and understand information relating to decisions in which their consent could be sought (Adshead, 2001). In achieving this, there seems to be a primary role for speech and language therapists, but also for every other health or social care professional who is involved in giving information, or in developing client information packs.

Another issue is the fact that people with LD, especially if not living independently, have little day-to-day experience of autonomy in making decisions or lifestyle choices (Arscott, Dagnan & Stenfert Kroese, 1999; Harris, 2003). Hillery et al (1998) suggest that theoretical and experiential training in decision-making should become part of the care plan for every person with a LD, hoping that this would enhance capacity to consent. There is a role for everyone involved in the care and support of people with LD to facilitate autonomous day-to-day experiences. Ground-level staff would need
to ensure that opportunities to exercise true autonomy over day to day decisions are offered – obviously to the extent of the client’s abilities. Management and service providers would need to ensure that their services are set up in a way that allowed autonomy to be exercised by clients. This would require a departure from current service provision models, where real choice is often limited in areas such as daytime activities or choice of residence as a result of block contract purchasing (Stalker & Harris, 1998).

A further concern is how should consent be assessed, and who should assess it in which situation. It is clear that guidance from government is needed to clarify this issue, and that further research into standardised assessment packages by health and social care professionals, especially clinical psychologists, is needed. However, the development of such packages could create as many difficulties as it solved, as standardised packages with cut off scores can be misused, and the issue of borderline scores on such packages is always a difficult one.

In conclusion, the issues surrounding assessing consent in people with LD are complex ones affecting a great many professional disciplines. More research, time, resources and attention need to be given to them in order to reach a useful and legal consensus which would protect both the client from abuse of human rights and the professional from litigation.
REFERENCES


CAF Essay

Submitted March 2004

What developmental and psychological theories could explain Asperger’s syndrome and what implications do these have for assessment and intervention?
This essay will first attempt to reach a working definition of Asperger’s syndrome — most specifically in its distinction (or otherwise) from high functioning autism. Current opinion and recent research on the underlying causes of Asperger’s syndrome will then be discussed. This will focus on cognitive and neuropsychological/biological theories. From these causative theories, implications for assessment and treatment will be discussed. Some attempt will be made to distinguish that which is clinically relevant from that which is purely academically interesting.

What is Asperger’s syndrome?

The Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV, American Psychiatric Association, 1994) sets out the diagnostic criteria for Asperger’s syndrome as:

A. Qualitative impairment in social interaction, as manifested by at least two of:
   (1) Marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
   (2) Failure to develop peer relationships appropriate to developmental level.
   (3) A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g. by a lack of showing, bringing or pointing out objects of interest to other people).
   (4) Lack of social or emotional reciprocity.
B. Restricted repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following:

(1) Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.

(2) Apparently inflexible adherence to specific, non-functional routines or rituals.

(3) Stereotyped and repetitive motor mannerisms (e.g. hand or finger flapping or twisting, or complex whole-body movements.

(4) Persistent preoccupation with parts of objects.

C. The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D. There is no clinically significant general delay in language (e.g. single words used by age 2, communicative phrases used by age 3 years).

E. There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behaviour (other than in social interaction) and curiosity about the environment in childhood.

F. Criteria are not met for another specific Pervasive Developmental Disorder or Schizophrenia.

The World Health Organisation’s (1993) diagnostic criteria specify the same pattern of difficulties. However, despite there being diagnostic criteria for Asperger’s
syndrome in both the major diagnostic manuals, as well as numerous other suggested
diagnostic criteria – for example, Gillberg’s (1989) criteria, Tantam’s (1988) criteria,
and Szatmari, Brenner and Nagy’s (1989) criteria – there is widespread debate as to
whether or not Asperger’s syndrome should be considered distinct from High
Functioning Autism (HFA) (Gillberg & Ehlers, 1998; Schopler, 1996; Wing, 1991). It
should be remembered that, as the diagnostic criteria for Asperger’s syndrome rely on
deviation from societal norms of development and behaviour, that it is possible
definitions will vary within and between cultures.

Many researchers argue that Asperger’s syndrome and HFA do not differ in term of
distinctive, independent features, but only in the degree of impairment (Freeman,
Cronin & Candela, 2002; Ozonoff, South & Miller, 2000; Prior, Eisenmajer, Leekam,
Wing, Gould, Ong, & Dowe, 1998; Schopler, 1996; Wing, 1991), whereas others
would assert that Asperger’s syndrome and HFA are indeed distinct, on the basis of
neuropsychological, neuroimaging and behavioural data (David, David & Riley, 2003;
Klin, Volkmar, Sparrow, Ciochetti & Rourke, 1995; Klin & Volkmar, 2003; Volkmar,
Klin, Schultz, Rubin & Bronin, 2000). Even where differences have been found,
some would argue that these differences are due to the diagnostic criteria assigning
less impaired individuals to the Asperger’s syndrome diagnostic category, and the
more impaired individuals to the HFA diagnostic category (Howlin, 2003; Ozonoff,
South & Miller, 2000).

The more typical approach, at present, is to see Asperger’s syndrome within the
spectrum of pervasive developmental disorders, resting between autism and normalcy
(Klin & Volkmar, 2003), and this is the working definition that will be used for the
remainder of this essay. Certainly, the difficulties presented clinically by people with a diagnosis of Asperger’s syndrome and a diagnosis of high functioning autism are so similar in type and extent (Howlin, 2003; Szatmari, 1998) that differentiating intervention on the basis of either of these diagnoses would be redundant (Willemsen-Swinkels & Buitelaar, 2002).

**What theories could explain Asperger’s syndrome?**

There is little disagreement that Asperger’s syndrome, and other disorders of intuitive social competence, have a significant genetic component (David, David & Riley, 2003), with a recurrence rate of between three and eight percent in families (Raplin, 1997). Specifically to Asperger’s syndrome, up to 33% of first degree relatives of individuals with Asperger’s syndrome have social difficulties (Volkmar, Klin & Pauls, 1998). Ciaranello and Ciaranello (1995) suggest that many epidemiological studies of social and communication disorder underestimate recurrence rates due to the tendency to have no further children after the birth of a child with autistic spectrum difficulties, however, no studies have addressed this stoppage rule directly, and given the average age at which difficulties are identified (21 months old for Asperger’s syndrome and 15 months old for high functioning autism; Howlin, 2003), the extent to which this could have an effect is questionable.

There have been a number of explanations for Asperger’s syndrome, and other autistic spectrum disorders, put forward by various authors. The main theories fall broadly into two categories – cognitive and neurological. Evidently, these categories do not
Cognitive: Theory of Mind

An early cognitive explanation for the social deficits associated with autistic spectrum disorders was the concept of theory of mind deficits. An intact theory of mind would enable an individual to attribute beliefs to another person and use the knowledge of these beliefs to understand, explain, and predict the other person’s behaviour (Baron-Cohen, Leslie & Frith, 1985, 1986). A number of attributional false-belief tasks were developed in order to attempt to assess theory of mind. The simplest tasks assessed first-order theory of mind - that is to say the ability to understand that other people can hold false beliefs about the world and that their behaviour can be predicted on the basis of these false beliefs, rather than what is actually true. More able individuals with autistic spectrum disorders were able to succeed at these first order tasks (Baron-Cohen et al, 1985). More difficult false-belief tasks, assessing second-order theory of mind, have proved more difficult for able individuals with autistic spectrum disorders (Baron-Cohen, 1989). A second order theory of mind would enable an individual to predict a person’s behaviour on the basis of that person’s false belief about another person’s true belief about a state of affairs.

Suggestions that individuals with Asperger’s syndrome completely lack a theory of mind seem unsupported by evidence. For example, Baron-Cohen et al (1985, 1986) and Bowler (1992) found that some participants with higher functioning autistic spectrum disorders or Asperger’s syndrome were able to perform well on first order
theory of mind tasks. Bowler (1992) in fact, found no significant difference between individuals meeting diagnostic criteria for Asperger’s syndrome and normal population controls in success with second order false belief tasks. Rather, it is suggested that people with Asperger’s syndrome do not lack a theory of mind – rather, they develop one later in development than normal, and that this might be later than a critical threshold for normal theory of mind attuning (Baron-Cohen, 1989; Blackshaw, Kinderman, Hare & Hatton, 2001; Bowler, 1992). This untuned theory of mind will have missed a critical period of normal development and therefore the person with Asperger’s syndrome will struggle with the less obvious subtleties of social interaction (Blackshaw et al, 2001). Support for the late development of theory of mind in Asperger’s syndrome, rather than its absence, exists in more recent longitudinal studies (Nordin & Gillberg, 1998; and Szatmari, Bryson, Boyle, Streiner & Duku, 2003).

Evidence supports the idea that individuals with Asperger’s syndrome do not totally lack a theory of mind, rather that it is not fully and normally functional. Blackshaw et al (2001), Bowler (1992), Happe (1995) and Hillier and Allinson (2002) all suggest that individuals with Asperger’s syndrome do use their theory of mind, but in a structured, after the fact problem solving manner, rather than in an intuitive manner, and it is this lack of naturalness that leads to awkwardness in social situations. Frith (1989), and Frith and Happe (1994), however, point out that there is more to autistic spectrum disorders than the classic triad of impairments which can be explained by theory of mind difficulties. They draw attention to a number of characteristics, including a restricted repertoire of interests and preoccupation with parts of objects (both of which are necessary for a DSM-IV (APA, 1994) diagnosis), which cannot be
explained by theory of mind difficulties. Instead, they suggest that there might be an underlying weak central coherence underlying many of the difficulties experienced by people with autistic spectrum disorders.

*Cognitive: Central Coherence*

The underlying idea in central coherence theory as an explanation for autistic spectrum disorders is that both assets and deficits spring from a single cause at the cognitive level. Frith (1989) proposed that autism is characterised by an imbalance in integrating information at differing levels. She suggested that normal information processing was characterised by a tendency to draw together diverse information to construct higher level meaning within a context. This drawing together of information and context to create meaning were what she termed central coherence. This theory suggests that autistic individuals would be better at tasks requiring attention to local detail than they would be at tasks requiring the recognition of global meaning. Frith and Happe (1994) stress that rather than a deficit, weak central coherence should be viewed as a cognitive style, with as many positive and negative attributes as would be found with strong central coherence. They highlight the evolutionary benefits of good theory of mind abilities, and as such, suggest that theory of mind and central coherence theory should be viewed as two very distinct cognitive underpinnings of autistic spectrum disorders.

Evidence for the theory of weak central coherence as a cognitive style in autistic spectrum disorders is emerging in family and sibling studies (Briskman, Happe & Frith, 2001; Happe, Briskman & Frith, 2001). In both experimental assessments
(Happe et al, 2001) and real life self report of social and non-social preferences and activities (Briskman et al, 2001) among the families of children with autism, evidence of a familial phenotype of weak central coherence was found. Specifically to high functioning autism and Asperger’s syndrome, Jolliffe and Baron-Cohen (2000) explored global coherence in linguistic processing in comparison to normal controls, and found that the two clinical groups were less able to use context to make global inference. Weak central coherence as a potential explanation for autistic spectrum disorders is still generating research. Mottron, Burack, Iarocci, Belleville and Enns (2003) found weak central coherence assessed through measures of hierarchical processing could not differentiate between individuals with autistic spectrum disorders and their typically developing peers on some of those measures. This does not necessarily cast doubt on the usefulness of this theory in explaining Asperger’s syndrome, however, as the theory was originally postulated as a cognitive style present to greater and lesser degrees in the general population, rather than a pathology specific to the autistic spectrum.

Certainly, considered together, theory of mind deficits and weak central coherence synthesise a plausible cognitive basis for the lack of understanding in Asperger’s syndrome.

Cognitive: Executive Functioning

Whether deficits in executive functioning as an explanation for Asperger’s syndrome is a separate idea from either or both theory of mind or weak central coherence theory
is questionable. The term ‘executive function’ covers a multitude of higher cognitive functions and so is likely to overlap somewhat, if not completely, with both theory of mind and central coherence theory. In essence, the idea of individuals with Asperger’s syndrome exhibiting deficits in executive function suggests that it is an inability to organise (similar to weak central coherence) and interpret information in an appropriate way, but also an inability to inhibit or regulate response. It is suggested that the inability to organise and interpret information could underlie the tendency of individuals with Asperger’s syndrome to misunderstand complex social information, and to attend more to parts rather than wholes. It is also suggested that the inability to inhibit or regulate responses underlies the tendency of individuals with Asperger’s syndrome to perseverate with particular topics of conversation, and also to make socially inappropriate comments.

Much research has been carried out focussing on this area, with mixed results. Shu, Lung, Tien and Chen (2001) compared executive functioning as measured by a card sort in children with high functioning autism with their normally developing peers, and found that the high functioning autism group had significantly more difficulty than their typically developing peers. Manijivonia and Prior (1999) compared the executive function of a large sample of children with high functioning autism with a sample of children with Asperger’s syndrome and concluded that, although both groups showed impairments, they did not differ significantly from one another. Rinehart, Bradshaw, Moss, Brereton and Tonge (2001) and Rinehart, Bradshaw, Tonge, Brereton and Bellgrove (2002) demonstrated that, in a variant Stroop task where the conflicting stimuli are an emotional descriptor and a face depicting an emotion, individuals with Asperger’s syndrome have difficulty inhibiting their pre-
potent response, which is to read the word. This is interesting evidence, as it supports not only the central executive theory of Asperger’s in that it shows lack of organisation and inhibitory control, but also the theory of mind assumption, as it demonstrates the preference of individual’s with Asperger’s syndrome to deal with factual information as preference to socioemotional information.

Cognitive: Summary

This essay has not provided an exhaustive description and evidence base for all the variants and nuances of the cognitive theories which have been suggested as explanations for Asperger’s syndrome. However, the three main domains, theory of mind, weak central coherence, and executive function deficit have been discussed. These three positions are not mutually exclusive – all could be contributing to one or more aspects of the presentation of Asperger’s syndrome. Whilst beginning to understand the cognitive profile of Asperger’s syndrome permits theorising and research and is of academic interest, it does not answer the question of where the cognitive deficit originated. To understand the origins of these cognitive deficits, one must look to more neurodevelopmental and biological explanations.

Neurodevelopmental/Biological: Social Brain Theory

Brothers (1990) suggested a neural basis for social intelligence which came to be termed the social brain theory. She synthesised evidence from a number of neurological studies on both animals and humans and suggested that the amygdala, orbito-frontal cortex, and superior temporal gyrus together comprise the social brain.
Baron-Cohen, Ring, Wheelwright, Bullmore, Brammer, Simmons and Williams (1999) used functional magnetic resonance imaging (fMRI) to compare the brain activity of individuals with Asperger’s syndrome or high functioning autism with normal controls whilst attempting a task which required the participant to identify the thoughts or feelings of another person by looking just at the eyes. Baron-Cohen et al (1999) found that, although the orbito-frontal cortex and superior temporal gyrus were activated during this task in all groups, only the normal controls showed activation in the amygdala during this task. Baron-Cohen et al (1999) suggest that this is evidence for Brother’s (1990) social brain theory in general, and the amygdala theory of autism specifically, which suggest that it is the failure of the amygdala in the social brain network which causes the impairments in socioemotional interaction that characterise autistic spectrum disorders (Baron-Cohen, Ring, Bullmore, Wheelwright, Ashwin & Williams, 2000).

Neurodevelopmental/Biological: Sensorimotor Gating

McAlonan, Daly, Kumari, Critchley, van Amelsvoort, Suckling, Simmons, Sigmundsson, Greenwood, Russell, Schmitz, Happe, Howlin and Murphy (2002) have proposed a sensorimotor gating theory as an explanation of deficits found in Asperger’s syndrome, specifically the inability of people with Asperger’s syndrome to inhibit repetitive thoughts, actions and dialogues. They compared brain anatomy and sensorimotor gating in people with Asperger’s syndrome and matched controls. Significantly, they found that sensorimotor gating was significantly impaired in individuals with Asperger’s syndrome. Other interesting findings from this study included age-related reductions in volume of cerebral hemispheres and caudate nuclei.
in controls but not people with Asperger’s syndrome, and that people with Asperger’s syndrome had significantly less grey matter in fronto-striatal and cerebellar regions, and widespread differences in white matter. McAlonan et al (2002) hypothesised from these findings that Asperger’s syndrome was associated with abnormalities in fronto-striatal pathways resulting in defective sensorimotor gating, and consequently characteristic difficulties inhibiting repetitive thoughts, speech and actions.

An Integrated View

It could be argued that no single theory as yet can fully explain the quantitative and qualitative impairments found in Asperger’s syndrome, and yet all theories discussed meaningfully explain at least some of the characteristics. Cognitive and neurodevelopmental/biological theories which have been suggested to explain Asperger’s syndrome are complementary rather than exclusive to one another. An understanding of organic differences between individuals with Asperger’s syndrome and the typical population will help to advance causative understanding on a tangible, scannable level; whilst an understanding of differences on a functional, cognitive level will help advance understanding of the specific difficulties these individuals face in day to day life, in trying to make sense of the social world around them, and in trying to process complex information. Thus, it seems sensible to understand the lack of theory of mind in light of the lack of amygdalic involvement in emotion recognition, and the executive function lack of inhibitory control in the light of impaired sensorimotor gating. It seems that greater cooperation between the cognitive theorists and neuropsychological theorists would lead to more encompassing, common-sense explanations of Asperger’s syndrome.
What implications do these have for assessment?

It is striking that, although the theories which have been put forward to explain Asperger’s syndrome cover cognitive, neuropsychological, and biological aetiologies, current diagnostic criteria and assessment schedules for Asperger’s syndrome are based exclusively on observable, behavioural characteristics. It could be argued that, regardless of theorised aetiology, the presentation of Asperger’s Syndrome is the same, in that the individual with Asperger’s Syndrome will experience a qualitative impairment in social interaction, and that this should remain the focus of assessment. However, there is value in our growing understanding of the causes of Asperger’s syndrome, and it could equally be argued that this knowledge should begin to be integrated into the way clinicians diagnose Asperger’s syndrome. Szatmari (1998) suggests that more emphasis should be put on the cognitive and neuropsychological aspects of Asperger’s syndrome as accessory diagnostic tests. However, discussion of assessment of Asperger’s syndrome may be premature as there is currently much debate as to whether or not the current diagnostic criteria for Asperger’s syndrome are accurate, or even whether Asperger’s syndrome is distinct from other autistic spectrum or pervasive developmental disorders (Howlin, 2000).

Current assessment for Asperger’s syndrome should include assessment of the individual’s cognitive and neuropsychological profile as well as assessment of their strengths, weaknesses and individual level of functioning. It seems clear from the evidence supporting some very different aetiological theories of Asperger’s syndrome that Asperger’s syndrome is a pervasive syndrome, operating on many levels – from
the neuroanatomical, through cognitive, and into behavioural arenas, and this breadth of impact would render any narrowly focussed assessment clinically meaningless.

Howlin (2000) in a recent review of assessment instruments for Asperger’s syndrome remarks upon the striking paucity of such instruments, and the lack of adequate standardisation for those that do exist. She reflects that a major factor contributing to this is the confusion inherent in established diagnostic systems in differentiating Asperger’s syndrome from high functioning autism and nonverbal learning disability. As discussed earlier, it is not clear from neuropsychological, cognitive, clinical or behavioural data that Asperger’s syndrome (as delineated by the diagnostic systems currently in place) is truly distinct from other pervasive developmental disorders. What is clear is that there is a group of individuals who are falling outside of the typical population experience of the social world, and whose characteristics need to be understood better by professionals in order to be able to offer appropriate support.

Clearly, diagnostic consensus needs to be reached in order to clarify the position, or existence, of Asperger’s syndrome with regard to other pervasive developmental disorders. This is important not only in terms of providing a sound base for research and clinical understanding, but also in terms of commissioning of services and provision of support for the individuals whose characteristics could be understood as Asperger’s syndrome.
What implications do these have for intervention?

One could argue that no matter what the underlying genetic, biological, neurological or cognitive reasons for Asperger's syndrome, the social impairment and desire for sameness which is characteristic of Asperger's syndrome is present and causing difficulties for the individual. As such, practically useful interventions will be those which will help the individual feel more comfortable in social situations, or which will help the individual be more acceptable and therefore not so persecuted or bullied.

Current intervention strategies for people with Asperger's syndrome focus mainly on teaching social skills and strategies for dealing with the stress, frustration and anger associated with being an intelligent individual existing in a social world which is beyond comprehension.

Implications for Treatment: Cognitive

Attwood (2000), however, pointed out that whilst the difficulties of social interaction for individuals with Asperger's syndrome are well documented, there is little evaluation of the strategies designed to overcome them. There has since been more evidence published supporting the efficacy of social integration strategies for individuals with Asperger's syndrome. Attwood (2000) outlines several strategies which have proved useful in working with individuals with Asperger's syndrome. He outlines a psychoeducational component, mainly for the benefit of the individuals family, in order to help them to understand the particular set of characteristics present in their relative. This has, obviously, grown in scope as our professional understanding of Asperger's syndrome has expanded. Given that deficits in theory of
mind are demonstrated to be present in Asperger's syndrome, Attwood (2000) suggests that a specific component in an intervention would be teaching these skills. Some success has been reported in using concrete metaphors to achieve this. Swettenham, Baron-Cohen, Gomez and Walsh (1996) reported successfully using the metaphor of the mind as a camera, whereas McGregor, Whiten and Blackburn (1998) employed a teaching method where a picture was physically put inside a doll's head. Another technique which has been successfully reported is the use of thought bubbles (Parsons & Mitchell, 1999).

The cognitive theories which can be suggested as explaining Asperger's syndrome centre around underdeveloped cognitive abilities – theory of mind, central coherence, and executive function. As such, it seems appropriate that intervention strategies should focus on teaching these. Many of the social skills training programmes include, to some extent, attempts to teach theory of mind, or a facsimile thereof (Barnhill, Tapscott Cook, Tebbenkamp & Myles, 2002; Broderick, Caswell, Gregory, Marzolini & Wilson, 2002; Spence, 2003).

Blackshaw et al (2001) highlight the growing awareness of the need to develop more appropriate clinical intervention for people with Asperger's syndrome. Hare and Paine (1997) outlined three interventions which have been successfully used with people with Asperger's syndrome – general counselling, personal construct psychology, and cognitive behaviour therapy. However, there is no single psychotherapeutic approach that appears to be generally efficacious with this population (Blackshaw et al, 2001) – possibly due to the heterogeneous nature of what
is currently considered to be Asperger's syndrome, and the blurred boundaries of diagnosis.

Given the concept of theory of mind as a cognitive structure which develops later in people with Asperger's syndrome than in the general population, therapy centred around helping the individual with Asperger's syndrome to develop fully this interpretative ability could be beneficial. Blackshaw et al (2001) suggests that schema-focussed cognitive therapy could be beneficial in this area. They suggest that schema-focussed cognitive therapy, because of its focus on themes, would be helpful to individuals with Asperger's syndrome. If social interaction and rules, emotional understanding, and reciprocal relationships are considered themes for which individuals with Asperger's syndrome do not have functioning schemata, whether due to late developing theory of mind or other reasons, then therapy focussing on developing functional schemata would be indicated.

Blackshaw et al (2001) point out that any form of cognitive therapy with people with Asperger's syndrome requires adaptation to the client group, due to the social ideas of these individuals affecting the nature of the client-therapist relationship.

Most of the evidence to date has supported the use of strategies attempting to develop the individual’s theory of mind abilities. There is much less available attempting to address the other cognitive differences found in individuals with Asperger’s syndrome. Recently, Dunn, Saiter & Rinner (2002) have outlined a conceptual model for intervention planning around the Asperger's syndrome characteristic of difficulty with sensory processing (central coherence). More, or more evidence to support
interventions addressing cognitive aspects of Asperger's syndrome other than theory of mind are needed. The cognitive evidence supporting central coherence theory, theory of mind, and executive functioning theory in Asperger's syndrome suggest that no single one of these ideas can fully explain the pattern of characteristics. The clinical implications are that strategies to remediate these other aspects are needed in addition to strategies addressing theory of mind deficits.

Neurodevelopmental/Biological

With regard to intervention, there are currently no known pharmacological interventions yet proven to have any effect on the underlying impairments of Asperger's syndrome (Blackshaw, Kinderman, Hare & Hatton, 2001), despite growing knowledge of the neuropsychological underpinnings, although as knowledge of the neurochemical and structural differences between Asperger's syndrome grows, more advances in this arena may follow. Willemsen-Swinkels and Buitelaar (2002) report possibilities for use of agents which act on the serotonin neurotransmitter system, based on evidence of abnormalities in whole blood serotonin levels in some individuals with autistic spectrum disorders.

It is, however, significant that Asperger's syndrome has been demonstrated to have several underlying neuroanatomical abnormalities, and in much the same way as for cognitive explanations, interventions must allow for the fact that the brain of an individual with Asperger's syndrome is structured differently and works differently to that of a person without Asperger's syndrome.
Conclusions

There have been many explanations for Asperger’s syndrome suggested, mainly focussing on cognitive and neuroanatomical/neurochemical differences between individuals with and without Asperger’s syndrome. Nevertheless, the main diagnostic criteria outline purely behavioural and observable characteristics. In the light of growing evidence to support aetiological theories of autism, surely some changes to the diagnostic understanding need to follow.

In a similar vein, mainstream assessment and intervention techniques tend towards the behavioural, in terms of skills training, and yet cognitive theories attempting to explain Asperger’s syndrome suggest that there are very real cognitive deficits — in terms of theory of mind, central coherence, and executive functioning. Psychology, and clinical psychology in particular has much to offer in terms of neuropsychological rehabilitation or remediation and in terms of restructuring deficient or faulty schemata relating to social interaction. These routes are potentially fruitful when considering the future of intervention for Asperger’s syndrome.

However, whatever the underlying causes of Asperger’s syndrome, the behavioural characteristics are perhaps the most obvious and problematic for the individual — in terms of the responses of others within the social system. This suggests that there is real value in the currently used approaches which attempt to help the individual with Asperger’s syndrome fit more comfortably within their social world.
REFERENCES


What is the role of the clinical psychologist in services for people with dementia and their families? How can we evaluate our contribution as psychologists?

Stylistic Note: Although the author generally disagrees with the use of acronyms within academic writings, on the basis that it dehumanises the person or people being discussed, economy of numbers dictates that this is necessary within this essay, and acronyms such as PWD (people with dementia) will be used.
Introduction/Overview

This essay will first attempt to arrive at an operational definition of dementia. An attempt will then be made to outline the journey through and experience of dementia for the sufferer and their family, drawing on the available literature and personal clinical experience. The essay will then discuss the role of the clinical psychologist (CP) in services for people with dementia (PWD) and their families, including consideration of with whom, where, and how CPs could apply their skills. Finally, there will be a discussion of how CPs can evaluate their contribution to dementia care, both in terms of individual interventions and in terms of CP’s contribution to multidisciplinary teams (MDTs).

What is dementia?

The International Classification of Diseases, 10th Edition (World Health Organisation, 1992) defines dementia as:

“A syndrome due to the disease of the brain, usually of a chronic or progressive nature in which there is disturbance of multiple higher cortical function… Consciousness is not clouded. The impairments of cognitive function are commonly accompanied, and occasionally preceded by deterioration in emotional control, social behaviour or motivation”
Within the diagnosis of dementia, there are a number of sub-types; including Alzheimer’s disease and vascular dementia.

Regardless of cause or sub-type, a diagnosis of dementia means, on a day-to-day basis, loss of procedural, episodic, recognition and prospective memory; with more recently acquired memories usually the first to suffer (Alzheimer’s Society, 2003). Orientation to time and place is also adversely affected, as is ability to communicate, inhibit one’s responses, or make reasoned decisions. Throughout this essay, the term dementia will be used to refer to this type of progressive deterioration due to an organic cause.

Dementia is often viewed as a devastating diagnosis for which nothing can be done (Clare, Baddeley, Moniz-Cook & Woods, 2003), and to some extent, this is true, since deterioration and death are currently the inevitable consequences of dementia. However, it is important to remember that, as with other terminal diagnoses, PWD can be supported in such a way as to maximise quality of life and minimise distress (Alexander, 2004). Albinsson (2003) compared support needs of families of PWD and families of people with terminal cancer, and found a dominant need for both groups was to be listened to and have access to information. In dementia care, however, there was more importance placed on support groups for families, respite care, trying to relieve sense of guilt, and supporting the family after the person’s death.
Experience of the Journey Through Dementia

Dementia is almost always a progressive condition (LoGiudice, 2002), and the life expectancy from diagnosis to death is approximately 5-9 years (LoGiudice, 2002), although biases in documented onset may affect these figures. Dementia is usually a disease of older age, and estimates suggest that prevalence is 6% in people over 65 years of age, increasing to 20% in people over 85 years of age (Her Majesty’s Stationery Office {HMSO}, 2000. However, it is estimated that as many as 18,500 people under the age of 65 have dementia (HMSO, 2000). PWD and their families have different needs at different points in time, and these will be affected by factors such as financial resource, support network, age of PWD, status of non-professional caregiver (child, spouse or other/no relation), and sometimes by cultural, ethnic or religious background.

The subjective, personal experience of dementia is an area in which there has been a paucity of academic writing and research, due in part to obstacles in conducting such research (Husband, 1999; Phinney & Chesla, 2003). Cayton (2004) stresses the importance of understanding not only the genetics, biology or sociology of dementia, but also the narratives people hold, which shape the experience of their own dementia or that of a family member. Gaugler, Pearlin, Devay and Zarit (2000) and Gaugler, Zarit and Pearlin (2003) describe the experience of dementia as a longitudinal, dynamic process which places different demands on PWD and their families over time.
More recently, there has been qualitative investigation into individual experiences of dementia. Husband (2000) interviewed 10 PWD, and found all were worried about people finding out about their diagnosis, and of embarrassing themselves or their families in public. Teel & Carson (2003) conducted a qualitative investigation of fourteen families of PWD. They noted unease about the certainty of a diagnosis, and of uncertainty as to what reaction would be appropriate. Other findings included a feeling of loneliness in having to deal with the multiple physical and emotional challenges in providing care for the family member, and that support groups were perceived as a lifeline for lone family carers. Phinney & Chesla (2003) similarly conducted interviews with nine people experiencing mild to moderate dementia and their family caregivers. They identified three themes: being slow, being lost, and being a blank. The links between these themes appeared to centre around trying to find one’s way in a world which is no longer familiar and no longer contains familiar faces.

Cayton’s (2004) emphasis on understanding individual narratives behind dementia suggests that the spiritual, religious, ethnic, cultural, social and economic backgrounds of people with dementia will affect the way in which they and their families experience it. There is a paucity of research addressing these issues, although recently, some interest has been attracted. Nightingale (2003) investigated how five African-American and five white American caregivers perceive their religious beliefs/spirituality and ethnic values have impacted on their experience and understanding of the process of caring for a family member with dementia. She found that all caregivers felt their spirituality and/or religious practices shaped how they
approached providing care and all felt influenced by their ethnic background. Most stated that religious practices and spirituality affected how they felt about providing care and that helped them deal with difficult challenges.

Snyder (2003) emphasised the importance of considering the spiritual or religious perspective of PWD in helping them to cope with, and find meaning within dementia, and stressed the importance in providing for these needs within the care setting. She found that sensitive exploration and consideration of religious and spiritual beliefs helped some PWD find meaning in, cope with, and accept dementia.

It is well documented that continued care-giving is a stressful experience for the caregiver that often leads to physical and psychological ill-health (Pinquart & Sorensen, 2003; Vitaliano, Zhang & Scanlan, 2003; Vitaliano, Young & Zhang, 2004). The burden of care increases as the dementia progresses, with increasing stress caused by changing family roles and responsibilities (Wackerbarth & Johnson, 2002). Vitaliano, Young & Zhang (2004) found caregivers reported poorer global health, had 23% higher levels of stress hormones and 15% lower antibody response than did age and sex matched non-caregiving controls. Bodnar & Kiecolt-Glaser (1994) found that 33% of caregivers had sought help for anxiety or depression during their care-giving years, compared with only 5% of age and sex matched non-caregiving controls. Furthermore, they found that caregivers were at increased risk of psychological illness after the death of their spouse, and were more likely to experience difficulties with the grieving process.
Dementia, far from being purely a diagnostic criteria, is a social, emotional, psychological, sometimes religious and spiritual experience which affects the whole person in innumerable ways.

**With Whom Can the Clinical Psychologist Work?**

*The Person and Their Family*

Within the framework of a dementia care or older people’s service, CPs may be able to work with individuals, couples, wider family groups, groups of individuals, couples or families, with professional carers or in a wider organisational framework in terms of policy development or consultation.

Intervention with PWD and their families is likely to vary according to how far the dementia has progressed. In earlier stages, psychological input is likely to take the form of neuropsychological assessment and support in accepting diagnosis, if made. In the early-mid stages, intervention is likely to focus around memory strategies or help with affective disorders. Towards later stages, intervention is unlikely to focus on one-to-one work with the individual, but more on the systems around that person in terms of behavioural strategies or emotional support.

*Professional Carers*

It is likely that there will always be more demand for psychological input than can be fulfilled (DCP, 2001), and by working with professional carers of people with
dementia (such as nursing home, day centre or hospital ward staff), CPs will allow access to psychologically informed practice for many more people than would be possible otherwise. Fraser (1999) emphasises the importance of staff training in order to foster a supportive environment for both staff and residents of care homes, and that improved levels of education foster a more open-minded and questioning approach to work.

The General Population

Dementia is a diagnosis with wide-reaching social implications for the sufferer, many of which appear to be driven by a lack of understanding and fear (Harding & Palfrey, 1997; Husband, 1999). The Alzheimer’s Society is actively involved in trying to improve awareness and understanding of dementia, with strategies such as ‘Dementia Awareness Day’. CPs could, arguably, employ their expertise in cognitive and learning processes, as well as in understanding prejudice, in supporting the design and delivery of such awareness activities.

Wider Organisational Levels

CPs may have greatest impact on the psychological well-being of service-users by working at organisational or systemic levels (DCP, 2001). Through involvement with policy and service development for PWD, CPs could work towards creating psychologically informed practice on a service-wide level. Allan (2001) argues that it is important to involve people with dementia in consultation and service development,
and there may be a role for CPs in supporting individuals to become involved, perhaps in terms of facilitating communication and understanding.

What Can the Clinical Psychologist Do?

*Person Centred Care......and Beyond*

"The work of clinical psychologists is based on the fundamental acknowledgement that all people have the same human value and the right to be treated as unique individuals." (DCP, 2001, p.2)

The idea of valuing each person as a unique individual, a product of their past experiences and learning, and not just as PWD, is central to the idea of person centred care, which is a theoretical approach advocated by Kitwood (1997), who stated

"Our frame of reference should no longer be person with DEMENTIA, but PERSON with dementia.” (p.7)

Kitwood (1987) argued that most studies into dementia supported a medical model based on neurobiology and neurochemistry, and that this focus had led to a closing down of a psychosocial understanding of PWD. It seems that CPs, with their training in formulation and their emphasis on understanding the whole person are ideally placed to assist with the psychosocial understanding of PWD. CPs spearheaded this person-centred approach in the 1980’s and 1990’s, and it has impacted on the theoretical and practical way in which dementia care is provided. There is a role for
CPs in developing these ideas, and perhaps encouraging new ways of thinking about PWD (Bryden, 2002).

**Assessment of Dementia**

"Clinical psychologists assess the suitability of different measurement procedures depending on the purpose for which the assessment is needed, as well as individualised assessment procedures." (DCP, p.3)

CPs are arguably the best placed and most appropriately trained professionals to perform wholistic assessments of people with suspected dementia. Assessment activities could include the use of psychometric tests for cognitive function, ability, mood, and personality; the application of systematic observation of behaviour (of staff and PWD); and the use of formal and informal interviews. They are also well placed, as a function of their training, to assess the impact of dementia on the person and their day-to-day emotional, psychological, and cognitive functioning. As part of MDTs, the assessment activities of CPs could be viewed as key to reaching a full understanding of the person and their needs.

In practice, within MDTs, CPs are likely to perform assessments for three main reasons: to differentiate between depression and dementia; to help diagnose the type of dementia; or to investigate capacity in order to inform decisions about, amongst other things, advanced directives.
Assessment of Capacity to Consent

The loss of capacity to consent is an inevitable consequence of dementia (Katz, Abbey, Rydall & Lowy, 1995; Marson, Chaterjee, Ingram & Harrell, 1996). However, it is important to remember that within the population diagnosed with dementia, there is differential ability and so generalisations cannot be made. Within such a wide range of ability, individualised assessments of capacity to consent are imperative.

It is commonly understood that consent should be considered along three dimensions: information, voluntariness, and capacity (Department of Health {DoH}, 2002). A central concept in assessing capacity to consent in PWD is that capacity is not a static trait. PWD may be able to consent to some things, such as where to live but not others, such as for post-mortem examination of their brain.

A number of assessment measures have been developed to attempt to assess the capacity to give informed consent in vulnerable adults, including The Consent Screening Interview (Lindsey, 1994), and the MacArthur Competence Assessment Tool (Grisso, Appelbaum & Hill-Fotouhi, 1997). However, these assessments could be considered simplistic, and there is arguably a role for CPs in assessing PWD’s capacity to consent.
Risk Assessment

Often, it is important for the physical safety of PWD that they be moved to residential or hospital accommodation (Shah, Foli & Odutoye, 1999). PWD are at risk of abuse, physical, psychological, sexual or financial. There has been much attention paid recently to financial abuse among PWD, and there is again a role for CP in assessing the risks posed to a person if they are managing their own finances (Gilmour, Gibson & Campbell, 2003).

Intervention: Targeting Symptoms of Dementia

Intervention should always be based on the formulation (DCP, 2001). Therefore, there is a role for CP, even if purely in an advisory capacity, to ensure that any intervention, no matter how seemingly basic, is applied with due respect and consideration for the unique characteristics of the individual. The first psychological therapies specifically designed for PWD include reminiscence therapy (RT-Butler, 1963; Ebersole, 1978; both cited in Spector, Orrell, Davies & Woods, 2004b), reality orientation (RO-Folsom, 1966; cited in Spector, Orrell, Davies & Woods, 2004a), and validation therapy (VT-Feil, 1982; cited in Neal & Briggs, 2004).

RO is an intervention which aims to improve the orientation to time and place of PWD by providing prompts in a structured manner throughout the day. On the most basic level, this could mean calendars and clocks in prominent places throughout the residence, or a noticeboard with details of the date and weather. Taken further, this could mean regular discussion groups designed to enhance awareness of what is
happening and where they are. There is some evidence that this intervention is helpful in improving orientation, cognition and behaviour (Spector, Orrell, Davies & Woods, 2004a), however, if the reality is unpleasant, it is not necessarily helpful to remind PWD, as this could be experienced as distressing or even abusive by the recipient.

The author is reminded of an elderly relative, who was moved to a residential nursing home after his wife died. He had led a full and independent life, with a successful professional career, including a period in the navy during the second world war. He constructed an elaborate story whereby he was back on board his ship in the navy—the dining room was the mess hall (rationalising the intrusion of dining with strangers); his wife was waiting for him back on shore (rationalising the absence of his wife), and the nursing staff who cared for him were ‘the galley girls’. He was always surprised and pleased when he received visitors, as he said he appreciated the journey we had made to the port to meet his ship. He was happy and content within his story, and did not pose a management problem for the nursing home. However, when attempts were made to orient him to time, place, and the mortal status of his wife, he became tearful and sometimes aggressive, having been known to hit nursing staff with his walking stick. In this case, it could certainly be considered aversive, if not abusive, to attempt to orient him to what is an unpleasant reality.

In contrast to RO, VT attempts to understand the importance and function of PWD’s feelings and attempts to express them. Rather than correcting factual errors in conversation, VT aims to seek meaning behind verbal and non-verbal communication to gain an empathic understanding of the individual. For instance, using the example above, the expression of hoping his wife will visit next time he is in port could be used
to discuss feelings of loneliness rather than reminding him that she is dead. There is little objective evidence that this approach slows the progress of dementia, but it is beneficial on a humanistic, quality-of-life level as it encourages professional systems around PWD to consider the emotional and psychological consequences of dementia.

RT encourages recollections of details or events in an individual's life, on an individual or group basis. In RT, prompts such as music, photographs or video can be used to encourage discussion. The author has witnessed, whilst running a memory group, the lively discussion generated when photographs of childhood were shared. The experience seemed pleasant for all involved (including the group facilitator). Reminiscence can facilitate in-depth discussion of the person's life. Similarly to VT, RT can allow professional carers to gain a greater insight into the life of PWD, and assist them in seeing beyond the dementia. However, a recent Cochrane review concluded that no firm conclusions about the efficacy of RT could be made, and highlighted the need for further research (Spector, Orrell, Davies & Woods, 2004).

Other interventions have focussed on cognition and memory rehabilitation, employing techniques of cognitive stimulation or memory training. Techniques might include diary keeping, mnemonic or practical strategies, or formalised memory training groups. A number of studies have reported improved memory function as a result of the application of these techniques both in the short-term (Moore, Sandman, McGrady & Kesslak, 2001) and at one year (Arkin, 2001). However, a systematic review of these types of intervention has not been undertaken to the best of the author's knowledge, although a Cochrane Review (Cameron & Clare, 2004) is in process. Affective factors, such as depression or anxiety (often at the thought that one might
forget) can influence memory, and often be improved as a function of greater confidence in memory, as evidenced by both the Moore et al (2001) and Arkin (2001) studies which report improvements on mood scales for the participants.

Clearly, these therapies can be applied by a wide range of trained and untrained staff. A particular concern with these well-known interventions is a mechanistic application (Spector, Orrell, Davies & Woods, 2004a&2004b). Perhaps the role of CPs would be to provide staff support and supervision to ensure psychologically appropriate application, or to suggest ways in which basic application could be expanded to give psychological benefit.

Interventions: Psychotherapeutic

Traditionally, PWD have been considered unsuitable for specific psychological therapy due to the belief that their cognitive impairment is a barrier to their understanding of and engagement with the psychological process. However, more recently, there is evidence that cognitive therapies for affective disorders can benefit people with mild to moderate dementia (Koder, Brodarty & Anstey, 1996; Husband, 1999; Thompson, Wenger, Zeuss & Gallagher, 1990). As drug therapies for dementia become more advanced, and cognitive abilities are preserved for longer, there will be more scope for CPs to intervene in this way. Guss and Hawkins (2002), however, suggest that with creativity, many psychological interventions can be adapted for use with PWD. Clare and Woods (2001) stress the importance of further developments in this area, and there is undoubtedly a role for CP.
Interventions: Other

More recently, there have been attempts to evaluate the use of family therapy (FT) with PWD and their families (Akister, 2003). However, FT is an area with a controversial evidence base, due to reasons such as there being no universally accepted definition of FT entails, and the fact that it is still not accepted as an essential part of psychological services in all parts of the country (Roy-Chowdhury, 2003). FT is a flexible approach which can tackle difficulties throughout the system, and would undoubtedly be of some benefit to PWD.

Interventions with Carers

As discussed earlier, a diagnosis of dementia impacts severely on the spouse or wider family of the person with dementia. One of the most common interventions provided for family carers of PWD is the support group. Offering discussion, practical and emotional support, as well as education and information, these have traditionally run purely for carers, but more recently have been introduced for carers and PWD together. The majority of support groups are run by voluntary organisation and would not form a routine part of a CP’s role. However, it would be beneficial for CPs to have some input into these groups, either as an invited speaker, or in advising on content.

Published evaluations of and suggestions for carers of PWD have focussed mainly on the provision of group support, and this type of intervention has been found to have “modest but significant benefits” (Brodarty, Green & Koschera, 2003). However,
given the impact caregiving has been found to have on psychological and physical wellbeing, it could be argued that more needs to be done. The clinical experience of the author indicates that carers of PWD are often offered individual intervention, but it seems that there are no published studies evaluating this. Wisdom would dictate that carers would benefit from interventions addressing depression, anxiety, grief and self-esteem issues, just as psychologically unwell non-caregivers would. There appears to be a role for CPs in providing this, and in generating evidence to support its provision.

*Interventions For Behaviours Perceived as Challenging*

As dementia progresses, the person is likely to exhibit at least some behaviours which carers, whether professional or familial, will find challenging. Bird (1999) summarises these as: yelling or screaming; physical or verbal aggression; repetitive demands; disinhibited sexual activity; disordered sleep patterns; hoarding; wandering; resistance to personal care; unjustified accusations; trespass; destruction of property; incontinence; compulsive actions; and self-harm/dangerous actions. The author would add to this summary behaviours which seem bizarre and without obvious reason. Bird (1999) identifies two main focuses for behavioural intervention – to reduce the severity or frequency of the troubling behaviour, and to reduce carer distress. However, Moniz-Cook, Woods and Richards (2001) highlighted another role of CP in intervening with behaviours perceived as challenging – to understand the function and meaning of that behaviour for that person in that context. They also criticise simplistic behavioural interventions that attempt to offer one set of procedures (such as aromatherapy or diversion) for complex behaviours (such as agitation or wandering).
In a publication outlining functional assessment of behaviours perceived as challenging, Moniz-Cook, Woods and Richards (2001) report uncovering underlying reasons associated with superstition, including a fisherman who would attack anyone wearing green (green is an unlucky colour at sea) and a man who would attack staff on staircases (who believed that crossing on the stairs was unlucky). The underlying motivations for these apparently bizarre behaviours were uncovered after intensive observation and discussion with family members and friends. Without careful functional analysis, there would be a very real risk that these people would have been inappropriately medicated.

In order for a behavioural intervention to be efficacious, evidence suggests that full functional analysis should be carried out (Allen-Burge, Stevens & Burgio, 1999; Opie, Doyle O’Connor, 2002). Other than carrying out the assessment and intervention, another role for CPs could be educating general practitioners, nursing home staff, and even psychiatrists in the ideas of functional analysis. This may improve the quality-of-life for people with dementia in that psychological support may be sought before psychoactive medication is prescribed.

Interventions: A Note on Individuality

As has been expressed throughout this essay, the experience of dementia for both the person and their family is heavily influenced by their previous experiences, whether cultural, economic, religious, spiritual, ethnic, or other individualised factors.
Gallagher-Thompson et al (2003) highlight the necessity to tailor assessment or intervention to take account of these idiosyncratic factors.

**Research**

"The ability to design and carry out applied research is a skill developed to doctoral level." (DCP, 2001, p.4)

Within MDTs, CPs are well placed to conduct research which would help improve professional understanding of, and the experiences of PWD. Nightingale (2003) stresses the importance of more qualitative research within the field of dementia care for these reasons. Bird (1999) similarly stresses the opportunities for psychology to develop both research methodology and the qualitative evidence base for psychological interventions in dementia care.

**How can we evaluate our contribution as psychologists?**

**Measuring outcome: General**

In assessing the effectiveness of an intervention, Sperlinger (2002) emphasises the importance of considering the reason for seeking help, and evaluating the intervention against this. Considering dementia, common reasons for seeking help would include concern about a perceived memory problem, depression or anxiety, or behavioural support for a person with dementia who is proving challenging to his or her carers. Following Sperlinger’s (2002) suggestion, positive outcomes in the above examples
could be, respectively, satisfactory neuropsychological assessment of cognitive function, alleviation of depression or anxiety, or reduced frequency or severity of challenging behaviour.

Berger (1996; cited in Sperlinger, 2002) states that

"..the outcomes of psychological interventions are the amalgam of a complex of factors and... attempts to assess such outcomes need to take account of the complexity." (p.23)

Considering these points of view, it would be important to specify the purpose for which the outcome is being assessed, and whether from the perspective of the user, the carer, the clinician, the service commissioner, or some other agency.

With older people, interventions are usually evaluated by considering factors such as orientation, communication, behaviour, and life satisfaction. There is also the important issue of clinical versus statistical significance. Within dementia care, the former is perhaps the most important consideration as interventions often aim to improve or positively augment the experience of dementia rather than remove or reduce the symptoms of the condition. Schultz et al (2002) suggest that important issues to consider in clinical significance include quality of life and social validity.
Measuring Outcome: Intervention

The aim of intervention ought to be clear from the outset (Zarit & Leitsch, 2001), and therefore the outcome evaluation should be directly linked to this aim. However, as already mentioned, the outcomes of psychological interventions are a complex amalgam of factors, and not all may be easily assessed. For instance, could a memory group be considered successful if it did not improve memory, but did reduce the anxiety of the person about failing memory? The answer is probably yes.

There have been some attempts to develop universal outcome measures, such as the positive response schedule (Perrin, 1997), and these are useful in that they provide an outcome measure against which different studies can be compared. However, as Berger (1996, cited in Sperlinger, 2002) asserts, outcomes of psychological interventions are complex, and simplistic, standardised outcome measures rarely tell the whole story. Beck (2001) suggests that research is needed to identify what is an appropriate outcome measure in dementia care services, especially as deterioration is inevitable. Can delayed deterioration, or lack of deterioration be viewed as a positive outcome in this context?

It has been suggested that preserved or improved quality of life is an appropriate outcome measure in services for people with dementia and their families (Selai & Trimble, 1999; Thorgrimsen, Schweitzer & Orrell, 2002), and research is needed to advance this important area of measurement.
Measuring Outcome: Contribution to Services

It would be difficult to objectively assess the contribution made by CP to services for PWD, and the author is unaware of any studies addressing this. However, as a reflective practitioner, one should be considering this. It would, maybe, be useful to ask the questions "What would the service be like without the input of CP?" and "Does having a CP on the team improve the experience or quality of life for PWD or their families?"

Given the scarcity of CPs nationally, and most specifically in services for older people, some answers to these questions could begin to be formed. For example, if enough services could become involved, it may be possible to compare satisfaction/quality of life (subject to the vagaries of assessing these attributes) in services with CPs and without. Obviously, there would be potential confounding factors given that there are different ways of providing services within and between regions.

Conclusion

Psychological understanding and intervention in dementia care services is a relatively small, but evolving and developing field. Given the evidence presented in this essay, there is clearly a role for CPs within MDTs at every stage of dementia care from diagnosis through to death. CPs also have a role at very different levels of intervention, from direct work with individuals or families, through staff training and support to providing wider systemic advice and consultation.
CPs have a responsibility to encourage and conduct research and evaluation of existing psychological interventions, and to be involved in developing new and innovative ways to help PWD and their families.

Within the context of MDTs, many of the functions of CPs could arguably be performed by other professionals. However, it is unlikely that many other professional groups could perform as many of these functions as CPs. The ability to 'see the whole therapeutic picture' is an important one when working clinically with complex, long-term presentations, such as those of PWD, and this is, perhaps, something unique to CP. However, the role of CPs for PWD and their families must remain within the MDT, as there are many skills, such as medical assessment and drug therapies, which are not part of the CP's repertoire and without which the care of PWD would be seriously compromised.
REFERENCES


INTRODUCTION TO THE CLINICAL SECTION

The clinical section of this portfolio comprises two parts. The first consists of summaries of five case reports written over the three years of training. These case reports are submitted in full in Volume Two. The second part of this section consists of summaries of the four core and two elective placements undertaken. Full details of these placements, including client contacts and evaluation forms are submitted in full in Volume Two. Some details and all names in the summaries have been changed to maintain the anonymity of the individuals concerned.

Both parts of this section are presented in the order in which the placements were undertaken, namely, adult mental health, people with learning disabilities, children and families, older people, paediatric oncology, and, finally, child protection/child and adolescent mental health.
A COGNITIVE-BEHAVIOURAL ASSESSMENT AND INTERVENTION FOR
A 55-YEAR OLD WOMAN WITH PROBLEMS RELATING TO ANXIETY

Referral and Assessment

Jane Smith, a 55 year-old white British woman, for whom English is the first
language, was referred by her GP for help with nausea and loss of appetite. On
assessment, Jane reported that her primary concern was anxiety when faced with any
decision, responsibility, new situations or new people, or being required to do
anything alone. This anxiety began in January 2001, when Jane had a colostomy bag
fitted, and became significantly worse when Jane’s mother died in July 2001. Clinical
interviews with Jane were the main source of information. With Jane’s permission,
telephone calls to Jane’s G.P., care manager, gastrointestinal surgeon, and sister-in-
law were made to gather further information.

On assessment, Jane scored within the borderline range on the depression subscale of
the Hospital Anxiety and Depression Scale (HADS – Zigmond & Snaith, 1983),
outside of the clinical range on the Beck Depression Inventory (BDI – Beck, 1978),
and significant anxiety on the anxiety subscale of the HADS.

Background Information

Jane reported always having been a nervous person and had never moved away from
home and had an extremely close relationship with her mother. Jane left school at 15
and worked in a shoe shop until it closed. She has never had an intimate relationship,
nor did she have any friends. Jane's mother developed dementia whilst Jane was in hospital and deteriorated very quickly, becoming unable to cope with tasks of daily living. Jane had never had to initiate tasks such as shopping, cooking, or paying bills, and as a result, was unable to take over this role from her mother. As a result, Jane lost a great deal of weight over a short period of time and was readmitted to hospital. Jane's mother died during Jane's second admission. Jane was discharged into a small community home for older adults with physical health needs. At the time of engagement, Jane had progressed from her least functional point, working one Saturday a fortnight in a charity shop and attending a day centre for older adults once a week.

**Formulation**

Jane had never had to learn independent living or decision making skills, and her mother took responsibility and made decisions for her until her death in 2001. In addition to grief, the shock and debilitating nature of her own health problems, and the loss of her feeling of safety and security, Jane faced unfamiliar challenges associated with independent living. These caused feelings of extreme anxiety for Jane, and she was placed in a situation where she didn’t have to do these things (care home for disabled older adults) – which was helpful in keeping her fed, clean and clothed, but unhelpful in enabling acquisition of new skills. Jane’s sister-in-law was providing support to enable Jane to attend appointments and pay bills, but, again, this was unhelpful in enabling Jane to learn new skills. As a result, Jane was not in a position to test unfamiliar situations, and did not want to due to her anxiety.
Although there are elements of separation anxiety (unable to cope without her mother), social phobia, agoraphobia, simple phobia, and generalised anxiety disorder, Jane’s presentation does not fit comfortably within any of these diagnostic criteria. It was helpful to view Jane’s difficulties in terms of phobias when considering the intervention; however, Jane’s difficulty is not simply a specific phobia, and there are elements of other types of anxiety disorder present. In addition, all clinical staff who worked with Jane agreed she had a low I.Q., which complicated her difficulties. This could be the reason for continued dependence on her mother into later life.

**Intervention**

Graded exposure is reportedly efficacious in treating phobic reactions (Taylor, 1996; Stravynski & Greenberg, 1998; Oei, Llamas & Devilly, 1999; Blomhoff, Haug, Hellestrom, Holme, Humble, Madsbu & Wold, 2001). Therefore, graded exposure should be considered as an intervention for Jane. Jane’s difficulties cannot be completely summed up as phobias - although phobic reactions are clearly present, there are also elements of other anxiety disorders. Cognitive-behavioural strategies are reportedly efficacious in treating other anxiety disorders (Taylor, 1996; Barlow, Gorman, Shear & Woods, 2000; Flannery-Schroeder & Kendall, 2000; Ladouceur, Dugas, Freeston, Leger, Gagnon & Thibodeau, 2000), and should be considered an intervention for Jane in conjunction with the graded exposure.

Aspects of the intervention included identifying feelings and thoughts around anxiety, establishing expectations, developing relaxation skills, cognitive restructuring, exploring and challenging the environment, graded exposure, planning for the future
and attending to Jane’s limited understanding. The intervention was delivered over ten sessions, once a week, and included meetings with Jane’s carers.

**Outcome and Follow-Up**

Jane’s anxiety and depression scores on the HADS decreased. Jane became noticeably more cheerful as the sessions progressed. She had found it difficult even to talk about the things she found anxiety-provoking in the earlier session, and frequently cried and exhibited physical symptoms of anxiety. In the final sessions, Jane was more controlled, and reported that this improvement in coping had generalised to her everyday life, and that she was less distressed in general. Jane’s sister-in-law, home manager and care manager agreed with this.

Jane’s ability to carry out tasks of daily living improved significantly over the course of our sessions. A list was made of the things that Jane had done for the first time over ten weeks was compiled in the final session.

**References**


AN EMOTION RECOGNITION SKILLS TRAINING GROUP FOR SEVEN
PEOPLE WITH A SIGNIFICANT LEARNING DISABILITY

Referral and Assessment

The manager of a day centre for people with significant and severe learning
disabilities asked the service in which the trainee was working to facilitate a social
skills training group for the clients. Three women, aged 39, 43, and 23, and four men,
aged 24, 60, 44, and 31 took part. All were white British and had English as their first
language. There were no specific difficulties to be addresses, the main reason for this
intervention was to enhance quality of life through improving each individual’s ability
to relate to those around them more easily and to form more reciprocal relationships.

Once all exclusion and inclusion criteria had been applied, group members took part
in an assessment session in which three tasks were completed. The first was
identification of five emotions (happy, sad, angry, scared, and surprised) depicted by
good quality, colour, A4 photographs. These emotions were chosen as a result of
Ekman’s (1976) work, which identified six universal emotions, and Maricham and
Wang’s (1996) work, which found disgust was easily confused with anger and the
most difficult of the six to identify. The second task was aural identification of the
same five emotions in a prepared tape recording of a neutral message, spoken five
times using inflection to convey one of the five emotions, as suggested by Wilkinson
and Canter (1985). The third task was to draw five faces, each depicting one of the
five emotions. The responses of the group members are displayed in Table 1, below.
Table 1: Summary of each group member’s assessment responses

<table>
<thead>
<tr>
<th>Group Member</th>
<th>Photographs (maximum score=5)</th>
<th>Voices (maximum score=5)</th>
<th>Interpretation of the set of five drawings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lydia</td>
<td>2</td>
<td>1</td>
<td>Good differentiation between all five emotions; demonstrated by different mouth shapes.</td>
</tr>
<tr>
<td>Kelvin</td>
<td>5</td>
<td>3</td>
<td>Good differentiation between all five emotions; demonstrated by different mouth, eye and eyebrow shapes and positions.</td>
</tr>
<tr>
<td>John</td>
<td>0</td>
<td>2</td>
<td>No differentiation between any of the emotions.</td>
</tr>
<tr>
<td>Leanne</td>
<td>1</td>
<td>3</td>
<td>Good differentiation between happy, sad and surprised; demonstrated by different mouth shapes. Angry indistinguishable from scared.</td>
</tr>
<tr>
<td>Martin</td>
<td>2</td>
<td>3</td>
<td>Drew a face with eyes and then wrote the emotion underneath. No other features even when asked “Is there anything missing?”</td>
</tr>
<tr>
<td>Seth</td>
<td>1</td>
<td>1</td>
<td>Good differentiation between all five emotions; demonstrated by different mouth and eye shapes.</td>
</tr>
<tr>
<td>Janet</td>
<td>5</td>
<td>3</td>
<td>Differentiation only between positive and negative emotions. Happy face for happy and surprised, sad face for angry, scared and sad.</td>
</tr>
</tbody>
</table>

Background Information

Within the group of people with a significant learning disability, there was considerable spread of abilities and personal circumstances. Lydia, and Kelvin still live with their parents. John lives with his brother and sister-in-law. Leanne, Martin, Seth, and Janet live in de-registered fully staffed homes. All had acceptable verbal communication skills. Lydia, John, Leanne, Martin, Seth, and Janet attend day centres every day. Kelvin attends day centres four days a week and is supported in manual
employment one day a week. Lydia, Kelvin, Martin, and Seth are able to move about the community safely on their own; John, Leanne, and Janet are not.

Psychological Perspective

Acquisition of social skills and the cognitions associated with them is a slow and accretive process. There are a number of factors which can influence how well, how fast, or even if these develop, and one of these is developmental delay of any kind (Wilkinson & Canter, 1985). Some studies have suggested that there is a direct correlation between language acquisition and understanding of emotions (Reed & Clements, 1989), and there exists evidence which suggests that people with a learning disability have difficulty recognising facial expression of emotion, and in handling their own emotions (Gray, Fraser & Leudar, 1983).

In people with learning disabilities, a large part of any difficulty in recognising or expressing emotion could be attributed to an institutionalised upbringing, although the rate of emotional difficulties is the same whether the person was raised in an institution or not (Felce & Emerson, 1996; Kroese, Dewhurst & Holmes, 2001). Many people with learning disabilities could be considered lacking adequate vocabulary to describe their feelings (Reed & Clements, 1989). Arthur (2003) would go as far as to say that the emotional lives of people with learning disabilities are neglected.
Being able to accurately recognise, label, and interpret emotional states in others, as well as within ourselves, is an essential component in generating and maintaining social relationships (Hext & Lunsky, 1997 - cited in McKenzie et al, 2000).

With intervention, people with learning disabilities have demonstrated a good capacity for recognising and expressing their own emotions (McAlpine, Singh, Kendall & Hampton, 1992; Lindsay, Michie, Baty, Smith & Miller, 1994), suggesting that interventions attempting to enhance this ability should be carried out.

**Intervention**

A skills training framework was used as the basis for the group. Wilkinson and Canter (1985) set out a basic skills training framework utilising several stages within each session. These stages were instruction, warm-up exercises, modelling/role-play, feedback/reinforcement/social rewards, and homework.

The group ran for five weeks, once a week, for an hour-and-a-half each time. The group session followed a regular format, where the group rules were first revisited, then a warm-up task with therapeutic relevance was conducted, and then the main body of the group time was spent on directive tasks. Pictorial hand-outs were given out. Time was spent at the end of each session ensuring that group members understood the homework task.
Outcome and Follow-Up

The assessment tasks were re-administered on completion of the group. The responses of the group members are displayed in Table 2, below.

Table 2: Summary of each group member’s re-assessment responses (assessment scores in brackets)

<table>
<thead>
<tr>
<th>Group Member</th>
<th>Photographs-maximum score=5</th>
<th>Voices-maximum score=5</th>
<th>Evaluation of Drawings in Comparison With Assessment Drawings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lydia</td>
<td>5(2)</td>
<td>3(1)</td>
<td>Improved.</td>
</tr>
<tr>
<td>Kelvin</td>
<td>5(5)</td>
<td>3(3)</td>
<td>No change (ceiling effect at assessment).</td>
</tr>
<tr>
<td>John</td>
<td>-(0)</td>
<td>-(2)</td>
<td>N/A</td>
</tr>
<tr>
<td>Leanne</td>
<td>5(1)</td>
<td>2(3)</td>
<td>Improved.</td>
</tr>
<tr>
<td>Martin</td>
<td>5(2)</td>
<td>3(3)</td>
<td>Improved.</td>
</tr>
<tr>
<td>Seth</td>
<td>1(1)</td>
<td>1(1)</td>
<td>Improved.</td>
</tr>
<tr>
<td>Janet</td>
<td>5(5)</td>
<td>3(3)</td>
<td>No change.</td>
</tr>
</tbody>
</table>

Overall, participation in the group appears to have improved some of the group member’s ability to recognise and interpret emotions in others and in themselves.
References


INTERVENTION WITH A 10-YEAR-OLD BOY WITH AUTISTIC SPECTRUM DIFFICULTIES, HIS FAMILY, AND HIS SCHOOL

Referral and Assessment

Toby Carter, a 10-year white British boy, with English as first language, was referred to the team psychiatrist by his mother, a school nurse. Concerns included difficulty coping socially and with criticism at school, angry outbursts, low self-esteem, and inability to cope with his own strong emotions—which has led to self-harm (banging his head on the table) on a few occasions.

Toby was initially assessed by the team psychiatrist and a short form Conner’s assessment (Multi-Health Systems, 1997) was administered. The Conner’s is a screening tool for attention deficit hyperactivity disorder, oppositional problems, cognitive problems/inattention, and hyperactivity. Although indicating some problems at school, the profiles did not indicate further investigation.

My supervisor and I then met with Toby and Mrs Carter, for a one-hour assessment session. Toby completed Kidcope (Spirito, Stark & Williams, 1988), which assesses levels of distress and coping; Life in School Checklist–Junior School Version (LSC/JSV–Arora & Thompson, 1987), which is an informal assessment of life in school, including bullying; and the Locus of Control Scale for Children (LCSC–Nowicki & Strickland, 1973), which assesses internal vs external locus of control in children. Kidcope indicated that Toby reported a high level of distress, and that his most commonly used coping strategies were social withdrawal, blaming others,
wishful thinking, and distraction. LSC/JSV indicated no bullying and a satisfactory
school life. LCSC indicated high external locus of control for Toby. There were no
child protection concerns.

**Background Information**

Toby lives with both his parents and his younger brother. Both parents work; Mr
Carter as a full-time special operative in the police force and Mrs Carter as a part-time
school nurse.

Toby was born following a normal pregnancy, although concerns were expressed that
Mrs Carter had experienced premature rupture of the membranes, as there were signs
of chronic amniotic fluid infection. Toby was delivered by caesarean section as
labour failed to progress. Toby was a colicky baby and difficult to settle. He
experienced recurrent tonsillitis, ear infections, diarrhoea, urine infections, and renal
infection. At eight months, he was admitted to hospital as he was floppy and making
grunting noises.

Toby’s milestones were within normal limits with the exception of speech, which was
late to develop. He received speech therapy once a week from the age of four until the
age of six. Most of his speech difficulties were resolved, although he still experiences
difficulty in producing words occasionally, especially when nervous.

Toby did not enjoy starting school, and was bullied until he transferred to a different
school at the age of eight. Bullying has not recurred.
Toby functions well in the home, except for when frustrated, as he will often hit out. He attends cubs once a week and enjoys this. He functions well at school academically although he finds peer relationships difficult to manage. He “hates” sports, especially rugby, and has had many difficult experiences on the rugby field. Toby finds it difficult to acknowledge criticism without taking it personally, and has cried when there have been red-pen corrections on his work. Toby finds lunch-breaks challenging, and prefers to spend time inside and alone if possible.

Toby presents as an anxious boy who has extreme reactions to mildly provoking stimuli.

**Formulation**

Toby’s difficulties can be understood as Asperger’s Syndrome (AS). However, it does not follow that having mild ASD leads automatically to problems in daily life. It is the interaction of Toby’s profile with the systems in which he interacts that creates problems. Some of Toby’s AS characteristics cause him difficulties, such as taking criticism personally causing problems when his work is corrected; his highly developed sense of right and wrong leading him to report all wrongdoing, causing peer relation problems; and finding crowds and unstructured situations stressful leading to difficulty at break time. Others of Toby’s AS characteristics interact positively with his environment, such as his enthusiasm bordering on obsession for subjects he enjoys leading to high achievement at school; and his genuine desire to always do the right thing leading to little problems with rule-breaking.
Due to difficulties at school, Toby is often cross and angry on returning home, especially if he considers something to have been unfair. His family are generally tolerant and supportive, but tempers are lost at times, leading to angry exchanges, leaving all parties upset. As a result of his ‘failures’ in social interactions, or not ‘getting things right’, Toby does not have a very high opinion of himself.

**Intervention**

Intervention was structured around Herbert’s (1998) assertion that any intervention for a child with ASD needs to cover four main points:

1. Foster social and communicative development
2. Enhance learning and problem solving
   - School environment is key
3. Decrease behaviours that interfere with learning and access to opportunities
4. Help families to cope
   - Put in contact with local/national societies
   - Provision of counselling or support for parents
   - ‘Parent Training’ in communication, behaviour management, antecedent control, and theory of mind training

Work was also planned around helping Toby to develop a peer support network, dealing with his anxiety and anger, and developing his self-esteem.
I met with Toby alone or with his mother once a fortnight for 12 sessions. My supervisor met with Mrs Carter once a month. Intervention had three main focuses – work with Toby (e.g. managing his anger/anxiety); work with his parents (e.g. discussing the rage cycle and management of children with AS); and work with his school (e.g. understanding a child with AS, practical strategies for helping Toby in school).

Outcome

Copies of the assessment questionnaires were given to the family, although at the time of writing, these questionnaires had not been returned. Qualitatively, Mrs Carter reported an improvement in her ability to manage. She reported feeling more able to deal with, and less to blame for, Toby’s difficult behaviours. She told me that she had found it reassuring to hear about Toby's potential for development, and helpful to have a focus for her own research into how to help Toby.

References


NEUROPSYCHOLOGICAL ASSESSMENT OF A 59-YEAR-OLD MAN WITH SEVERE MEMORY IMPAIRMENT AND A HISTORY OF CHRONIC, HEAVY ALCOHOL CONSUMPTION

Referral

Mr Ashley, a 59-year-old man with English as his first language, was referred by the consultant psychiatrist for neuropsychological assessment to clarify his specific difficulties.

Background Information

Mr Ashley was experiencing memory difficulties of acute onset. He did not acknowledge any problem. Mr Ashley appeared to have no insight into where he was. He was amenable to direction and appeared happy and content. He could hold a general, shallow conversation (for instance about the weather), although has no memory of this afterwards. He did not appear to remember anything—such as where he is, what was for breakfast, or the names of staff members. He could, however, find his way to the toilet and his room.

It was difficult to establish a clear history as Mr Ashley had lived alone for some years prior to involvement with services and had infrequent contact with his family. What is known is that, in December 2003, he approached his GP complaining of loss of appetite and epigastric pain. When his adult children visited for Christmas, they noticed he appeared confused and disorientated. He was admitted to hospital and begun on a course of B-vitamins. There was no improvement. He continued to deteriorate, became incontinent of urine, unable to carry out self-care, and was rude.
and violent towards staff and patients. He was moved to a psychiatric hospital in April 2003, and to his current residential home in May 2004. Mr Ashley’s cognitive functioning appears to fluctuate significantly.

Mr Ashley left school with no formal qualifications and worked as a building contractor until four years ago, when he sustained a leg injury. He has lived alone since his wife dies five years ago. Mr Ashley has been a life-long heavy drinker, although none of his family were able to quantify his alcohol intake with any certainty. It is likely that his drinking increased after he became unemployed.

**Literature Review**

Long-term chronic alcoholism can result in impairment of cognitive abilities (Bates, Bowden & Barry, 2002; Evert & Oscar-Berman, 1995; Thomas & Rockwood, 2001). However, the cognitive abilities affected, and the extent to which these are affected can vary from subtle deficits in memory, problem solving and visuospatial abilities to a more severe presentation with profound global cognitive decline. Two of the more chronic and severe neurological disorders that may arise as a result of prolonged and heavy alcohol consumption are Korsakoff’s syndrome (KS) and alcoholic dementia (AD).

KS is characterised by prominent memory and new learning impairment whilst other cognitive functions remain relatively intact. Memory for events or episodes are severely affected. It has been postulated that the main problem is acquisition of these memories as opposed to accelerated forgetting or problems in retrieval (Bates,
However, implicit and semantic memories are usually preserved (Salmon, Butters & Heindel, 1993). KS is often characterised by great difficulty in formulating, organising and initiating plans of action (Salmon, Butters & Heindel, 1993).

In contrast to the relatively specific memory deficit of KS, some chronic alcoholics develop a global dementia characterised by severe memory and general intellectual impairment (Bates, Bowden & Barry, 2002; Lishman, 1990).

People with AD exhibit amnesia which is as severe as that of people with KS (Longmore & Knight, 1988). However, in contrast to KS, the memory impairment of AD is not significantly more prominent than their deficits in other cognitive abilities. In addition to the amnesia, people with AD will exhibit severe deficits in conceptual and problem solving abilities and visuospatial abilities, although simple tasks requiring these skills (such as simple copying or rule-shift tasks) are often performed acceptably (Salmon, Butters & Heindel, 1993).

Assessment

The domains assessed were pre-morbid functioning, current functioning, attention/concentration, executive function, verbal abilities, visuo-spatial abilities, and memory using brief or short-forms of assessments. Pre-morbid functioning was assessed using the National Adult Reading Test–Revised (NART-R-Nelson, 1991). Current functioning was assessed with the Mini Mental State Examination (MMSE-Folstein, Folstein & McHugh, 1975), the Dementia Rating Scale (DRS-Mattis, 1988),
and a four-subtest administration of the Wechsler Adult Intelligence Scale, 3rd Edition (WAIS-III-Wechsler, 1997). Mnemonic function was assessed with the Recognition Memory Test (RMS-Warrington, 1984), and the digit-span sub-test of the WAIS-III. Verbal fluency was assessed using FAS (Benton & Hamsher, 1989) and category naming (Spreen & Strauss, 1991). Executive function was assessed using sub-tests from the Behavioural Assessment of the Dysexecutive Syndrome (BADS-Wilson, Alderman, Burgess, Emslie & Evans, 1996). Mood was assessed qualitatively.

**Findings**

Results of assessment suggested that Mr Ashley’s pre-morbid IQ was in the average-high average range. Pro-rating of the four WAIS-III sub-tests suggested that his current functioning was not significantly to his pre-morbid functioning. His scores on the MMSE fluctuated significantly, from within the severely impaired range to the mildly impaired range. Mr Ashley’s scores on the DRS revealed an uneven profile, with good attention, construction and conceptualisation, borderline initiation/perseveration, and impaired memory. His overall score did not indicate the presence of dementia.

Mr Ashley’s scores on the RMT indicated severely impaired recognition memory. His immediate/working memory was assessed as being within the normal range, although slow.
There were no visuospatial or verbal fluency problems noted. He demonstrated ability within simple executive function assessments, but significant impairment in higher order executive function tasks.

There was no evidence of features of depression or anxiety in his presentation.

Conclusions

Given these findings and Cutting's (1978) assertion that KS be applied only to those people who demonstrate a circumscribed memory deficit, and that people with more global impairments be considered to have AD, it seems most likely that Mr Ashley is suffering from an atypical alcoholic dementia. However, given the lack of comprehensive history, this cannot be a definitive diagnosis. The following recommendations were made:

- MRI scan to investigate any possible organic pathology.
- Review of medication to chart neuropsychological deficits attributable to this and not to organic causation.
- Staff advised as to the potentially fluctuating nature of Mr Ashley's risk to himself and to others.
References


Referral and Assessment

Eddie Lam, a 4-year-old Chinese British boy was referred to the paediatric psychology department by a social worker based at the hospital, after his mother raised concerns about his behaviour. Eddie was diagnosed with acute lymphoblastic leukaemia in January 2004. Eddie had no expressive English. The family's first language was Cantonese. Mr and Ms Lam spoke fluent English.

The initial assessment session was a one-hour interview with Mrs Lam. Mrs Lam was given behaviour record sheets to complete at this session, although these were not returned completed at any stage during our work. There were no child protection issues.

Mrs Lam reported difficulties around sleeping, eating, and general non-compliance. She reported difficulties in around medical procedures, port access (a port is a device implanted under the skin, on the chest in Eddie's case, which allows central venous access without venepuncture, but needs to be accessed by breaking the skin with a needle).
Background Information

Eddie lives with both his parents and is an only child. Both parents work as accountants; Mr Lam full-time and Mrs Lam (39), part-time. Mr and Mrs Lam grew up in Hong Kong and have little family support in England. Eddie’s Aunty supports the family practically, and cares for Eddie when both parents are at work.

Eddie was born at full term following a normal pregnancy. He was well until his diagnosis of leukaemia. There is no other significant illness history. Eddie reached his developmental milestones “fast”.

Eddie was diagnosed with, and began treatment for, acute lymphoblastic leukaemia on 15th January 2004. Eddie’s treatment involves a number of medications administered in a number of different ways (orally, intravenously, intrathecally – into the spine, and intramuscularly). Eddie has blood samples taken on a regular basis. The side-effects of Eddie’s medication include: upset stomach; nausea; vomiting; taste change; loss of appetite; sore mouth; diarrhoea; headache; dizziness; tiredness; weakness; hair loss; sleep difficulties; restlessness and agitation; low mood; anxiety; confusion; bladder irritation; and flu-like symptoms.

Eddie presents as an initially shy, and then confident boy who does his best to communicate non-verbally with adults who do not speak Cantonese.
Child Tax Credit

Child Allowance

Childcare vouchers

No more $5175 (66380 if 51)
Formulation

Although Eddie’s difficulties could be conceptualised as oppositional-defiant disorder, given the stressors in his life and potential affective side-effects of his medication, it does not seem helpful to pathologise Eddie’s difficulties in this way; his behaviour is perhaps better understood as an adjustment reaction to an external stressor, namely the experience of and treatment for cancer.

Medication considerations add an additional dimension to understanding Eddie’s behaviour, as does the fluctuating nature of Eddie’s health and wellbeing. Due to his medication regime, he will variously feel nauseous and unwell (chemotherapy), irritable (steroids) and in some pain (chemotherapy). Each of these states will differently affect Eddie, causing him to be, variously, quiet, sad and sleepy; grumpy and aggressive; and clingy and tearful. Clarke, Davies, Jenney, Glaser and Eiser (2005) in a study of fifty-five families where a child had leukaemia found that 84.1% reported negative behavioural or negative mood changes in their ill child. Houtzager, Grootenhuis, Caron & Last (2004) suggest that constant uncertainty regarding the course of the illness, and changes in the child’s health and behaviour are a source of high anxiety amongst parents of children with cancer.

Parental guilt is a pervasive feature of childhood cancer (Faulknor, Peace & O’Keeffe, 1995). (Darbyshire, 1994) has suggests this may be due to a number of factors, including the idea that “allowing” their child to become ill contradicts the basic parental need to protect their child. This idea of “allowing” harm to come to one’s child is particularly relevant to invasive medical procedures, such as port access, since
the parent not only "allows" health professionals to hurt (treat) their child, but is often required to assist, perhaps by restraining a struggling. It is likely that this guilt will feed into Mrs Lam’s interactions with Eddie, causing her to be more indulgent than she would be otherwise, and leaving her with fewer emotional resources to cope with Eddie’s difficult behaviours.

Mrs Lam seems to have developed an understanding of the situation which could be summarised by the statement “I am an ineffective parent and I can’t cope with Eddie’s behaviour”, a story of ineffectiveness. In addition, Eddie and Mrs Lam have developed a pattern of interaction whereby neither is certain what to expect, leading Eddie to feel confused and unboundaried, and Mrs Lam to feel stretched with regard to her resources and anxious about how she is dealing with Eddie. The interaction of Eddie’s challenging behaviours, Mrs Lam’s guilt and story of ineffectiveness, and medical considerations is complex, with guilt and ineffectiveness undermining the strategies Mrs Lam uses, medical considerations and inconsistent use of strategies feeding into Eddie’s challenging behaviour, and medical considerations and Eddie’s challenging behaviour feeding back into Mrs Lam’s guilt and feeling of ineffectiveness.

**Intervention**

Parent-training in behavioural strategies has been shown to be effective (Brestan & Eyberg, 1998; Kazdin & Weisz, 1998; Farley, Adams, Lutton & Scoville, 2005). Strategies discussed included star charts, countdowns, timers, warnings, positive and negative reinforcement, distraction, and the importance of routine.
Narrative and solution-focussed influences were most evident in the language and interaction style of the therapists. The language used did not feed into Mrs Lam’s story of ineffectiveness, but rather facilitated a story of effectiveness in the face of difficult and unpredictable challenges. Attending to unique positive outcomes was also a feature of the intervention, as was the use of the miracle question. Mrs Lam was complimented for her resilience and all progress made.

**Outcome**

Eddie’s behaviour improved quickly, to the point that, after three sessions, Mrs Lam felt so much progress had been made that she no longer needed such intensive input. However Eddie’s health deteriorated, and he spent three weeks in hospital. On return home, Mrs Lam felt that “things were back at square one” behaviourally. After re-instatement of behavioural strategies, Eddie’s behaviour rapidly improved.

The improvement-deterioration-improvement of Eddie’s behaviour was useful in enriching the story of effective parenting in the face of difficult circumstance. Mrs Lam’s understanding of the situation changed over the course of the session to include the belief that there will be good and bad periods in Eddie’s behaviour because of his illness and associated treatment, and that he will often behave in a more challenging way than other children his age.
References


SUMMARY OF CLINICAL PLACEMENT EXPERIENCE

Adult Mental Health Core Placement, 16th October 2002 to 28th March 2003.
This placement was split between Kingston Community Health Team (0.5wte), supervised by Dr Iwnicki, and Kingston Primary Care Psychology Service (0.1wte), supervised by Dr Zena Dowling. The clinical work encompassed individual and family work with people between the ages of 24 and 66, and a variety of assessments and interventions. In addition to working with people of a white British background, I worked with a Peruvian woman, and a Viennese woman, and had input into work with a Lebanese man. I worked with some people with very strongly held religious beliefs. Presenting difficulties encountered on this placement included psychosis, bipolar affective disorder, borderline personality disorder, anxiety, depression, bereavement, physical health problems, histrionic personality disorder, post-traumatic stress disorder, obsessive-compulsive disorder, and cognitive decline.

This placement was based at Mole Valley Community Team for People with a Learning Disability and was supervised by Mrs Carol Hagland. The clinical work encompassed individual, group and family work with identified clients between the ages of 8 and 60, and a variety of assessments and interventions. All people I worked with were from a white British background. Reasons for referral on this placement included assessment of sexual awareness and vulnerability, anger management, PICA behaviour, assessment of autistic spectrum disorder, baseline assessment of dementia in a man with Down’s syndrome, declining participation, self-harm, and emotion recognition skills training.

This placement was split between Epsom Child and Adolescent Mental Health Service (0.3wte) and Epsom Under-5's Psychology Service (0.1wte), supervised by Dr Penny Bebbington, and East Elmbridge Child and Adolescent Mental Health Service (0.2wte), supervised by Dr Rebecca Scarth. The clinical work encompassed individual and family work with children between the ages of 4 and 15, and a variety of assessments and interventions. In addition to working with people of a white British background, I worked with a South African family. I worked with some people experiencing economic disadvantage. Reasons for referral on this placement included oppositional behaviour, temper tantrums, trichotillomania, suspected autistic spectrum disorder, low mood, anger, eating disorder, encopresis, cognitive assessment, school refusal, and assessment of attention deficit hyperactivity disorder.

Older People Core Placement, 7th April 2004 to 24th September 2004.

This placement was based at Guildford Community Mental Health Team for the Elderly, supervised by Mrs Diana Chanfreau, with additional supervision from Dr Sarah Agnew for cognitive assessment work. An isolated cognitive assessment was undertaken at Haslemere Hospital, under the supervision of Dr Ian Kneebone. The clinical work encompassed individual, group and family work with identified clients between the ages of 59 and 96, and a variety of assessments and interventions. All people I worked with were from a white British background. Reasons for referral on this placement included referral to a depression and anxiety management group, referral to a memory group, anxiety, panic, depression, exploration of past abuse, psychosis, withdrawal, and obsessional-compulsive behaviour.

This placement was based at The Royal Marsden Hospital, supervised by Dr Samantha Peacock. The clinical work encompassed individual, group and family work with identified clients between the ages of 4 and 18, and a variety of assessments and interventions. In addition to working with people of a white British background, I worked with a Chinese family. I worked with one family with strongly held Buddhist beliefs. Reasons for referral on this placement included low mood, catastrophic thinking, cognitive assessment, behaviour management, disturbing dreams, precocious puberty, poor school performance, and difficulty in adjusting and coping with illness.


This placement was split between The Umbrella Service, a specialist expert witness team for child protection cases (0.4wte) and Sutton Child and Adolescent Mental Health Service (0.2wte), supervised by Dr Anne-Marie Sawyer. The clinical work at the Umbrella Service has been contributing to multi-disciplinary assessment of child protection issues, which has involved interviews with adults, children, involved professionals, and cognitive assessment. The clinical work at Sutton CAMHS has encompassed individual and family work with people between the ages of 6 and 17, and a variety of assessments and interventions. All families worked with on this placement have been from a white British background. I have worked with families experiencing economic disadvantage. Presenting difficulties encountered in CAMHS included assessment of autistic spectrum difficulties, depression, obsessive-compulsive behaviour, anxiety, and school related difficulties.
INTRODUCTION TO THE RESEARCH SECTION

The clinical section of this portfolio comprises two parts. The first consists of two pieces of research carried out over the three years of training. The first piece of research is the service related research project completed in the first year; the second is the major research project, completed in the third year.

The second part is the research log book, which attempts to summarise the research skills developed over the three years of training.
Service Related Research Project
Submitted June 2003

Working with Clients with a Personality Disorder in CMHT's: Casenote Audit and Staff Opinions
I would like to thank everyone who was involved in helping me to carry out this work: my field supervisor, my university supervisor, and of course, the care managers who took the time to provide me with information.

Thank you.
# Contents

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>160</td>
</tr>
<tr>
<td>Introduction</td>
<td>161</td>
</tr>
<tr>
<td>Method:</td>
<td></td>
</tr>
<tr>
<td>Participants</td>
<td>164</td>
</tr>
<tr>
<td>Design</td>
<td>164</td>
</tr>
<tr>
<td>Materials</td>
<td>164</td>
</tr>
<tr>
<td>Procedure</td>
<td>165</td>
</tr>
<tr>
<td>Results:</td>
<td></td>
</tr>
<tr>
<td>Data From Case Notes</td>
<td>166</td>
</tr>
<tr>
<td>Qualitative Data From Questionnaire</td>
<td>171</td>
</tr>
<tr>
<td>Discussion</td>
<td>176</td>
</tr>
<tr>
<td>References</td>
<td>181</td>
</tr>
<tr>
<td>Appendices:</td>
<td></td>
</tr>
<tr>
<td>Appendix One: Questionnaire</td>
<td>183</td>
</tr>
<tr>
<td>Appendix Two: Audit Tool</td>
<td>185</td>
</tr>
<tr>
<td>Appendix Three: First Letter Sent to Care Managers</td>
<td>186</td>
</tr>
<tr>
<td>Appendix Four: Second Letter Sent to Care Managers</td>
<td>188</td>
</tr>
<tr>
<td>Appendix Five: Feedback to Service</td>
<td>189</td>
</tr>
</tbody>
</table>
ABSTRACT

Introduction: This study addresses questions raised by the Borough Personality Disorder Working Party, which was set up in the service in which the trainee was working. Goals included profiling demographics and service use of clients with a personality disorder active on the caseload of the four borough Community Mental Health Teams (CMHT’s). A further goal was to identify difficulties staff encountered when working with these clients, and staff perceptions of their own training, support and supervision needs. Method: All care managers across the four CMHT’s (n=36) were asked to complete a brief questionnaire which asked them to identify clients on their caseload diagnosed with, or suspected of having a personality disorder, as well as asking their opinions about difficulties encountered and their own training, support and supervision needs. Results: 19 care managers responded. An overview of the demographics and service use of these clients was developed. Main difficulties encountered by staff when working with these clients were mainly service related (e.g. lack of services to refer to) rather than within the client (e.g. therapy interfering behaviour). Staff indicated that training specifically focussed on working with these clients would be beneficial, and that they would feel more supported if some organisational changes were made around working with these clients (e.g. team working, specific guidelines). Discussion: A more thorough exploration of the responses to the questionnaire and the demographics, and discussion in light of current knowledge. Also, possible implications for the service are discussed.
INTRODUCTION

There has been much recent interest in personality disorder (P.D.). It has been argued that P.D. is not mental illness, and therefore should not be treated or managed within adult mental health services (Kendell, 2002). The DSM-IV (APA, 1994) characterises P.D. as pervasive, inflexible, stable over time, and with onset in adolescence or childhood.

The implementation guide for community mental health teams (Department of Health (DoH), 2002), states “most patients treated by the CMHT will have time limited disorders and be referred back to their GP’s after a period of weeks or months.....when their condition has improved” (p.4). P.D., due to it’s pervasive, inflexible, and stable nature does not fall within this remit. The implementation guide, however, does suggest “a substantial minority.......will remain with the team.....for periods of several years” (p.4), and that this minority includes people with ‘..severe disorders of personality where these can be shown to benefit by continued contact and support’ (p.4).

The feeling among staff that clients with a P.D. are difficult to manage is well documented (Nehls, 2000; White, Berry, Dalton, Napthine, Prendeville & Roberts, 2001; Davison, 2002); the impact of working with these clients in under-resourced services is undeniable. Nehls (2000) interviewed CMHT staff and found they often feel under-supported and under-trained in establishing relationships with and effectively managing personality disordered clients. With reference to managing these clients, Dunn and Parry (1997) state “the staff are often stressed and deskilll;
the psychiatrist is frustrated and irritated” (p.19). Adshead (2001) notes the lack of specialist staff or services for Clients with a P.D.; this may lead to CMHT staff feeling they are trying to manage challenging clients in unsuitable environments. It has been documented these clients take up a disproportionate amount of care manager's time (Norton, 1996; Nehls, 2000; Davison, 2002).

In the wake of the draft Mental Health Bill, the Department of Health (DoH) has published “Personality Disorder: No Longer a Diagnosis of Exclusion” (DoH, 2003). Difficulties in working with P.D. clients expressed by front-line staff are acknowledged, including the staff reluctance to work with these clients because “they believe they have neither the skills, training or resources to provide an adequate service, and.......believe there is nothing that mental health services can offer” (p.5).

The document emphasises the importance of providing training in assessment, diagnosis and treatment of clients with a P.D.

Importantly for CMHT staff, the document states service provision for personality-disordered clients can most appropriately be provided in specialist multi-disciplinary P.D. teams and day services. It acknowledges that:

.....general mental health services struggle to provide an adequate service.......people with personality disorder are treated at the margins – through A&E, through inappropriate admissions to inpatient wards, on caseloads of community team staff who.......may lack the skills to work with them (p.13).
Money has been promised to services to develop provision for clients with a P.D., but until then, it is inevitable that management will continue in CMHT’s.

In November 2002, the service in which the researcher was working set up a Borough Personality Disorder Working Party (BPDWP). At the first meeting, a number of goals were identified, including:

- Identification of numbers and demographics of personality disordered clients being worked with by CMHT's across the Borough, and the care they receive
- Identification of staff support, supervision and training needs

The researcher agreed to conduct an exploratory study to begin to address these initial goals. The research questions to be addressed were:

What are the demographic profiles of clients with a P.D. being managed by the borough CMHT’s.

What is or has been the service use of clients with a P.D. being managed by the borough CMHT’s.

What are the main difficulties experienced by care managers when working with clients with a P.D.?

What do CMHT care managers see as their supervision/support/training needs relevant to working with clients with a P.D.?

It was hoped that the information gained from this would inform the BPDWP in decisions and future directions.
METHOD

Participants

All care managers and clinical psychologists across the four borough community mental health teams (CMHT’s) were invited to take part in the study (n=36).

Design

A non-experimental survey design was used in conjunction with a case note audit.

Materials

A questionnaire was developed in consultation with the BPDWP, asking respondents to identify clients on their caseload who have, or are suspected to have, a P.D. In addition, the questionnaire included four open-ended questions asking about the participants own expertise in working with these clients; their own training, support or supervision needs; the main difficulties experienced when working with this client group; and what they perceive as the main gaps in services for these clients and their carers. A copy of this is in Appendix 1.

Also in consultation with the BPDWP, a casenote audit tool was developed to facilitate the collection of the following information: gender; age; living situation; co-morbid diagnoses; length of time involved with service; referral route; involvement of team members; and use of services. A copy of this is Appendix 2.
Procedure

Four weeks before the start of data collection, a letter was sent to all care managers explaining the proposed study, outlining the involvement required, and inviting comments or queries. A copy of this is in Appendix 3.

At the start of data collection, another letter was sent to care managers reiterating the requirements, with the questionnaire enclosed. A copy of this letter is in Appendix 4. The postal return was poor (6), despite reminder phone calls, and so the researcher arranged to present the research at team meetings, and for the team managers to allow a period of time after the presentation available for care managers to complete the questionnaires. Nine more fully completed questionnaires were collected as a result of this. Care managers who felt that they did not have the time to complete the questionnaire were given the option of simply providing the names of people on their caseload diagnosed with or suspected of having a P.D., so that the demographic data could be collected. Four partially completed questionnaires were returned as a result.

Two months after the start of data collection, the casenotes of those clients identified by care managers were examined. Due to the number of clients identified (69) and limited time, it was decided to randomly sample half (35) of all identified client’s casenotes at each team base.
RESULTS

Data from Case Notes

One team manager declined participation for their team, resulting in an accessible population of 28. Nineteen care managers responded, four of these only provided names of clients.

The diagnostic status of those clients identified by care managers are shown in Tables 1 and 2.

Table 1: Diagnostic status of sampled clients by sex and age (% of total in brackets).

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Diagnosed with a personality disorder</th>
<th>Suspected of having a personality disorder</th>
<th>Total (n=35)</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24 years old</td>
<td>Male 0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
</tr>
<tr>
<td></td>
<td>Female 0(0)</td>
<td>1(2.8)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td></td>
<td>Total 0(0)</td>
<td>1(2.8)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td>25-34 years old</td>
<td>Male 3(8.6)</td>
<td>2(5.7)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td></td>
<td>Female 3(8.6)</td>
<td>2(5.7)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td></td>
<td>Total 6(17.1)</td>
<td>4(11.4)</td>
<td>10(28.6)</td>
</tr>
<tr>
<td>35-44 years old</td>
<td>Male 1(2.8)</td>
<td>1(2.8)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td></td>
<td>Female 11(31.4)</td>
<td>1(2.8)</td>
<td>12(34.2)</td>
</tr>
<tr>
<td></td>
<td>Total 12(34.3)</td>
<td>2(5.7)</td>
<td>14(40)</td>
</tr>
<tr>
<td>45-54 years old</td>
<td>Male 0(0)</td>
<td>1(2.8)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td></td>
<td>Female 2(5.7)</td>
<td>2(5.7)</td>
<td>4(11.4)</td>
</tr>
<tr>
<td></td>
<td>Total 2(5.7)</td>
<td>3(8.6)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td>55-64 years old</td>
<td>Male 1(2.8)</td>
<td>1(2.8)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td></td>
<td>Female 1(2.8)</td>
<td>2(5.7)</td>
<td>3(8.6)</td>
</tr>
<tr>
<td></td>
<td>Total 2(5.7)</td>
<td>3(8.6)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td>TOTAL SAMPLE</td>
<td>Male 5(14.3)</td>
<td>5(14.3)</td>
<td>10(28.6)</td>
</tr>
<tr>
<td></td>
<td>Female 17(48.6)</td>
<td>8(22.9)</td>
<td>25(71.4)</td>
</tr>
<tr>
<td></td>
<td>Total 22(62.9)</td>
<td>13(37.1)</td>
<td>35(100)</td>
</tr>
</tbody>
</table>

166
Table 2: Diagnostic status of clients (all).

<table>
<thead>
<tr>
<th></th>
<th>Number</th>
<th>Percentage of Total (n=69)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosed</td>
<td>29</td>
<td>42</td>
</tr>
<tr>
<td>Suspected</td>
<td>40</td>
<td>58</td>
</tr>
<tr>
<td>Total</td>
<td>69</td>
<td>100</td>
</tr>
</tbody>
</table>

The proportion of clients diagnosed with as opposed to suspected of having a P.D. was different in the total sample (n=69; diagnosed=42%, suspected=58%) and the casenote sample (n=35, diagnosed=63%, suspected=37%). This may have been due to random sampling error, but should be borne in mind when interpreting the data from the casenotes.

The length of time clients have been involved with the service is shown in Table 3. “This episode” refers to time since activation of current care episode. “First contact” refers to time since the first referral to the CMHT in which the active care episode is being managed. Table 3 also shows how long the client has had a diagnosis of personality disorder, if diagnosed.
Table 3: Length of time since diagnosis, first contact, and beginning of current care episode. Note: if unclear when the diagnosis was made, cases are excluded from the analysis for diagnosis, but included for other analyses.

<table>
<thead>
<tr>
<th></th>
<th>Mean (months)</th>
<th>Median (months)</th>
<th>Standard deviation (months)</th>
<th>Minimum (months)</th>
<th>Maximum (months)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>{years}</td>
<td>{years}</td>
<td>{years}</td>
<td>{years}</td>
<td>{years}</td>
</tr>
<tr>
<td>Diagnosis (n=19)</td>
<td>70.32</td>
<td>49</td>
<td>67.84</td>
<td>6</td>
<td>266</td>
</tr>
<tr>
<td></td>
<td>{5.86}</td>
<td>{4.08}</td>
<td>{5.65}</td>
<td>{0.50}</td>
<td>{22.17}</td>
</tr>
<tr>
<td>This episode (n=35)</td>
<td>20.54</td>
<td>17</td>
<td>16.45</td>
<td>4</td>
<td>81</td>
</tr>
<tr>
<td></td>
<td>{1.71}</td>
<td>{1.42}</td>
<td>{1.37}</td>
<td>{0.33}</td>
<td>{6.75}</td>
</tr>
<tr>
<td>First contact (n=35)</td>
<td>66.09</td>
<td>62</td>
<td>45.04</td>
<td>8</td>
<td>242</td>
</tr>
<tr>
<td></td>
<td>{5.51}</td>
<td>{5.17}</td>
<td>{3.75}</td>
<td>{0.67}</td>
<td>{20.17}</td>
</tr>
</tbody>
</table>

The current living situation of clients is shown in Table 4.

Table 4: Living situation by sex and age (% of total in brackets)

<table>
<thead>
<tr>
<th>Own home</th>
<th>Alone</th>
<th>Shared (not with family)</th>
<th>With family</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Female</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>4(11.4)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td>Total</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>4(11.4)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td>Privately rented</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Female</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>3(8.6)</td>
<td>4(11.4)</td>
</tr>
<tr>
<td>Total</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>3(8.6)</td>
<td>4(11.4)</td>
</tr>
<tr>
<td>Council/housing association</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5(14.3)</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>6(17.1)</td>
</tr>
<tr>
<td>Female</td>
<td>3(8.6)</td>
<td>7(20)</td>
<td>4(11.4)</td>
<td>14(40)</td>
</tr>
<tr>
<td>Total</td>
<td>8(22.9)</td>
<td>8(22.9)</td>
<td>4(11.4)</td>
<td>20(57.1)</td>
</tr>
<tr>
<td>Residential care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2(5.7)</td>
<td></td>
<td></td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Female</td>
<td>1(2.8)</td>
<td></td>
<td></td>
<td>1(2.8)</td>
</tr>
<tr>
<td>Total</td>
<td>3(8.6)</td>
<td></td>
<td></td>
<td>3(8.6)</td>
</tr>
<tr>
<td>Homeless/vulnerably housed</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2(5.7)</td>
<td></td>
<td></td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Female</td>
<td>1(2.8)</td>
<td></td>
<td></td>
<td>1(2.8)</td>
</tr>
<tr>
<td>Total</td>
<td>3(8.6)</td>
<td></td>
<td></td>
<td>3(8.6)</td>
</tr>
<tr>
<td>All housing</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7(20)</td>
<td>3(8.6)</td>
<td>0(0)</td>
<td>10(28.6)</td>
</tr>
<tr>
<td>Female</td>
<td>6(17.1)</td>
<td>8(22.9)</td>
<td>11(31.4)</td>
<td>25(71.4)</td>
</tr>
<tr>
<td>Total</td>
<td>13(37.1)</td>
<td>11(31.4)</td>
<td>11(31.4)</td>
<td>35(100)</td>
</tr>
</tbody>
</table>
Co-morbid diagnoses of clients are shown in Table 5.

Table 5: Co-morbid diagnoses by sex (% of total in brackets). Note: totals come to more than 100% because most clients have multiple co-morbid diagnoses.

<table>
<thead>
<tr>
<th>None</th>
<th>Eating disorder</th>
<th>Anxiety disorder</th>
<th>Depressive disorder</th>
<th>Psychotic disorder</th>
<th>Substance dependency</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Male</strong></td>
<td>1(2.8)</td>
<td>1(2.8)</td>
<td>3(8.6)</td>
<td>5(14.3)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td><strong>Female</strong></td>
<td>1(2.8)</td>
<td>7(20)</td>
<td>15(42.9)</td>
<td>19(54.3)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>2(5.7)</td>
<td>8(22.9)</td>
<td>18(51.4)</td>
<td>24(68.6)</td>
<td>3(8.6)</td>
</tr>
</tbody>
</table>

94.3% had at least one co-morbid diagnosis.

Reason for and source of referral at the beginning of this care episode are shown in Table 6b, the codes used for this are in Table 6a.

Table 6a: Codes used in Table 6b.

<table>
<thead>
<tr>
<th>Code</th>
<th>Explanation</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP</td>
<td>Referred by general practitioner</td>
</tr>
<tr>
<td>CMHT</td>
<td>Referred from other CMHT</td>
</tr>
<tr>
<td>Self</td>
<td>Self referral</td>
</tr>
<tr>
<td>Inpat</td>
<td>Referred from psychiatric inpatients on discharge</td>
</tr>
<tr>
<td>Other</td>
<td>Referred from other agency (e.g. drugs team, probation service).</td>
</tr>
<tr>
<td>A&amp;E</td>
<td>Referred from A&amp;E after presenting with psychiatric difficulties</td>
</tr>
<tr>
<td>Fr/Fa</td>
<td>Referred by a friend or family member</td>
</tr>
<tr>
<td>A&amp;M Dep.</td>
<td>Referred for assessment and management of depression</td>
</tr>
<tr>
<td>A&amp;M Anx.</td>
<td>Referred for assessment and management of anxiety</td>
</tr>
<tr>
<td>Det. MH</td>
<td>Referred because of deteriorating mental health</td>
</tr>
<tr>
<td>Biz. Beh.</td>
<td>Referred because of 'bizarre behaviour'.</td>
</tr>
<tr>
<td>Crisis</td>
<td>Referred for support after crisis incident</td>
</tr>
<tr>
<td>Trans.</td>
<td>Transfer of care from other service.</td>
</tr>
</tbody>
</table>
Table 6b: Reason for and source of referral (% of total in brackets).

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred by</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>GP</td>
<td>6(17.1)</td>
<td>2(5.7)</td>
<td>3(8.6)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>1(2.8)</td>
<td>12(34.3)</td>
</tr>
<tr>
<td>CMHT</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>7(20)</td>
<td>7(20)</td>
</tr>
<tr>
<td>Self</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>2(5.7)</td>
<td>0(0)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Inpat</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>2(5.7)</td>
<td>0(0)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Other</td>
<td>1(2.8)</td>
<td>1(2.8)</td>
<td>1(2.8)</td>
<td>0(0)</td>
<td>2(5.7)</td>
<td>2(5.7)</td>
<td>7(20)</td>
</tr>
<tr>
<td>A&amp;E</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>3(8.6)</td>
<td>0(0)</td>
<td>3(8.6)</td>
</tr>
<tr>
<td>Fr/Fa</td>
<td>0(0)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>2(5.7)</td>
<td>0(0)</td>
<td>0(0)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Total</td>
<td>7(20)</td>
<td>3(8.6)</td>
<td>4(11.5)</td>
<td>2(5.7)</td>
<td>9(25.7)</td>
<td>10(28.6)</td>
<td></td>
</tr>
</tbody>
</table>

The coding of reasons for referral was checked for inter-rater reliability by another trainee recoding a sample of 10, and analysing with Cohen’s Kappa. In this case, Kappa=0.875, which shows an excellent level of agreement (Fleiss, 1981).

The involvement of team members and the services accessed, or declined, by clients; both now and in the past; is shown in Tables 7 and 8.

Table 7: Involvement of team members (% of total in brackets).

<table>
<thead>
<tr>
<th>Team Member</th>
<th>Now</th>
<th>Past</th>
<th>Now or Past</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Worker</td>
<td>9(25.6)</td>
<td>15(42.9)</td>
<td>24(68.6)</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>25(71.4)</td>
<td>4(11.5)</td>
<td>29(82.9)</td>
</tr>
<tr>
<td>Occupational Therapist</td>
<td>3(8.6)</td>
<td>7(20)</td>
<td>10(28.6)</td>
</tr>
<tr>
<td>Community Psychiatric Nurse</td>
<td>28(80)</td>
<td>5(4.3)</td>
<td>33(94.3)</td>
</tr>
<tr>
<td>Clinical Psychologist</td>
<td>9(25.7)</td>
<td>8(22.9)</td>
<td>17(48.6)</td>
</tr>
<tr>
<td>Support Worker</td>
<td>6(17.1)</td>
<td>1(5.7)</td>
<td>7(20)</td>
</tr>
</tbody>
</table>

Note: where a team member is involved both now and in the past, only current involvement is shown.
Table 8: Services accessed or declined (% of total in brackets).

<table>
<thead>
<tr>
<th>Service</th>
<th>Now</th>
<th>Past</th>
<th>Now or Past</th>
<th>Declined</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child and Family</td>
<td>5(14.3)</td>
<td>4(11.5)</td>
<td>9(25.7)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Day Services</td>
<td>16</td>
<td>7(20)</td>
<td>23(65.7)</td>
<td>3(8.6)</td>
</tr>
<tr>
<td>Inpatient</td>
<td>3(8.6)</td>
<td>11(31.4)</td>
<td>14(30)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Eating Disorders</td>
<td>0(0)</td>
<td>3(8.6)</td>
<td>3(8.6)</td>
<td>2(5.7)</td>
</tr>
<tr>
<td>Community Drug &amp; Alcohol Team</td>
<td>2(5.7)</td>
<td>4(11.5)</td>
<td>6(17.1)</td>
<td>5(14.3)</td>
</tr>
<tr>
<td>Psychotherapy</td>
<td>6(17.1)</td>
<td>2(5.7)</td>
<td>8(22.9)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td>Housing/Homeless Peoples Unit</td>
<td>2(5.7)</td>
<td>11(31.4)</td>
<td>13(37.1)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Dialectical Behaviour Therapy</td>
<td>3(8.6)</td>
<td>0(0)</td>
<td>3(8.6)</td>
<td>0(0)</td>
</tr>
<tr>
<td>Residential Rehabilitation</td>
<td>1(2.8)</td>
<td>6(17.1)</td>
<td>7(20)</td>
<td>1(2.8)</td>
</tr>
<tr>
<td>Women’s Centre</td>
<td>2(5.7)</td>
<td>2(5.7)</td>
<td>4(11.5)</td>
<td>0(0)</td>
</tr>
</tbody>
</table>

Note: where a service is accessed both now and in the past, only current involvement is shown.

Qualitative Data from Questionnaire

All data were subjected to content analysis and frequency counts. The coding of responses to questions were checked for inter-rater reliability by another trainee recoding a sample of 10, and analysing with Cohen’s Kappa.

The content analysis of the responses to the open-ended questions, and frequency counts, are shown in Tables 9b, 10b, 11b, and 12b. Explanation of the coding categories used are in Tables 9a, 10a, 11a, and 12a.
What is your own expertise in working with people with a personality disorder?

Table 9a: Coding categories for Question 4.

<table>
<thead>
<tr>
<th>Category</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>The respondent stated ‘none’.</td>
</tr>
<tr>
<td>Experience</td>
<td>The respondents cited their own experience.</td>
</tr>
<tr>
<td>Associated</td>
<td>The respondent cited one or more training courses they had attended dealing with issues often presented by clients with a personality disorder (e.g. deliberate self-harm, violence towards staff).</td>
</tr>
<tr>
<td>Specific</td>
<td>The respondent cited one or more training courses they had attended dealing specifically with issues presented by clients with a personality disorder.</td>
</tr>
</tbody>
</table>

Table 9b: Responses to Question 4 (n=15).

<table>
<thead>
<tr>
<th></th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>None</td>
<td>1</td>
</tr>
<tr>
<td>Experience</td>
<td>14</td>
</tr>
<tr>
<td>Associated</td>
<td>4</td>
</tr>
<tr>
<td>Specific</td>
<td>4</td>
</tr>
</tbody>
</table>

Cohen’s Kappa=1, which shows complete agreement (Fleiss, 1981).
What do you think your own training/support/supervision needs are in relation to working with people with a personality disorder?

Table 10a: Coding categories for Question 5.

<table>
<thead>
<tr>
<th>Category</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Supervision</td>
<td>More, or more regular supervision is needed.</td>
</tr>
<tr>
<td>Guidelines</td>
<td>Specific guidelines for working with people with a personality disorder should be available to staff (e.g. self-harm, threatened suicide, boundaries, time allocation).</td>
</tr>
<tr>
<td>Team working</td>
<td>Clients should have more than one named care manager sharing the load and taking it in turns to be the main contact.</td>
</tr>
<tr>
<td>Caseload</td>
<td>Managers should be aware that these clients take up a disproportionate amount of time, and should allocate accordingly.</td>
</tr>
<tr>
<td>Specific Training</td>
<td>Training specifically focussed on care management of people with a personality disorder should be available to care managers.</td>
</tr>
<tr>
<td>Emotions</td>
<td>Time is needed in a team or supervisory environment for individuals to discuss their emotional response to these clients.</td>
</tr>
<tr>
<td>Expert to Refer</td>
<td>A named individual with developed skills should be available for consultation and advice.</td>
</tr>
</tbody>
</table>

Table 10b: Responses to Question 5 (n=15).

<table>
<thead>
<tr>
<th>Grouping</th>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Management / Procedural Support</td>
<td>Supervision</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Guidelines</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Team working</td>
<td>9</td>
</tr>
<tr>
<td></td>
<td>Caseload</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td>Emotions</td>
<td>5</td>
</tr>
<tr>
<td>Training</td>
<td>Specific Training</td>
<td>8</td>
</tr>
<tr>
<td>Resources</td>
<td>Expert to Refer</td>
<td>5</td>
</tr>
</tbody>
</table>

Cohen's Kappa=0.525, which shows a fair level of agreement (Fleiss, 1981).
What are the main difficulties you experience in working with this client group?

Table 11a: Coding categories for Question 6.

<table>
<thead>
<tr>
<th>Category</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caseload</td>
<td>Difficulties in dealing with clients with a personality disorder on top of a full caseload of less demanding clients</td>
</tr>
<tr>
<td>No Services</td>
<td>Client’s needs not being met in a CMHT, without a more appropriate service to refer to</td>
</tr>
<tr>
<td>Under-diagnosis</td>
<td>Culture of not diagnosing personality disorders makes accessing specialist services difficult</td>
</tr>
<tr>
<td>Behaviour</td>
<td>Client’s own behaviour interfering with therapy or management</td>
</tr>
<tr>
<td>Emotions</td>
<td>Dealing with own emotional response to these clients.</td>
</tr>
<tr>
<td>Attitudes</td>
<td>Lack of empathy, or clear antipathy towards personality disordered clients by other staff</td>
</tr>
<tr>
<td>Change</td>
<td>Lack of positive change in clients despite best efforts</td>
</tr>
<tr>
<td>Medical Model</td>
<td>Difficulty managing these clients within a service led by the medical model – feeling constrained by a culture which strives to cure medically, when personality disorders are not known to have a biological basis.</td>
</tr>
</tbody>
</table>

Table 11b: Responses to Question 6 (n=15).

<table>
<thead>
<tr>
<th>Grouping</th>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service/Procedural</td>
<td>Caseload</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>No Services</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Under-diagnosis</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Attitudes</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Medical Model</td>
<td>6</td>
</tr>
<tr>
<td>Within client</td>
<td>Behaviour</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Change</td>
<td>5</td>
</tr>
<tr>
<td>Within Self</td>
<td>Emotions</td>
<td>14</td>
</tr>
</tbody>
</table>

Cohen’s Kappa=0.735, which shows a good level of agreement (Fleiss, 1981).
What do you think the current gaps are in the service provided for people with a personality disorder, their partners, families, and carers?

Table 12a: Coding categories for Question 7.

<table>
<thead>
<tr>
<th>Category</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specialist Services</td>
<td>Lack of appropriate services to refer to.</td>
</tr>
<tr>
<td>Designated Time</td>
<td>Care managers need designated therapeutic time in order to use their skills in working with these clients</td>
</tr>
<tr>
<td>Outreach</td>
<td>Lack of outreach service for these clients</td>
</tr>
<tr>
<td>Cohesiveness</td>
<td>Need to create a shared understanding and consistent approach when working with these clients</td>
</tr>
<tr>
<td>Family</td>
<td>No provision for family interventions</td>
</tr>
<tr>
<td>Crisis</td>
<td>No service which can respond to crises out of hours</td>
</tr>
</tbody>
</table>

Table 12b: Responses to Question 7 (n=14).

<table>
<thead>
<tr>
<th>Grouping</th>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extra Services</td>
<td>Specialist Services</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Outreach</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Crisis</td>
<td>9</td>
</tr>
<tr>
<td>Extra Resources</td>
<td>Designated Time</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Family</td>
<td>5</td>
</tr>
<tr>
<td>Training/Team Issue</td>
<td>Cohesiveness</td>
<td>7</td>
</tr>
</tbody>
</table>

Cohen’s Kappa=0.675, which shows a good level of agreement (Fleiss, 1981).
DISCUSSION

Demographics and Historical

The highest proportion of diagnosed P.D.'s was in the 35-44 year age group, whilst the highest proportion of suspected P.D.'s was in the 25-34 year age group, but this is not markedly different from that in either the 45-54 or 55-64 year age groups. This may reflect diagnostic trends over the past few decades, or possibly there is a tendency to wait before diagnosing P.D., so other diagnoses such as depression or bipolar disorder can be excluded. This second supposition is supported by no clients in the 18-24 year old age group being identified as diagnosed with a P.D., and only one suspected of having a P.D. As P.D.'s begin in childhood or adolescence, and are stable over time (APA, 1994), clearly those in older age groups had a P.D. in their youth, and one would expect a similar proportion of younger people do have a P.D., but it may currently be understood differently.

There was a lot of variation in data concerning how long clients have had a diagnosis or been involved with the service. It should be noted that 40% of the sample were referred to the CMHT from other health agencies – 20% because of change of address, 20% for transfer of care. This 40% may have had a lengthy psychiatric career prior to coming into the service, and this would not be represented in the ‘time since first contact’. If data could be traced regarding when these clients became involved in services generally, a clearer pattern may emerge.
Of note from the living circumstances was that none of the men lived with families, whereas 44% of the women did. Equally, none of the men were owner-occupiers, whereas 20% of the women were. This suggests women with a personality disorder are more securely housed than men with a personality disorder. The most common living circumstance was council or housing association accommodation, but a worrying proportion of the sample were homeless or vulnerably housed. This is concerning, as living alone or being vulnerably housed are significant risk factors in mental health and suicide risk.

Forty percent of all referrals to the CMHT were from other health agencies, not GP’s (e.g. other CMHT’s, outpatient services), suggesting a longer history than evident from accessible casenotes. Of particular note is the fact that none of the sampled clients was referred for help with P.D., nor was P.D. mentioned in sampled referral letters. After transfer of care, the most common reason for referral was input after crisis event (e.g. suicide attempt). This suggests a lack of help seeking skills – an issue which poses a particular problem for personality-disordered clients (Adshead 2001). A significant proportion of clients were referred for assessment and management of depression. Although the most common co-morbid diagnosis was depression, the failure to mention P.D. in the referral indicates lack of recognition, or reluctance to suggest, the presence of P.D.’s in primary care services.

There had been a wide range of team members involved in most clients care. Interestingly, 82.9% had or were seeing the psychiatrist, and only 48.6% had or were seeing the clinical psychologist, despite relatively low efficacy of drug treatments in P.D. compared to clinical psychology input (Bateman & Tyrer, 2003). Undoubtedly,
a reason for this imbalance in professional involvement is the presence of other mental health problems, such as anxiety or depression. However, drug treatment is not known to be efficacious for treating P.D., whereas it is useful in treating mental health problems such as depression and anxiety (Roth and Fonagy, 1996). Does this mean that problems co-morbid to P.D. are being treated, whereas P.D. is not? This perhaps reflects the reliance on the medical model of the service, as suggested by responses to the open-ended questions. This could have implications when considering future service provision and skills mix.

**Qualitative**

Ninety-three percent of staff recognised their own experiential learning was valuable as a skill for working with clients with a P.D., but 53.3% wanted specific training to be available. Davison (2002) suggests that a useful approach to this need is to help staff operationalise their skills for working with these clients, and that a series of workshops is effective in maximising staff efficacy.

A recurring theme in the data was current service, management and procedural limitations. 46.7% cited caseload relief as a source of support needed, whilst 73.3% cited caseload management as a difficulty experienced when working with these clients. Similarly, dealing with the emotions engendered working with clients with a P.D. was cited as both a support need and a difficulty. Staff seemed to feel that supervisory time could usefully be increased; perhaps this would help to deal with the emotional impact. Guidelines for working with these clients were stated as a support need, as was a different approach to working with these clients by having a planned
change of care manager periodically. Again, this can be related back to emotional response, whereby, if the load is shared, the care manager does not feel completely responsible for a volatile and demanding client’s needs and safety. Related to this need to share responsibility, a third of respondents would like to have a named expert to refer problems and queries to.

Care managers found the service attitude (medical model and under-diagnosis) made it difficult to work with these clients, and about half stated that attitudes of other health professionals (antipathy, hostility) made it difficult to work with these clients. This is supportive of the DoH (2003) statement that clients with a P.D. are not best managed in CMHT’s.

Very few care managers located the difficulties they experience within the client; only 33.3% cited therapy interfering behaviour, and 33.3% cited lack of positive change as a source of difficulty. When this is considered with the other responses, it seems care managers feel they could work more effectively with these clients if changes were made to the service or procedures (team working, guidelines, caseload relief, attitude), and extra resources made available (services or expert to refer to). This idea is supported by responses to the question about gaps in services; 33.3% stated that designated therapeutic time would allow them to work more effectively, and 33.3% stated that there should be some provision to allow care managers to work with families. However, the idea that the CMHT is not meeting the needs of these clients is pervasive throughout the data.
This study has addressed the research questions generated from the goals identified at the BPDWP meeting. With regard to identifying demographics and service use of these clients, the picture that emerges is of a vulnerable, transient group of clients who place a high demand on services and have very diverse needs both therapeutically and practically (e.g. housing) – although there is no comparison with other groups of clients within the CMHT’s to compare this with. The perception among the staff in the service in which the researcher was working was that these clients take up a disproportionate amount of time. Another piece of research was being simultaneously carried out by members of the BPDWP to address these issues.

With regard to difficulties encountered by staff and staff training/support/supervision needs, the picture that emerges is of a staff group who feel under-supported in terms of applying or developing the skills they do have, in practical terms (e.g. caseload management), and in personal terms (dealing with emotions).
REFERENCES


APPENDIX ONE

ALL INFORMATION PROVIDED WILL BE KEPT CONFIDENTIAL AND ANONYMOUS

1) Please list the names of the people on your caseload who have been diagnosed with, or whom you suspect have, a personality disorder. (If you need more space, please continue on a separate sheet, maintaining the numbered format if possible).

<table>
<thead>
<tr>
<th>No.</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td></td>
</tr>
</tbody>
</table>

2) In the case of the patients you have named above, which of them have been formally diagnosed with a personality disorder? Please write the numbers and state which personality disorder.

3) In the case of those patients who have not been formally diagnosed, but whom you suspect have a personality disorder, why do you suspect that this is the case? Please write the number (from question 1) corresponding to each client, and give your reason below.

<table>
<thead>
<tr>
<th>No.</th>
<th>Reason</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4) What is your own expertise in working with people with a personality disorder?
5) What do you think your own training/support/supervision needs are in relation to working with people with a personality disorder?

6) What are the main difficulties you experience in working with this client group?

7) What do you think the current gaps are in the service provided for people with a personality disorder, their partners, families and carers. Please try to be specific.

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE
APPENDIX TWO

Name:

Gender:

Age:

Living situation of service user:

Diagnosis:

If not, why?

If so, when?

Additional diagnoses?

Length of time involved with service?

Where referred from?

What referred for?

Team members involved now?

Team members involved in past?

Services accessed now?

Services accessed in past?

Services offered but not accessed?
Dear Colleague,

As you may know, in 2002, a borough personality disorder working party chaired by was formed. The first meeting was held in November 2002.

Many local needs were identified at this meeting – not least of which was the need to audit and profile the number of people diagnosed with or suspected of having a personality disorder active on the caseloads of the four CMHT’s in order to effectively consider next steps. Other needs identified included:

- The need to identify what is currently on offer for this client group and their carers in terms of assessment, diagnosis, referral routes and therapy, and to identify gaps in the service.
- The need to identify local staff expertise in working with this client group.
- The need to identify staff supervision and training needs.

As a result, an audit will be carried out addressing the above points and also to create an accurate picture of the service and resource use and needs of these clients.

I will carry out the bulk of the data collection by accessing case notes to identify referrals made, diagnoses made, and professional involvement, among other things. A complete list of the information I intend to glean from the case notes is attached. Before I can do this, I need you to let me know the names of the people on your case load who are diagnosed with, or whom you suspect have, a personality disorder. I also hope that you will be willing to provide me with the following information:

- If no formal diagnosis of personality disorder has been made, why do you suspect that this individual has a personality disorder?
- What is your own expertise in working with people with a personality disorder?
- What do you think your own training/support/supervision needs are in relation to working with people with a personality disorder?
- What are the main difficulties you experience in working with this client group?
- What do you think the current gaps are in the service provided for people with a personality disorder, their partners, families and carers?
All information/opinions will be treated in the strictest confidence, and anonymity will be maintained at all times in the reporting of the information I receive.

By providing this information to enable me to carry out this audit, you will be helping to create a clear picture of the strengths and weaknesses of local services in relation to this client group and staff support. This will help to inform the working party, and hopefully have an impact on future developments. I will, of course, provide anonymised feedback to the CMHT’s regarding the findings of this audit.

In the next few weeks I will be sending a letter and brief record form asking you for this information. If you have any questions, please do not hesitate to get in touch.

Yours faithfully

Caroline Haigh
Trainee Clinical Psychologist

---------------------------------------------

Information I will be getting from the case notes:

- Gender of service user
- Age of service user
- Length of time service user has been involved with the service
- Where referral of service user came from
- What was service user referred for?
- If a formal diagnosis, when was it made, and who made it?
- Does service user have any additional diagnoses?
- Which team members are involved in the care of the service user?
- Which team members have been involved with the service user historically?
- Which services are/have been accessed by the service user (what referrals have been made)?
- Which services have been offered but not accessed (what referrals have been made)?
- Living situation of the service user

If there is any other information that you think would be important for me to get from the case notes, please let me know as soon as possible. Thanks.
Dear Colleague,

A short time ago, I sent you a letter informing you about a borough personality disorder audit. I hope you have had time to think about the clients on your caseload and your own opinions about what is currently on offer for these clients.

Please find attached a response form. I would be grateful if you could return this to me at CMHT as soon as possible. Thank you.

I would like to remind you that all information/opinions provided will be treated in the strictest confidence, and anonymity will be maintained at all time in the reporting of the information I receive.

Once all the data is collected and collated, I hope to be able to feedback the findings to the teams, perhaps by presenting them at a team meeting.

If you have any questions, please do not hesitate to get in touch.

Yours faithfully

Caroline Haigh
Trainee Clinical Psychologist

Please complete the form with reference only to those clients active on your caseload as at 14th February 2003. Thank you.
Dear Caroline

Re: Service Related Project - *Working with Clients with a Personality Disorder in CMHT’s: Casenote Audit and Staff Opinion*

I am writing to confirm receipt of the completed service related project that you carried out on placement in the Adult Mental Health Service, South West London and St. George’s Mental Health Trust. Thank you also for the summary document that you sent for dissemination to the Working Party on Personality Disorders, which I discussed in the recent meeting.

With best wishes

Yours sincerely

Dr Anna Iwnicki
Chartered Clinical Psychologist
Preparation for General Anaesthesia: Who Needs It?

Factors Associated with Peri-Operative Distress in Children

by

Caroline Haigh

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

Department of Psychology
School of Human Sciences
University of Surrey

July 2006

© Caroline Haigh 2006

Word Count: 19759
## CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abstract</td>
<td>193</td>
</tr>
<tr>
<td>Introduction</td>
<td>194</td>
</tr>
<tr>
<td>Aims and Hypotheses</td>
<td>220</td>
</tr>
<tr>
<td>Method:</td>
<td></td>
</tr>
<tr>
<td>Process</td>
<td>222</td>
</tr>
<tr>
<td>Amended Hypotheses</td>
<td>225</td>
</tr>
<tr>
<td>Timeline</td>
<td>226</td>
</tr>
<tr>
<td>Setting</td>
<td>226</td>
</tr>
<tr>
<td>Recruitment</td>
<td>227</td>
</tr>
<tr>
<td>Participants</td>
<td>230</td>
</tr>
<tr>
<td>Design</td>
<td>234</td>
</tr>
<tr>
<td>Procedure</td>
<td>234</td>
</tr>
<tr>
<td>Measures</td>
<td>236</td>
</tr>
<tr>
<td>Ethical Considerations</td>
<td>244</td>
</tr>
<tr>
<td>Results</td>
<td>246</td>
</tr>
<tr>
<td>Summary of Significant Results and Trends</td>
<td>264</td>
</tr>
<tr>
<td>Discussion</td>
<td>265</td>
</tr>
<tr>
<td>References</td>
<td>281</td>
</tr>
<tr>
<td>Appendices:</td>
<td></td>
</tr>
<tr>
<td>Appendix One: Letter to Parents</td>
<td>297</td>
</tr>
<tr>
<td>Appendix Two: Letter to Consultant</td>
<td>298</td>
</tr>
<tr>
<td>Appendix Three: EAS</td>
<td>299</td>
</tr>
</tbody>
</table>
ABSTRACT

Introduction: Preparation for distressing medical procedures may be useful for some children. Little direct research exists on which children will benefit. Focussing on induction to general anaesthesia, this study attempts to identify factors which could allow preparation to be more appropriately targeted.

Method: Families of children aged between seven and twelve were invited to take part in the study. Parents/guardians completed the Emotionality, Activity and Sociability (EAS) scale, the Children's Surgical Worries Scale–Revised (CSWQ-R) and the Behavioural Upset in Medical Patients–Revised (BUMP-R); and children completed the Spence Children's Anxiety Scale (SCAS) and the Children's Surgical Worries Questionnaire (CSWQ). Demographic and background information was collected. At induction, the Induction Compliance Checklist (ICC) was completed by a member of theatre staff.

Results: The following were found to be associated with less compliance at induction to general anaesthesia: more expressed preoperative worry (CSWQ); higher parental ratings of child's worry (CSWQ-R); more generalised anxiety traits (SCAS-GAD); less expressed negativity/agitation in hospital than at home; higher number of previous procedures.

Discussion: It is possible and desirable to identify those children most at risk of low compliance/high distress at induction to general anaesthesia. Measures such as the CSWQ/CSWQ-R; SCAS and BUMP-R are worthy of attention as predictive measures, and attention should be paid to background factors such as previous experience of medical/dental procedures.
INTRODUCTION

MEDICAL ANXIETY IN CHILDREN

Many factors may combine to make a medical experience frightening or anxiety provoking for a child. The environment is strange—there may be unfamiliar machines, sounds and smells. Many different professionals are present, usually wearing unfamiliar clothing, for example, white coats, nurse’s uniforms, or theatre scrubs. A child in hospital may become aware of others’ injuries or physical manifestations of illness (e.g. children with no hair in oncology settings, children in wheelchairs in orthopaedic settings). A sick child is not in control, they are told they “have” to do certain things, which may be painful or invasive. Even blood pressure measurement can be an intolerably uncomfortable and intrusive experience for a child (Saylor et al, 1987). Couple these novel and potentially threatening environmental stimuli with a child’s cognitive apparatus for dealing with the world, and it is easy to see why a child may find any hospital experience anxiety provoking.

Anxiety in medical situations among a paediatric population has been recognised since at least 1909, when Nicholl (1909) discussed the benefits of treating paediatric patients as outpatients to minimise the stress of admission and parental separation. Eckenhoff (1958) reported a link between “unsatisfactory” anaesthetic inductions and post-operative behavioural changes in children. This publication led to general acknowledgement of the importance of recognising and addressing children’s anxiety in the perioperative period. During the 1960’s and 1970’s, research was carried out into benefits of parental presence and preparation of children for procedures.
WHAT IS INDUCTION TO GENERAL ANAESTHESIA?

Induction to general anaesthesia, also referred to as anaesthetic induction, is the point at which the child is pharmaceutically rendered unconscious. There are two main methods of anaesthetic induction: inhalation induction, where the child breathes a mixture of volatile anaesthetic agents until loss of consciousness is achieved; and intravenous induction, where an anaesthetic drug is injected intravenously in a dose sufficient to produce unconsciousness. For elective surgery, which is most often day-case surgery where the child will arrive in the morning and leave in the afternoon, the child will not usually have a cannula inserted prior to entering the operating suite and so venepuncture is a part of the intravenous induction.

Generally, in the United Kingdom (UK), anaesthetic induction is carried out with at least one parent present in the operating suite, and younger children will often sit on their parent’s lap (Mellor, 2004). In his comprehensive review of paediatric anaesthetic practice, Mellor (2004) also reveals a preference in the UK for using intravenous induction over inhalation induction.

WHY IS ANAESTHETIC INDUCTION STRESSFUL FOR CHILDREN

Medical encounters can represent a frightening and anxiety provoking situation for children. Mellor (2004) suggests that, generally, psychological and behavioural issues due to immaturity may make induction of anaesthesia more challenging for children than for adults, although this statement could apply equally well to any medical
situation or procedure, or indeed, any novel situation in which the child feels threatened. Kain, Mayes, Weisman and Hofstadter (2000) suggest that specific factors relating to induction to general anaesthesia which make it a potential stressor include anticipated parental separation, pain, loss of control, and masked strangers working in a highly technical environment. There is also the intrusion/assault on the person—for intravenous induction, the needle or cannula will be inserted into the arm or hand; for inhalation induction, a mask with an odd smell will be clamped over the face.

HOW COMMON IS NON-COMPLIANCE?

The quoted incidence of non-compliance with and distress/anxiety during medical and dental procedures varies widely in the literature, as does the way in which non-compliance/distress/anxiety is assessed. Tyc, Klosky, Kronenberg, de Armendi and Merchant (2002) used a 12-item behaviour checklist to assess children’s behavioural distress prior to radiation therapy. They reported a 65% incidence of distress, and a 34% incidence of high behavioural distress. Ljungman, Gordh, Sorensen and Krueger (2001) reported that 20% of children undergoing lumbar puncture under conscious sedation demonstrated such high levels of behavioural distress and non-compliance that the procedure could not be performed.

Within the field of dentistry, Folayan, Idehen and Ojo (2004) suggest that the incidence of high dental anxiety is quoted within the literature as 3-43%. Holmes and Girdler (2005) quote an incidence of 16% negative behaviour during dental treatment, whereas Hosey et al (2006) quote an incidence of 42% induction distress in children having a general anaesthetic for dental treatment. For general anaesthesia more
generally, Proczkowska-Bjorklund & Svedin (2004) quoted an incidence of 16% non-compliant behaviour at mask placement or i.v. insertion, and Aguilera, Patel, Meakin and Masterson (2003) quoted an incidence of 8% non-compliant behaviour during inhalation induction and 38% non-compliant behaviour during intravenous induction. Lumley, Melamed and Abeles (1993) reported a 56% incidence of behavioural distress and a 4% incidence of high behavioural distress, and Kain, Mayes, O’Connor and Cicchetti (1996) reported incidence of 40% to 60% for high anxiety at induction. A study conducted at the hospital in which this research is carried out reported incidence of 58% unsatisfactory behaviour at inhalation induction and an incidence of 48% unsatisfactory behaviour at intravenous induction (Meyer & Lakheeran, 2002).

WHAT HELPS REDUCE THE STRESS/TRAUMA OF MEDICAL PROCEDURES?

Preparation Programmes

Many studies have evaluated the efficacy of different types of preparation programmes in reducing anxiety and non-compliance with medical procedures, including anaesthetic induction. Many of these studies are beset with the ubiquitous flaw discussed at greater length on pages 13-14 where the outcome measure is poorly defined or arbitrarily assessed.

Most common are programmes of information provision, and preparation programmes where the child role-plays the procedure either with a medical professional running through the procedure with the child, or the child administering the procedure to a doll.
or teddy. Other preparation programmes include meeting all staff to be involved with the procedure, touring the operating suite, playing with the equipment which will be used, or reading through story books about the procedure.

There is evidence linking effective provision of information with increased parental satisfaction with their child’s surgical procedure and decreased parental anxiety, as well as reportedly decreasing anxiety and increasing co-operation from the child (Babb, Mutendera & Rogers, 2002). Babb et al (2002) further note that anaesthetic clinics are not the norm in Britain, meaning that effective provision of information is not always possible other than on the day of surgery, since leaflets are infrequently read. They set up a project where parents and children could access a password-protected website with detailed information about having a general anaesthetic. The parents who participated reported high levels of satisfaction with their child’s procedure, however, Babb et al (2002) do not report whether provision of information affected the experience of the child, seeming to take the parent report of satisfaction as proxy for the child’s experience.

Similarly, Bellew, Atkinson, Dixon and Yates (2002) and Wisselo, Stuart and Muris (2004) explored the impact of, respectively, an information leaflet and an information video on levels of parental satisfaction and anxiety. There appears to be an acceptance in the anaesthetic literature that the correlation between parental anxiety or satisfaction and child anxiety or satisfaction is direct and causative. Although, as is discussed later, increased parental anxiety is associated with more problematic behaviour in children during medical procedures, the nature of this link, whether
situation specific symbiosis, genetic, familial socialisation, due to state-dependent factors, or a combination of these remains unclear.

Evidence for the effectiveness of psychosocial preparation programmes is mixed. Palermo, Drotar and Tripi (1999) reviewed 20 studies of psychosocial interventions for children undergoing outpatient surgical procedures. Ten of these involved preparation programmes such as leaflet/book provision, interactive preparation, video, play preparation, and tours of hospitals. For the remaining ten studies the psychosocial intervention was allowing parents to be present at induction. Randomised controlled trials were a small proportion of the studies, and there were methodological issues that limited the comparability of these studies. No effects of psychological preparation were demonstrated on children's behaviour during anaesthetic induction or in the post-operative period. Methodologically, the studies reviewed by Palermo et al (1999) use different end points for assessment of outcome (pre-, peri-, or post-operative, or a combination) and also consider different outcomes, such as child knowledge, child anxiety, behaviour problems, requests for medication. Common to much research in this area, most outcome measures are measured pre- or post-operatively, due to the difficulty of completing an outcome measure peri-operatively. Where outcome measures are completed peri-operatively, there is a tendency for oversimplification, due largely to the pressures and busyness of this period of time.

More recently, Hatava, Olsson & Lagerkranser (2000), in a randomised controlled trial, compared preoperative anxiety levels in a group of children who completed a preadmission visit with a group of children who were only provided with written
information about the procedure. Outcome measures included improved knowledge, and children’s attitudes to the preanaesthetic events. Children’s attitudes to the preanaesthetic events were assessed on a scale of “very good-good-poor-very poor”, and “calm-neutral-afraid-very afraid”. Hatava et al (2000) found that age and previous experience were more important predictors of emotional reaction at induction than was participation in a preparation programme.

Palermo et al. (1999) suggested that future studies should strengthen methodological rigour, make intervention relevant to outpatient surgery, and use developmentally appropriate intervention strategies. It would also be appropriate to attempt to focus preparation interventions towards those children most in need rather than providing them for all children who are in the right place at the right time. It could be argued that the apparent application of preparation strategies in the absence of selection criteria is not the best approach. It could be that, were studies focussing more on children within a specific developmental bracket, or on children who have been identified as at high risk of anxiety, that the results would prove more favourable.

**Behavioural Strategies**

In-situ behavioural strategies such as distraction, controlled breathing, progressive muscle relaxation, and visual imagery are commonly used as an aid to distressing medical procedures. In a review of these interventions amongst chronically ill children Slifer, Tucker & Dahlquist (2002) concluded that there were short-term benefits on single occasions, but no one in-situ behavioural strategy was consistently effective. Within an outpatient surgical population, a single occasion short-term
benefit may be all that is needed. Slifer et al (2002) also identify the need for development of efficient screening measures to identify children and families who are least likely to cope in order for priority allocation of limited psychosocial resources.

In their review of psychosocial intervention research, Palermo et al (1999) included studies using these types of behavioural strategy, and in common with the outcomes for preparation programmes, demonstrated no effect during induction or postoperatively. Additionally, it is interesting that the findings of Slifer et al (2002) and Palermo et al (1999) regarding this type of intervention differ – perhaps the focus on different populations of paediatric patients (outpatient surgical vs chronically ill) has impacted here.

**Parental Presence**

Infants and young children are often reassured by the presence of a parent in the anaesthetic room. This may not always be possible but if feasible and the parent is able to contain their own anxiety, benefit has been demonstrated, although findings are mixed. Piira, Sugiura, Champion, Donnelly and Cole (2005) conducted a systematic review of twenty-eight studies, and concluded that the effect of parental presence on measures of child distress and affect was unclear, with less rigorous studies more likely to report significant effects. They also concluded that parents who were present at induction were either better off or no different from parents who were absent regarding reported levels of satisfaction and distress.
Mellor (2004), a consultant paediatric anaesthetist, suggests that benefits of parental presence include the child being able to receive a cuddle, the parent persuading the child to co-operate, and the parents being able to distract children enough for them to receive an induction. However, it is important to note that, where parents are highly anxious themselves, their presence in the anaesthetic room may be detrimental to the emotional state of the child. Messeri, Caprilli and Busoni (2004) demonstrated significant positive correlations between both state and trait anxiety of present parents (as measured by the State-Trait Anxiety Inventory) and level of child stress at induction to anaesthesia (as measured using a four point scale). This fact may explain why many studies, such as those reviewed by Piira et al (2005) found no demonstrable difference in distress for children with or without their parent’s presence.

**WHY IS IT IMPORTANT TO HELP?**

There are three main reasons why it is important to identify those children at risk for anxiety reactions and difficult behaviour at induction to general anaesthesia. Firstly, there are humanitarian reasons—if there is anything that can be done to reduce distress in children at what is a stressful time, it should be done. It is important to identify those children most at risk for high anxiety/low compliance so limited resources can be effectively deployed, rather than utilising a strategy where either the child needs to have demonstrated extreme distress at a previous procedure, or just happens to be in the right place at the right time.

Secondly, there are medical reasons—it is more difficult and dangerous to induce an anxious or distressed child (Proczkowska-Bjorklund & Svedin, 2004). The
physiological changes associated with anxiety—increased heart and respiration rate, increased gastric pH level, shrinking of veins—can all cause medical complications (Litman, Berger & Chhibber, 1996). The potential behavioural changes—struggling, screaming, attempting to escape, becoming rigid or limp—make the process more difficult, stressful and upsetting for the medical staff, the parents, and the child.

Thirdly, there is evidence that a stormy induction to general anaesthesia is linked to negative post-operative mood and behaviour changes. Anxious or distressed behaviour at induction has been linked to postoperative arousal distress (Holm-Knudsen, Carlin & McKenzie, 1998; Kain, Wang, Mayes, Caramico & Hofstadter, 1999), sleep and eating disturbances (Kain et al, 1996), temper tantrums and new-onset enuresis (Kotiniemi, Ryhanen & Moilanen, 1997).

Clinical observation and research have shown that many children experience observable anxiety and distress during induction to anaesthesia. For example, Meyer and Lakheeram (2002) reported 53% "unsatisfactory" behaviour at induction. This distress can have several consequences in addition to those mentioned above. Firstly, that the planned procedure may be postponed or cancelled; this has practical and financial implications for the child, their family and also for the service. Secondly, there is evidence to suggest that children who experience anxiety and distress during a procedure requiring anaesthetic may later display behavioural difficulties in similar situations (Kain et al, 1996) and view future operations with dread (Watson & Visram, 2003).
REVIEW OF CURRENT RESEARCH INTO PREDICTING CHILDREN’S
REACTION TO DISTRESSING MEDICAL/DENTAL PROCEDURES

Difficulties in Reviewing the Literature

One difficulty encountered in reviewing the literature was disparity of practice between the United States (US) and Europe, most specifically the United Kingdom (UK). In the US, parents are most commonly not permitted to be present at induction of anaesthesia, whereas standard practice in the UK is for one parent to be present at induction (Mellor, 2004). Kain, Ferris, Mayes and Rimar (1996) surveyed US and UK anaesthetists and found that 58% of US anaesthetists allowed parental presence in less than 5% of cases, whereas 84% of UK anaesthetists allowed parental presence in more than 75% of cases. Kain et al. (1996) suggested that fear of legal proceedings for trauma on the part of the parents, or for injuries sustained in the operating suite may be behind the reluctance to invite parents into the operating suite in the US. Watson and Visram (2003) and Piira et al (2005) suggest that there is still a wide discrepancy in practice between the UK and the US. This has led to most US studies taking separation from parents as an end point in assessing children’s reactions to induction. Three main reasons to identify those children most at risk for anxiety reactions and difficult behaviour were considered: humanitarian reasons; medical reasons; and reasons pertaining to post-procedural behaviour disturbance. US studies taking separation from parents as the end point for assessing anxiety/behavioural distress address the humanitarian issues pre-induction, but not during induction. The service issues involved in cancelled/postponed procedures, impact on staff of needing to restrain a highly distressed child, and issues of post-procedure behavioural
disturbance as a result of a stormy induction are, arguably, neglected in studies taking separation as an end point.

A further difference in anaesthesia practice is choice of induction method. In the UK, intravenous induction is most common, whereas in the US, inhalation induction is most common, and use of premedication varies both inter- and intra-nationally (Mellor, 2004). Meyer and Lakheeran (2002) audited use of premedication at the hospital in which this research was carried out and found that premedication rates varied between 5% to 14%.

However, no one practice is universal within either the US or the UK. Some UK inductions will occur without parental presence, and a significant proportion of UK inductions will be by mask. Similarly, some US inductions will take place in the presence of the parents and a significant proportion of US inductions will be intravenous. Where this information is not reported in published studies, it renders interpretation and comparison difficult. However, within what is an already limited evidence base, to exclude US studies would be impractical, and, as such, these studies will be considered but the results treated with caution in terms of predictive value in a UK population.

A further difficulty concerns the outcome measures used in published studies. Many studies have used unstandardised and arguably oversimplified outcome measures, notionally assessing anxiety or distress on a likert-type scale. To take a specific example, Vetter (1993), in a study designed to identify children at risk for preoperative anxiety reactions, used an unstandardised three point behavioural rating
scale of anxiety where 1 = excellent (calm, co-operative), 2 = good (anxious but easily reassured), and 3 = poor (anxious, tearful, combative). Similarly, Aguilera et al (2003) used an unstandardised four point behavioural rating scale of anxiety where 1=crying or distressed and uncooperative, 2=anxious but cooperative, 3=awake and calm, and 4=asleep. In both these studies, no inter-rater reliability analyses were carried out.

Some studies use observer-rated measures, some use parent-rated measures, and few use child self-report measures. Studies using measures of child anxiety as an outcome measure are more common than studies using measures of child compliance with induction to general anaesthesia, addressing humanitarian but not service issues associated with stormy/postponed/cancelled procedures. Children have been referred to as “the silent consumers of healthcare” (Carter, 1998), and it has been noted that research focussing on children with health conditions has too often relied on parental and professional accounts rather than seeking out the voice of the child (Eiser, 2000). Stalker, Carpenter, Connors and Phillips (2004) point out that proxy responses are known to have poor reliability, and cannot be assumed to present life from a child’s perspective.

**Parental Factors**

Parental factors can be considered to affect a child’s response to aversive situations through several pathways. Firstly, within the framework of social learning theory, parents act as models for their children, and children can be considered to have acquired their behavioural responses through modelling of their parents.
Psychodynamic theory may speak of projection, introjection and containment, and parents who are themselves feeling anxious may be less available to respond to their child's needs. Genetics, also, may play a part—there is an increased risk of anxiety disorders among children of mothers with panic disorder (Turner, Beidel & Costello, 1987), and it is not unreasonable to assume that anxiety surrounding medical procedures follows a similar pattern.

Research evidence and clinical observation suggests a link between parental anxiety and coping and that of the child. Dahlquist (1997) states:

"We suspect that parental anxiety both results from seeing one's child upset and contributes to exacerbating child distress.......If the child's mother is crying throughout the treatment, it is unlikely that the child will remain calm."

(p.48)

Child's Trait Anxiety

There seems to be a paucity of research concentrating on trait anxiety as a possible predictor of state anxiety during or immediately prior to medical/dental procedures. Possible reasons for this include most of this research being led by medical or dental professionals; perhaps a lack of readily available reliable and easy to administer measures of trait anxiety; as well as much research focusing on efficacy of intervention rather than selective identification of children at risk of anxiety/distress reactions.

Quinonez, Santos, Boyar & Cross (1997), in a study assessing temperament and trait anxiety as predictors of child behaviour prior to general anaesthesia for dental surgery found no relationship between child trait anxiety and observer-rated disruptive behaviour in the preoperative period. It should be noted that Quinonez et al (1997) used the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds and Richmond, 1978), which, although widely used, is very brief and has been criticised for being developed from an adult measure rather than with children in mind (Greenhill, Pine, March, Birmaher, & Riddle, 1998) and is less sensitive to assessing anxiety in children than measures developed specifically for children (King, Muris & Ollendick, 2005).

In a review of more recent literature, Watson & Visram (2003) conclude that on balance, published evidence suggests that higher trait anxiety in children was predictive of higher state anxiety at induction to general anaesthesia in paediatric outpatient surgery patients. Holmes and Girdler (2005) in a study investigating
predictors of paediatric dental anxiety also found that higher trait anxiety is associated with higher state anxiety during difficult procedures, and also with post-procedure difficulties.

Sex

In general, published research suggests that there is no difference between boys and girls in the amount of anxiety or level of non-compliance surrounding medical/dental procedures. Neither Vetter (1993), nor Kain et al (1996) demonstrated significant difference between boys and girls for pre-operative anxiety, and Proczkowska-Bjorklund and Svedin (2004) demonstrated no significant difference between boys and girls in compliance with induction to general anaesthesia. This lack of difference is also present within the dentistry literature. Berge, Veerkamp and Hoogstraten (2002) and Holmes and Girdler (2005) reported no significant difference between the boys and girls in their studies both in terms of reported dental fears and state anxiety.

Given the tendency to equate non-compliance with anxiety, these findings are interesting, since on almost all measures of anxiety, girls score higher than boys (Morris, 2001), and in general, girls report more fears than boys (Ollendick & King, 1991).

Age

Much research suggests that younger children exhibit more anxiety/less compliance around medical and dental procedures. Kain et al (1996) found that children over
seven years of age exhibited less anxiety than children aged four to seven or children under the age of four. Similarly, Bevan (1990), Kain et al (2000), Kotiniemi et al (1997), and Vetter (1993) demonstrated that younger age was associated with higher anxiety in the operating suite. In a study focussing on compliance with induction to general anaesthesia rather than expressed anxiety, Proczkowska-Bjorklund and Svedin (2004) found no effect for age. Similarly, three studies which considered dental fear and anxiety found no effect for age (Berge et al, 2002; Holmes & Girdler, 2005; Rantavuori, Zerman, Ferro & Lahti, 2002).

It should be noted that the children taking part in the studies where an effect for age was found were seven or younger, and the trend may be different as the child’s development and understanding increases, as it is important to recognise that, as a child develops, it is not only their reasoning that matures, but also their ability to recognise, perceive, and anticipate threats. Therefore, increased age (with the inherent assumption that this equates to greater cognitive development and understanding) may affect anxiety or compliance with anaesthetic induction in two, or more, very different directions.

That children will be more compliant as they get older seems to be received wisdom within the field of anaesthesia. Mellor (2004), an anaesthetist, in a comprehensive review of practice suggests that younger children are more difficult to anaesthetise, and that older children are easier to anaesthetise if they are well informed. Watson and Visram (2003) suggest that there may be different fears at different developmental stages. Between the ages of one and three, they suggest that the most difficult aspect of the induction experience is separation anxiety, between four and six,
loss of control, between seven and twelve, desire to be involved in decision making, and thirteen and over, fear of losing face or failure to cope. These age groupings are somewhat congruent with Piaget’s (1952) theory of intellectual development (0-2 years sensori-motor; 2-7 years pre-operational; 7-12 years concrete operational; 12 years + formal operational). These developmental issues are more fully discussed on pages 38-41 of this report.

**Previous Experiences**

There are mixed findings regarding the impact of previous experience on distress and anxiety during medical/dental procedures. There appears to be no effect simply due to previous experience, but if the qualitative experience of previous procedures was poor for the child, research suggests that this will be a predictor for anxious or non-compliant reaction. Proczkowska-Bjorklund & Svedin (2004) used a regression model to investigate child-related background factors affecting compliance of induction of anaesthesia, as measured by observer ratings of behaviour. They found that parent-reported child experience of previous traumatic hospital experience or parent-reported child negative emotional reactions to vaccination predicted non-compliant behaviour at administration of premedication and at induction to general anaesthesia whether with mask or intravenously. Similarly, Kain et al (1996), Kotiniemi et al (1997) and Lumley et al (1993) found that what they described as “poor quality previous medical experience” was predictive of higher preoperative anxiety.
Similar findings are reported in the literature from the field of dentistry. Carson and Freeman (1997) suggest that:

“Anticipatory anxiety is composed of memories of past dental experiences remembered in an unusual way. All that is left of the memory is the affect (anxiety) which is foisted onto (sic) the anticipated anxiety to come.” (p.174)

Rantavuori et al (2002) found that the qualitative experience of the first dental visit was a predictor of child dental anxiety at subsequent visits, although they also reported that a difficult first experience could be mediated by subsequent positive treatment experiences. Berge et al (2002) in a study attempting to outline the etiology of childhood dental fear, found only a minor role for objective dental experiences, and suggest that subjective experiences are much more important.

**Behavioural Factors**

There is some evidence to suggest that pre-existing behavioural difficulties may be predictive of non-compliance to and distress during invasive medical/dental procedures including induction of general anaesthesia. Christiansen and Chambers (2005) state “Children who are combative at home or resist other therapeutic interventions are likely also to resist anaesthesia.” (p.422). Diver, Dahlquist & Hilley (2000) found that a pre-existing constellation of behaviours such as non-compliance, aggression, destruction, inattention and hyperactivity correlated significantly with qualitatively-observed behavioural distress during venepuncture in paediatric oncology patients. Proczkowska-Bjorklund & Svedin (2004) demonstrated no
significant effect on compliance for pre-existing behavioural difficulties, although they did find that children who became more withdrawn in hospital than outside of it were more likely to be non-compliant according to qualitative observational rating.

**Temperament**

Kagan, Reznick and Snidman (1987) reported that children's emotional responses in stressful situations can be predicted by temperament characteristics. For example, shy or inhibited children tend to become more anxious in novel situations. Considering the hospital environment in general and the induction experience specifically as a novel experience, one would expect that children with shy or inhibited traits would react more negatively. Dadds and Barrett (2001) state:

"Developmental models of anxiety disorders emphasise maximum risk in children with shy or inhibited temperaments who are exposed to high family anxiety and avoidance, and/or acutely distressing experiences" (p.999)

Research findings support this statement, for example, Proczkowska-Bjorklund and Svedin (2004) found that dependant/withdrawn behaviour and shyness predicted non-compliant behaviour at induction to general anaesthesia. Kain et al (2000) demonstrated that lower sociability (higher shyness) and lower activity (higher withdrawal) correlated significantly with higher pre-operative anxiety in children. Similarly, Kain et al (1996) found that shy, inhibited children as identified using the EAS (Buss & Plomin, 1984) exhibited higher preoperative anxiety as measured using
the m-YPAS (Kain et al, 1997) and Quinonez et al (1997) found that shyer children exhibited more disruptive behaviour preoperatively.

**Culture/Ethnicity/Language**

Fear of the unknown plays a part in making the hospital experience more anxiety provoking. However, it could be argued that for children growing up in the UK, it is more of a known experience than for children who have spent part or all of their lives elsewhere. In the UK, children meet with doctors and nurses for developmental checks, vaccinations, childhood illnesses and the inevitable bumps and scrapes. It is common for children to play "Dr's and Nurses", many leading toy manufacturers make play medical equipment, and children's television programmes such as Hilltop Hospital or family programmes such as Casualty serve to demystify the hospital experience. It needs to be acknowledged that some children coming to this country with their families in middle childhood may not have been exposed to these sorts of stimuli. Kolk, van Hoof and Dop (2000) state that:

"Culture or ethnicity possibly contribute to differences in distress reactions before and during venepuncture. However, their result is hardly studied and consequently not well understood." (p.252)

There is also the issue of what is normal for children and families. Children and families with different, non-western experiences and expectations of hospital care and standards may find the UK hospital experience more anxiety provoking than families with expectations closer to reality. Even families from western countries, but with
different healthcare experiences and expectations may find the differences between their expectations and reality a source of stress.

The issues surrounding language are clear. If the hospital staff and written information (which would include directional signs, leaflets, menu choices) use a language in which the family is not proficient, the experience will be less understandable and arguably more anxiety provoking.

Recently, some research has begun to explicitly address the issue of culture in dental fear, anxiety and compliance. Berge et al (2002), attempting to outline the etiology of childhood dental fear, found that in a western European hospital, children from a non-Western background were more fearful than children from a Western background. Ingman, Ollendick and Akande (1999) demonstrated that, within the same geographical region, Christian children reported more fears and anxieties than Muslim children. Folayan et al (2004) suggest that this may be due to the effect of Islamic culture, where Muslim children are encouraged to be braver in the face of adversity. Folayan et al (2004) suggest that culture will influence not only the context in which anxiety is experienced, but also the interpretation of anxiety, and individual reactions to it. The impact of culture, ethnicity and language on anxiety/distress/compliance around medical/dental procedures deserves more attention in future research.
RATIONALE FOR CURRENT STUDY

Anaesthetists at the hospital in which this study was carried out had identified a problem of many (48-58%-Meyer and Lakheeran, 2002) children displaying anxiety/non-compliant behaviour at anaesthetic induction, some to such a degree that their procedures had to be cancelled or they had to be physically restrained. As a result, the anaesthetists made contact with the paediatric psychology department at the hospital in order to set up a collaborative project to address this problem. The clinical psychologists in turn made contact with the University at which the author was studying to propose a collaboration for a doctoral researcher.

Previous research (e.g. Palermo et al, 1999; Piira et al, 2005) has shown that there is some benefit to be gained from appropriately targeted and developmentally sensitive preparation. However, the level of implementation of preparation is variable. Kain et al (2000) point out that, although induction to general anaesthesia is the most stressful procedure for a child having surgery, few studies focus on predictors of a child’s behaviour at this time, most concentrating on anxiety in the pre-operative period.

Currently there is no established method for clinicians to identify which children may be most likely to exhibit anxiety or distress at anaesthetic induction. More accurate identification would allow appropriate interventions to be targeted to those children most in need. Several interventions have been designed to alleviate the distress and anxiety surrounding planned procedures, for example the use of videos and play therapy (Watson & Visram, 2003). In the author’s experience, whether or not a child scheduled for elective day surgery receives preparation depends upon a number of
factors, few of which are dictated by clinical need. For example, a child presenting on
the ward for a morning procedure is unlikely to have time to receive preparation, since
the preoperative checks and paperwork take up a significant amount of time and the
child will be called to the operating suite in advance of their scheduled procedure
time. The converse of this is that most children presenting on the ward in the morning
for an afternoon procedure will receive preparation, as there will be a significant
amount of time to fill prior to being called to the operating suite. It has also been the
author’s experience that few day-surgery ward-based play specialists are full-time,
and so whether or not the child receives preparation may depend upon the preferred
working hours of that ward’s play specialist.

This is clearly not ideal, since it is likely that a number of children who would benefit
greatly from play preparation are not receiving it, and a number of children who
derive little or no benefit from play preparation are receiving it. In a perfect world,
resources would be such that all children could receive play preparation, since there is
clear benefit for some, and no harm for most, and playing is usually an enjoyable
experience which may help to deflect the beginnings of medical anxiety by providing
a pleasant and distracting experience within what is mostly an aversive experience.
However, limited resources are a very real fact. As such, a screening assessment
which would allow play preparation to be targeted to those most in need would serve
both a clinical and economic purpose.

Clinical reasons for a child receiving play preparation, or more targeted, intensive
preparation from a therapist such as a clinical psychologist or play therapist that the
author has experienced include situations where crisis point has been reached and the
child has refused a procedure, or situations where such high anxiety has been expressed by the parent or child that an intervention has been arranged. It could be argued that this first situation could be avoided by identifying the child at risk of such high anxiety/non-compliance prior to the crisis point and intervening preventatively rather than curatively, and that this second situation should be more common and not require such a high threshold of expressed anxiety in order to trigger a preventative response. Again, a screening assessment which would allow identification of children at risk of high anxiety or non-compliance at a lower threshold would serve both a clinical and economic purpose in these cases.

As has been discussed, the published literature addressing children’s anxiety/non-compliance utilises a variety of points in time when anxiety/non-compliance is assessed, such as separation from parents, in the waiting area, and rarely at the point of induction. The current study was designed after a specific need was identified by the Anaesthesiology department to concentrate on the point of induction to general anaesthesia. It is hoped that the use of point of induction as the outcome will provide clinically and operationally useful information which will help to address humanitarian, medical and service issues.

The outcome measures used in much of the published literature have often been oversimplified, using broad categories without adequate operationalisation. Another outcome measure weakness in the literature has been to equate behavioural non-compliance with anxiety. Children are different in their levels of externalising behaviour at times of stress, and there is a risk of highly internalising yet compliant
children being overlooked. It is hoped that this study will address this issue by using an assessment of anxiety as well as an assessment of non-compliance.

Other weaknesses in the literature include a lack of specifically UK based studies, a lack of studies using well-developed assessment measures to assess pre-operative factors, and a lack of consideration of cultural and language factors. It is hoped that this study will address these weaknesses by being based in a UK hospital, using a variety of well-developed tools to assess pre-operative factors, and including data on cultural and language factors in the analyses.
AIMS

This study aims to explore child, family and demographic/circumstantial factors which can be assessed in the pre-operative period which may be associated with non-compliance/anxiety at anaesthetic induction, and hopes to address the weaknesses identified in the existing literature.

HYPOTHESES

- Higher trait anxiety will be associated with less compliance with and higher state anxiety at induction to general anaesthesia.

- Greater behavioural change between home and hospital will be associated with less compliance with and higher state anxiety at induction to general anaesthesia.

- More self-reported pre-operative surgical worries will be associated with less compliance with and higher state anxiety at induction to general anaesthesia.

- More parent-reported pre-operative surgical worries will be associated with less compliance with and higher state anxiety at induction to general anaesthesia.

- Aspects of the child’s temperament will be associated with less compliance with and higher state anxiety at induction to general anaesthesia.
• Children who reacted badly to their immunisations will be less compliant with induction and more anxious at induction to general anaesthesia.

• Children who themselves, or whose parents, do not have English as a first language will likely be less compliant with and more anxious at induction to general anaesthesia.

It is possible that other background factors will be associated with level of compliance at induction to general anaesthesia. In addition to these specific hypotheses, and in the light of limited research evidence focussing on compliance with induction to general anaesthesia, the relationship between all background factors assessed and the ICC will be explored.
METHOD

Process

The proposal for this study started with the anaesthetists at the hospital in which this study was carried out identifying a problem of many (48-58% - Meyer and Lakheeran, 2002) children displaying difficult behaviour at anaesthetic induction, and ended with a proposal of collaboration with a doctoral researcher from the University at which the author was studying.

More than one researcher was interested in designing a study to investigate this issue. As a result of several meetings and much discussion, a decision was reached to conduct two studies with some overlap. The division of the two studies was made according to the age of the children, where age is taken as a proxy measure of developmental stage (the issues involved in this are discussed more fully on pages 38-41 of this report). The author began to design a study looking at children aged 7-11 and the other researcher began to design a study looking at children aged 4-7. Other than the developmental considerations discussed elsewhere, this division of research was sensible along practical lines as well, since questionnaires which are suitable for children aged 7-11 are not necessarily appropriate for children aged 4-7, and any attempts to utilise particular questionnaires across both these age groups may have resulted in meaningless data. However, some questionnaires – particularly parent-report – could meaningfully be used across both age groups.
Of benefit to both researchers was the fact that data collection could be shared between the researchers. Some parent-report measures were common across both age groups, and there was only one additional parent-report measure for the younger age group, and two additional child-report questionnaires for the older age group. Children aged seven fell within both age groups, and as such, the parents completed one additional measure over and above the common parent-report measures and the children completed two self-report measures.

At the insistence of the ethics committee, two parts of the original proposal for this research had to be omitted in order for their approval to be gained. The first was the removal of the modified Yale preoperative anxiety scale (m-YPAS; Kain et al, 1997). This scale has been specifically developed as a measure of anxiety immediately prior to induction to general anaesthesia and was originally included in order to attempt to identify children whose emotion at induction to general anaesthesia is expressed more as anxiety than as non-compliance. This was considered important in order to identify those children who would benefit in themselves from preparation for general anaesthesia and not just those children for whom preparation for general anaesthesia would ease the induction for all concerned.

The m-YPAS is quick and simple to administer, taking approximately 30 seconds to complete, and having a fixed tick box response format. The operating department assistants had agreed to complete it immediately prior to induction, with the agreement of the consultant anaesthetists. However, it was the opinion of the ethics committee that to complete the m-YPAS would be an unnecessary use of the ODA’s time since they did not consider it to add anything to the study. This was
disappointing, since the use of both the m-YPAS (a measure of anxiety) and the ICC (a measure of non-compliance/behavioural upset) was intended to address some of the weaknesses of previous studies in this area where the quality of outcome measures has been questionable at best, and where there has been some mixing of the terms anxiety, distress, and non-compliance.

The second part of the original proposal which had to be removed at the insistence of the ethics committee was the inclusion of families without English as the first language. There is a distinct lack of acknowledgement of the impact of culture, ethnicity and language in the published research concerning procedural distress in general and induction to general anaesthesia in particular, and it was considered important to try to address these issues in this study. The psychology department at the hospital had agreed to absorb the cost of using their in-house translation service, Language Line. However, it was the opinion of the ethics committee that this was an unnecessary expenditure of funds for a student project. Again, this was disappointing, since the inclusion of ethnicity and first language as variables was intended to address an area of weakness in the existing research literature. By excluding families who need an interpreter in order to converse competently in English, a significant proportion of families from backgrounds other than British and with first languages other than English will be excluded from participation, and this is likely to render interpretation of ethnicity and language data more difficult, as these groups are likely to be under-represented.

These alterations insisted upon by the ethics committee had an impact of the originally proposed hypotheses, in that the association of the pre-operatively assessed factors
with level of anxiety at induction to general anaesthesia could no longer form part of this study, and the hypothesis relating to culture and language had to be abandoned.

The amended hypotheses are:

- Higher trait anxiety will be associated with less compliance at induction to general anaesthesia.

- Greater behavioural change between home and hospital will be associated with less compliance at induction to general anaesthesia.

- More self-reported pre-operative surgical worries will be associated with less compliance at induction to general anaesthesia.

- More parent-reported pre-operative surgical worries will be associated with less compliance at induction to general anaesthesia.

- Aspects of the child’s temperament will be associated with less compliance at induction to general anaesthesia.

- Children who reacted badly to their immunisations will be less compliant at induction to general anaesthesia.

Once the outline of the project and measures to be used had been agreed by the ethics committee, meetings were arranged with the operating department assistants in order
to familiarise them with the outcome measure (ICC) and to ensure that they could competently and consistently complete it.

**TIMELINE**

The initial proposal was submitted to the ethics committee in May 2004 for consideration at the June 2004 meeting. The decision reached at the meeting was to reject the proposal and require resubmission of a new proposal which addressed the issues raised by the ethics committee. This decision was not communicated to the researchers until after the deadline had passed for submissions to be considered at the July 2004 meeting. The ethics committee did not meet in August, and the agenda for the September meeting was full. As a result, the new proposal could not be considered by the ethics committee until the October 2004 meeting. The decision at the October 2004 meeting was to award ethical approval subject to Chariman’s corrections, including the exclusion of the m-YPAS and speakers of languages other than English. Once final ethical approval had been gained, it was late November 2004. Since doctoral research is affected significantly by time constraints, a decision was made not to pilot the study separately, but to evaluate progress during data collection. Should this live evaluation reveal that changes to the protocol would be helpful, those changes would be worked in where helpful.

**Setting**

This study was conducted in an acute children’s NHS hospital with a national catchment for more specialist procedures and for children with particular needs and a
regional catchment for more routine procedures. Some children residing in Europe, especially those whose parent works for the armed forces, are also routinely treated at this hospital. The research was carried out across specialties and with the explicit cooperation of the Anaesthetic department.

Recruitment

What follows is a detailed description of the recruitment process. This process is summarised in a flow-chart at the end of this sub-section.

Once ethical approval had been obtained from the NHS Trust and University ethics committees, the hospital’s patient database was accessed. This database holds much information about patients, including the waiting lists for elective procedures under general anaesthetic. These waiting lists were accessed, and those children aged between seven and eleven years scheduled for procedures on data collection days were identified.

Of the children identified, all those scheduled to undergo procedures associated with a life-threatening condition were excluded. Children in this category would typically be under the care of the oncology or cardiology consultants. There were a number of reasons for this exclusion, including the likelihood of more surgical experience, stresses and worries associated with the condition itself, and different motivations for surgery. Taken together, these considerations are likely to create a distinct sub-population within children undergoing surgery.
The hospital's patient database also indicated whether the child/family required an interpreter in order to communicate with English speaking professionals. The original intention of this research was to include families who required an interpreter in order to communicate with English speaking professionals by accessing the hospital's internal translation service, Language Line. Language Line works by the English-speaking health professional calling the translation service, and then a three-way conversation would take place by the non-English speaking patient's bedside using the double-phone system installed for this purpose. The Psychology department had agreed to absorb the cost of accessing this service. However, the NHS ethics committee felt that this was unnecessary expenditure for a student project and requested that non-proficiency in the English language be included in the protocol as an exclusion criteria. Therefore, all families recorded on the database as requiring an interpreter in order to competently converse in English were excluded from the study.

Once these exclusions had been made, the parents/guardians of the children identified were contacted by post. This contact was made three to six weeks prior to the scheduled date of the procedure. The families were sent a letter inviting them to take part in the study. At the same time, the consultant responsible for the child's care was contacted, asking whether they had any objection to the child being included in the research project. Any reservations about the child's participation expressed by the consultant would result in exclusion from the study. A copy of the letter sent to parents is in Appendix 1, and a copy of the letter sent to consultants is in Appendix 2.
The final stage of recruitment was for one of the researchers to speak to the family on the ward on the day of the procedure to check their consent and willingness to proceed with the research.

**Summary Flow-Chart for the Recruitment Process**

Access elective procedure waiting lists (four to seven weeks prior to procedure)

↓

Exclude if child aged less than seven or more than eleven

↓

Exclude if child scheduled for procedure associated with a life-threatening condition

↓

Exclude if child needs an interpreter to be addressed in English

↓

Contact families by post (three to six weeks prior to procedure)

↓

Exclude if consultant raises objections

↓

Check consent on ward (day of procedure)

Demographic information was collected from those families who participated in the study and will be presented in the results section.
Participants

Outcome measures and other data were available for 74 children between the ages of 7 and 12 and their families.

A Note About the Choice of Age Range

“Children are in a state of continuing development, both physically and psychosocially. Their ability to understand and cope with the different aspects of hospital admission is affected by their age and developmental stage, and this is what makes their needs different from those of adults.”

(Runeson, Hallstrom, Elander & Hermeren, 2002, p.159)

Carney et al (2003) in a qualitative exploration of children’s views of hospitalisation, reported differences between what 4-8 year olds, 9-12 year olds, and 13-17 year olds reported as worthy of comment. Within the sample as a whole, 88.9% mentioned the physical environment (for example, type of food, access to television and computer games), although this emerged as more important for older children and adolescents. The second most mentioned aspect was the procedure, with 85.2% of the sample mentioning this in the semi-structured interview. Interestingly, this aspect of the hospital experience appeared to be more important for the 9-12 year olds (52.5% mentioned) than for either the 4-8 year olds (31.94% mentioned) or the 13-17 year olds (37.7% mentioned). Several other themes reported by Carney et al were reported more by the middle age group than the younger or older age groups, including negative staff interaction (6.94%; 11.25%; 6.56%), feeling well informed (2.78;
and feeling anxious (12.5%; 20%; 18.03%). This suggests that children of different ages/developmental stages have different priorities within the context of a hospital visit.

Harris, Olthof, Meerum Terwogt & Hardman (1987) presented 5 to 14 year old children with different emotion terms and asked them to talk about a situation that would elicit each emotion. They found that the younger children were able to suggest situations for emotions which were associated with a clear facial expression, such as afraid, happy, sad, and angry. However, it was not until the age of seven that the majority of children could offer appropriate situations for emotions with no clear facial expressions, such as proud, worried, jealous, grateful, guilty, and excited. From the age of ten, and reliably at age fourteen, the children were able to describe situations for more complex emotions such as relieved and disappointed. Harris et al (1987) concluded that by seven years of age, typically developed children had moved beyond the basic set of emotions to discover and understand more complex emotions.

As the examples above illustrate, children of different ages have differing understandings of emotion and have different priorities. What underpins these differences and what governs children's reactions to different situations?

Piaget's developmental theory groups children into age/stage categories according to their abilities to understand their environment. Age 0-2 years he termed the sensori-motor stage, where the child explores the world through his senses and begins to form internal mental representations and simple cause-and-effect understandings. Age 2-7 years he termed the pre-conceptual. He suggests that it is during this stage that
children's thinking is characterised by egocentrism, and tendency to focus on one aspect of a task. By the end of this stage, he suggests that children are able to use symbolic representation, take another's perspective, and to understand the conservation of number. Age 7-12 Piaget termed the concrete operational stage, where children become able to internalise the properties of objects, and their thinking becomes less egocentric. Children's growing capacity to internalise during this stage means they become able to put objects in order, or classify, without comparing them one with another. Age 12+ Piaget termed the formal operational stage, characterised by much more flexible thinking and reasoning.

In considering research with children and their families, particularly research in which the voice of the child is being sought, it is important to consider the ability of children to respond to questionnaires and Likert scales. Thinking about Piaget's theory, children in the concrete operational stage should be able to manage scaling questions if there is a visible representation of the scale. This idea is borne out in research carried out by Chambers and Johnston (2002) looking at developmental differences in use of rating scales in children aged 5 to 12 years. They found that 5 and 6 year olds displayed a tendency to rate at the extremes on a five-point Likert scale, but that this tendency was absent for the 7-12 year olds.

There is some evidence from research into children's fears which lends support to Piaget's framework when considering children's anxiety reactions. Gullone and King (1995), in a longitudinal study of normal fear, found a steady decrease in fears as children matured, with the exception of psychic-stress and medical related fears, which began to increase after the age of 11. Gullone and King (1995) suggest that this
may be due to increasing cognitive functioning. More recently, Gullone has suggested that although a child is capable of experiencing the physiologic and affective components of anxiety and fear at an early age, certain cognitive capacities are necessary in order for the state to be considered fear, since fear implies the ability to anticipate future events. Arnold et al (2003) suggest that anxiety disorders such as generalised anxiety disorder require this ability, and therefore are not usually evident until about the age of 7 or 8. This sits comfortably with Piaget’s stage theory.

Typically developed children aged between 7 and 12 can be considered to form a developmentally congruent group with regard to this research, since they have developed the emotional language and ability to anticipate future events to an extent which will allow the expression of fear/anxiety/worry. Additionally, they have developed the cognitive abilities to respond appropriately to the questionnaires and have not yet entered adolescence. Ecologically, this group represents an educationally distinct group (junior school), and is frequently used as a target group by other researchers (Li & Lam, 2003).

It is undoubtedly important to distinguish between age and psychosocial maturity. However, in research, it is not usually possible to conduct a sensitive appraisal of a child’s level of development, and so age is often taken as a proxy measure. It is also important to remember that Piaget’s is not the only theory of childhood development, although in terms of research it is perhaps the most helpful when using age as a proxy measure of psychosocial maturity.
Design

A within-subjects, correlational design was used.

Procedure

Each child identified as a potential participant was allocated an identification number to facilitate the process of confidentiality. The document linking identification numbers was stored separately to the data. Parents/guardians of the children identified were sent copies of the Emotionality, Activity and Sociability scale (EAS; Buss & Plomin, 1984), The Children’s Surgical Worries Questionnaire – Revised (CSWQ-R; adapted by the author from Quiles, Ortigosa, Mendez & Pedroche, 1999). Children were sent, care of their parents/guardians, copies of the Spence Children’s Anxiety Scale (SCAS; Spence, 1997) and the Children’s Surgical Worries Questionnaire (CSWQ; Quiles, Ortigosa, Mendez & Pedroche, 1999). Copies of these questionnaires can be found in Appendices 3, 4, 5, and 6 respectively. All questionnaires were labelled with the child’s unique identification number. Information sheets, consent and assent forms were included in the same mailing. Copies of these can be found in Appendices 7 to 11. Families were given the option of either posting the questionnaires and consent/assent forms back in a reply-paid envelope or bringing them when they attended for their child’s procedure.

Copies of the Induction Compliance Checklist (ICC; Kain, Mayes & Wang, 1998) were sent to the operating department assistants who would be completing them. Each ICC was labelled with the child’s unique identification number. To enable the
operating department assistants to identify which child the ICC should be completed for, a piece of paper bearing the child's hospital number and name was stapled to the ICC. Copies of the ICC can be found in Appendix 12.

On the day of the planned procedure, families were approached on the wards to check consent and to answer any questions. If the family had consented to take part but measures sent in the post had not been completed, families were asked to complete them at this time. Parents/guardians of the children were asked to complete the Behavioural Upset in Medical Patients – Revised (Saylor et al, 1987), a copy of which is in Appendix 13. Demographic information (age, sex, ethnicity, main care-giver's occupations, first language of child, first language of parents/guardians) was also collected at this time. As well as the demographic information, other potentially relevant information was collected, including number of previous intrusive medical procedures, involvement with other health and social care agencies, how the child reacted to immunisation, and whether the child had received any specific preparation for the procedure. A copy of the demographic/background information recording sheet can be found in Appendix 14.

Whilst in the operating theatre, immediately after the induction process is complete, an operating department assistant completed the ICC. When the completed ICC's were returned to the researchers, all identifying information other than the child's unique identification number was removed and disposed of in a confidential rubbish bin.
Measures: Child Completed

*Children's Surgical Worries Questionnaire (CSWQ)*

The CSWQ was chosen to use as a measure of children's worries regarding their upcoming procedure. Another scale considered as a measure was the Fear Survey Schedule for Children-Revised (FSSC-R; Ollendick 1983). The FSSC-R is an 80-item instrument with a five-factor solution for fears and phobias, including specific phobias and social phobias. Although one of the factors is medical fears, the FSSC-R was rejected in favour of the CSWQ since it is a lengthy measure and would include information on less relevant worries and fears.

The version of the CSWQ used is a child completed measure consisting of seventeen questions which address concerns specifically related to the surgical procedure, such as having a needle in the arm for a long time or waking up before the operation is over. Each of the seventeen items is rated from 0 (not at all worried) to 4 (extremely worried), yielding scores from 0 to 68. Two versions of the CSWQ exist, the child version (seventeen items rated on a three point likert scale, ages 7-10) and the adolescent version (22 items rated on a five point likert scale, ages 11-14).

In a non-clinical (school based) sample, Mendez, Quiles & Hidalgo (2001) found the child version to have high internal consistency (Cronbach's alpha=0.83), good 7-10 day test-retest reliability (0.9), and good concurrent validity (Pearson's r = 0.6 with the Medical Fears scale of the Children's and Adolescent's Fear Inventory; Sosa et al, 1993 – cited in Mendez, Quiles & Hidalgo, 2001).
In a non-clinical (school based) sample, Quiles, Ortigosa, Mendez & Pedroche (2000) found the adolescent version to have high internal consistency (Cronbach’s alpha=0.876), and good internal consistency (65% of items achieved item-total correlations greater than 0.5.

The version used for the present research was a combination of the two forms. The items used were from the child version, but the response format was a five point likert scale. This was unfortunately due to an error in reading the Spanish-English translation of the paper, and the reliability and validity data cannot be considered to apply. However, Chambers and Johnston (2002) in an investigation into children’s use of rating scales found that children from the age of 7 could use five-point Likert scales appropriately. The seventeen-item, five-point Likert version was adapted to allow parent-report. This was done with Dr Mendez’s permission after e-mail correspondence.

Cultural issues must be considered when using a Spanish-developed measure within a British population, since, as discussed in the introduction (p.22-23), cultural and religious factors are likely to impact on the experience and expression of anxiety, fear, and worries.
Spence Children's Anxiety Scale (SCAS)

The SCAS is a child completed measure of trait anxiety consisting of 38 anxiety specific items, six filler items, and one open-ended, non-scored item. Each of these 38 items is rated from 0 (never) to 3 (always), yielding scores from 0 to 114. The SCAS includes sub-scales relating to: (1) Panic Attack and Agoraphobia, (2) Separation Anxiety, (3) Physical Injury Fears, (4) Social Phobia, (5) Obsessive Compulsive, and (6) Generalised Anxiety Disorder/Overanxious Disorder. In the original non-clinical (school based, 8-12 years old) standardisation sample, Spence (1998) found the SCAS to have good internal consistency (Cronbach’s alpha=0.92; Guttman split-half reliability of 0.9), good 6 month test-retest reliability (0.6), and good convergent validity (Pearson’s product-moment=0.71 with the Revised Children’s Manifest Anxiety Scale; Reynolds & Richmond, 1978). In the same standardisation sample, the subscales were found to have acceptable internal consistency (Cronbach’s alpha from 0.6 to 0.82), and acceptable 6 month test-retest reliability (Pearson’s product-moment from 0.45 to 0.57).

Subsequent school based standardisation samples with children aged between 6 and 18 years old have yielded very similar reliability and validity data (Spence, Barrett & Turner, 2003), including samples of non-English speaking children (German-speaking; Essau, Muris & Ederer, 2002; Japanese-speaking; Essau, Sakano, Ishikawa & Sasagawa, 2004; Dutch-speaking; Muris, Schmidt & Merckelbach, 2000 and Muris, Merckelbach, Ollendick, King & Bogie, 2002).
A number of other anxiety measures were considered and rejected in favour of the SCAS, including the State-Trait Anxiety Inventory for Children (STAI-C; Spielberger 1973); the Revised Children's Manifest Anxiety Scale (RCMAS; Reynolds and Richmond, 1978), the Screen for Child Anxiety Related Emotional Disorders (SCARED; Birmaher et al 1997), and the Multidimensional Anxiety Scale for Children (MASC; March, Parker, Sullivan, Stallings, & Conners, 1997). The STAI-C was rejected in favour of the SCAS largely due to cost and availability. The main reason for rejecting the RCMAS was that it is a little too brief for the purpose, consisting of a three-factor structure (physiological, worry/oversensitivity, and concentration anxiety). Additionally, the well established STAI-C and RCMAS have been criticised for being developed from adult measures rather than with children in mind (Greenhill, Pine, March, Birmaher, & Riddle, 1998) and are therefore less sensitive in assessing anxiety in children than measures developed specifically for children (King, Muris & Ollendick, 2005).

Both the SCARED and MCAS are more detailed than the RCMAS, and more available than the STAI-C. Additionally, both were developed as measures of anxiety specifically for children. The SCARED provides five scores (panic/somatic, separation anxiety, general anxiety disorder, social phobia, and separation anxiety), whilst the MASC provides four scores (social anxiety, physical symptoms, harm avoidance, and separation/panic). The main reason for selecting the SCAS over these other measures was the inclusion of a physical injury sub-scale in the SCAS, which felt ecologically relevant to this research.
Measures: Parent Completed

*Children's Surgical Worries Questionnaire – Revised (CSWQ-R)*

The CSWQ-R was adapted from the version of the CSWQ used in this study so as to be parent completed rather than child completed. The response format was altered from “I am worried about...” in the child completed version to “My child is worried about...”. In every other respect, the CSWQ and CSWQ-R were identical.

*Emotionality, Activity, Shyness (EAS)*

The EAS is a parent-completed questionnaire consisting of 20 questions about the child’s temperament. Each of the 20 items is rated on a scale of 1 (not characteristic of typical of your child) to 5 (very characteristic or typical of your child). Some of the items are reverse-rated, where a parent endorsement of 1 would result in a score of 5, and vice versa. The EAS ultimately yields scores of between 1 and 5 on each of the four sub-scales (emotionality, activity, sociability, and shyness). These are be calculated by totalling the score for each of the five items on each scale and dividing by five.

Mathieson & Tambs (1999) reported acceptable-good internal consistency for the four sub-scales (Cronbach’s alpha=0.48-0.79) and twelve-month test-retest reliability for the four sub-scales of between 0.67 (shyness) to 0.88 (activity).
The BUMP-R was selected as both a measure of pre-existing behaviour and as a measure of behaviour change between home and hospital. The BUMP-R consists of two 28 item questionnaires designed to provide a measure of the child’s behaviour both in the home and in the hospital. As such, difference in scores can be used to identify changes in the child’s behaviour during hospitalisation. Each of the 28 items is scored from 0 (never) to 4 (always), yielding scores from 0-112 on each questionnaire. Rodriguez & Boggs (1994) analysed the factor structure of the BUMP-R and demonstrated that, as well as yielding a global score, the BUMP-R provides four sub-scales: (1) Negativity/Agitation, (2) Amiability, (3) Dysphoria, and (4) Non-compliance.

The BUMP (adult version) has a test-retest reliability of 0.66 (Zeldow & Braun, 1985), although test-retest data for the BUMP-R has not yet been published. The BUMP-R has good internal consistency, with Cronbach’s alpha of 0.87 (Rodriguez & Boggs, 1994), and is reported to have good validity (Saylor et al, 1987).

Two other measures were considered as indicators of behaviour, the Child Behaviour Checklist (CBCL; Achenbach, 1991) and the Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997). The BUMP-R was selected over these measures for two main reasons. The first was that both the CBCL and SDQ are problem-focussed, being designed for use with children presenting high levels of difficulty, which could lead to a floor effect in the outpatient surgery population. The second reason was that
the BUMP-R offers home and hospital versions, allowing a difference score to be calculated.

**Measures: Researcher/Other Completed**

*Demographic data*

To assess the demographic and situational variables (such as previous surgical experience and first language) which research has suggested may affect the child’s reaction to a potentially distressing medical procedure, as well as to collect descriptive data, a brief interview schedule was designed to be administered by the researcher to the family whilst on the ward.

*Induction Compliance Checklist (ICC)*

The ICC was developed by Kain, Mayes, Wang, Caramico & Hofstadter (1998) as an outcome measure to observationally assess compliance of inhalation induction and level of distress in children aged 2-8 years. It is a quick and simple measure designed to be completed at or shortly after the induction to general anaesthesia by a person present in the operating theatre. It consists of eleven statements (e.g. “Crying, tears in eyes”, and “Requires physical restraint”), which are either endorsed or not. The first statement is “Perfect induction, does not exhibit negative behaviours, fear or anxiety”, and an endorsement of this statement results in a score of 0. The remaining ten statements relate to behaviours which could be considered to constitute a difficult
induction, and would attract a score of one if present. Therefore, the ICC yields scores between 0 and ten.

As the ICC was developed purely as an outcome measure, and not a clinical assessment measure, little reliability and validity data exist, other than the inter-rater reliability data from the original study (0.978). However, in the absence of any psychometrically evaluated measures of difficulty of induction, the ICC has been used with children aged 1-13 years (Varughese, Karolina, Byczkowski, Joel Gunter, & Kurth, 2004; Varughese, Viswanathan, Gunter, Kotagal, & Kurth, 2004), children aged 0-17 years (Wang, Shu, Maranets, Weinberg, Caldwell-Andrews, & Kain, 2004).

Whether inhalation or intravenous induction to general anaesthesia is chosen is governed mainly by the personal preference of the anaesthetist, it would unnecessarily limit the generalisability of this study to exclude those children who have induction using intravenous methods. As such, with the permission of Dr Kain after e-mail correspondence, the ICC has been modified slightly to produce a version for intravenous induction. Only three items: ([1] Turns head away from mask, [2] Pushes mask away with hands, pushes nurse/anaesthetist away with hands/feet, and [3] Covers mouth/nose with hands/arms or buries face) needed to be modified, since the other seven items were not inhalation specific. These items were changed to, respectively, [1] Pulls arm away from needle, [2] Pushes needle away with hands, pushes nurse/anaesthetist away with hands/feet, and [3] Tries to cover IV site.
An alternative outcome measure considered was the Observational Scale of Behavioural Distress (OSBD; Elliot, Jay and Woody, 1987), which rates 11 operationally defined behaviours that indicate anxiety and/or pain in children, with weights to represent the intensity of behaviour. The observer records the number of times that a behaviour is observed at 15 second intervals during the procedure, until return to a baseline state. Although the scale has demonstrated good validity for children aged 3-12 years undergoing needle procedures (Elliot et al, 1987) it was rejected in favour of the ICC since it was felt that the frequency of observation required would place unnecessary strain on the ODA who needs to play an active role in the anaesthetic process. Similarly to the ICC, the OSBD would also need to be altered to include inhalation induction.

**ETHICAL CONSIDERATIONS**

This study involved direct contact with children and families outside of normal clinical contact at a time which is already stressful. As such, ethical approval was sought, and granted, by the relevant Research Ethics Committees.

Although the law does not dictate that assent be sought from children, merely consent from parents, best practice and the researcher’s preferred way of working dictates that assent is sought. As such, two child-friendly versions of the information sheet were produced in addition to the parental information form, and an assent form was produced for the child to sign in addition to the consent form for the parents.
To avoid unnecessary intrusion, the ICC was completed by clinicians usually present at induction, with the support of the anaesthetic department.

It was possible that, in the course of this study, a child would be identified as at risk of extreme anxiety/non-compliance with induction. A plan of action was formulated for this eventuality which included discussing concerns immediately with the responsible consultant or supervising clinical psychologist, given the family’s permission.
RESULTS

All analyses were carried out using SPSS for Windows v11. Due to the nature of the data set, all analyses were conducted using pairwise exclusion rather than listwise exclusion. Similarly, where the outcome measure (ICC) was completed, yet an incomplete data set existed for a participant, data for that participant were used where they did exist, but excluded from analyses concerning the variable for which data were not held. Outcome data were obtained from 76 participating families.

Demographic Profile of the Sample

Forty families where the identified patient was male and 34 families where the identified patient was female took part. Data were not available on the sex of the identified patient for two families. The average age of the children was 9 years 4 months, with a range of 7 years 0 months to 11 years 11 months. Sixty of the families described the child’s ethnicity as white British, one family as Pakistani, one family as Bangladeshi, two families as other Asian, three families as black African, two families as black Caribbean, two families as mixed, and two families as “other”. Data were not available for three families.

Sixty-nine of the children had English as their first language, one had Somali, one had Danish, one had Phillipino, one had Sign, and data were not available for three families. Sixty-four of the parents had English as their first language. Of the remaining twelve families, one each of the following first languages were represented:
Somali, Danish, Albanian, Nigerian, Yoruba, Phillipino, Tagalog, Gujurati and Spanish. Data were not available for three families.

Data Screening and Treatment of Data

The Induction Compliance Checklist (ICC)

Scores on the ICC ranged from 0 to 6 from a possible minimum of 0 and maximum of 10. Data was available for 76 participants. On examination of the distribution of these data, acceptable kurtosis (0.798, standard error of kurtosis 0.545) but significant positive skewness (1.365, standard error of skewness 0.276) were noted. No outliers were identified. Further examination revealed this to be due to a large proportion (53.9%) of the sample scoring 0 – a completely smooth induction. This led to reconsideration of how best to deal with these data. Initially, a multiple regression had been planned, using total score on the ICC as the independent variable. However, an almost perfect 50:50 split in the data between smooth (ICC score = 0) and stormy (ICC score >0) induction leads logically to the conclusion that, rather than transforming logarithmically and losing the true distribution of the data, this variable should be considered as binomially categorical, as it seems clinically important that approximately half the children experience a stormy induction and half experience a smooth induction. Logistic regression can be performed onto a categorical outcome measure; however, Tabachnick and Fidell (2001) state that for logistic regression, the researcher should be using a dataset of 80 + 10 x number of variables. Since the dataset pertaining to this research does not quite reach the base number, a logistic regression analysis does not appear to be viable. As such, a decision was reached to
compare the scores on the predictor variables between the two emergent distinct
groups (smooth induction and stormy induction).

Whilst not as statistically sophisticated as regression analysis, comparison of the
smooth and stormy induction groups will still allow examination of the factors that
distinguish these two groups. The original research question involved identification of
which children would have most difficulty at induction to general anaesthesia, a
central facet of this question was the causal nature. Whilst tests of difference do not
allow for causal inferences, any significant difference between the two groups will
highlight a potentially predictive variable to which future attention should be paid.
Furthermore, Spearman correlations can be performed on the non-categorised ICC
data to examine the strength of the association between this and the independent
variables. It should be acknowledged that this will increase the chance of a type two
error and render the nature of this study investigative rather than predictive.

Inter-Rater Reliability for the ICC

The ICCs were administered by two identified operating department assistants
(ODAs). A number of inductions were identified for double-rating by both of these
ODAs. From this, five double-rated ICC’s were obtained. Agreement was good
between the raters. Examination of the agreement between raters using Spearman’s
correlation revealed a significant positive correlation, r=0.947, n=5, p=0.007. If
classification of induction as smooth or stormy is considered, there was 100%
agreement between the two raters.
Both the CSWQ and CSWQ-R yield total scores between a possible minimum of 0 and maximum of 68. Data was available for the CSWQ for 47 respondents, and data was available for 74 participants for the CSWQ-R.

Table 1, below, summarises the range, possible minimum and maximum, kurtosis, skewness, mean, and standard deviation for the total and subtest scores of the CSWQ and CSWQ-R.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Range</th>
<th>Possible Minimum</th>
<th>Possible Maximum</th>
<th>Kurtosis (st.error)</th>
<th>Skewness (st.error)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>CSWQ</td>
<td>0 - 63</td>
<td>0</td>
<td>68</td>
<td>1.195 (0.681)</td>
<td>0.748* (0.347)</td>
<td>24.7</td>
<td>14.1</td>
</tr>
<tr>
<td>CSWQ-R</td>
<td>0 - 60</td>
<td>0</td>
<td>68</td>
<td>-0.375 (0.552)</td>
<td>0.574* (0.279)</td>
<td>23.1</td>
<td>15.4</td>
</tr>
</tbody>
</table>

* denotes skewness or kurtosis significantly deviating from normal

There is kurtosis present for the CSWQ and CSWQ-R scores. On closer examination of the data, this appears to be due to a higher frequency count for points under the mean than for those over the mean. The correlation between scores on these measures and the ICC can be examined with a Spearman test and the difference between scores on the CSWQ and CSWQ-R for the smooth and stormy induction groups can be examined using a Mann-Whitney U test.
Spence Children’s Anxiety Scale (SCAS)

The SCAS yields a total score (STOT), but it also yields scores for several sub-scales – Panic and Agoraphobia (PA); Separation Anxiety (SA); Fear of Physical Injury (PI); Social Phobia (SP); Obsessive-Compulsive (OC); and Generalised Anxiety Disorder (GAD). Data was available for the SCAS for 51 participants.

Table 2, below, summarises the range, possible minimum and maximum, kurtosis, skewness, mean, and standard deviation for the total and subtest scores of the SCAS.

Table 2: Summary of Descriptive Statistics for SCAS

<table>
<thead>
<tr>
<th>Scale</th>
<th>Range</th>
<th>Possible Minimum</th>
<th>Possible Maximum</th>
<th>Kurtosis (st.error)</th>
<th>Skewness (st.error)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>STOT</td>
<td>3 - 77</td>
<td>0</td>
<td>114</td>
<td>1.824* (0.662)</td>
<td>1.250* (0.337)</td>
<td>25.6</td>
<td>17.0</td>
</tr>
<tr>
<td>PA</td>
<td>0 - 17</td>
<td>0</td>
<td>27</td>
<td>3.221* (0.662)</td>
<td>1.88* (0.337)</td>
<td>3.1</td>
<td>4.1</td>
</tr>
<tr>
<td>SA</td>
<td>0 - 15</td>
<td>0</td>
<td>18</td>
<td>1.696* (0.656)</td>
<td>1.215* (0.333)</td>
<td>4.9</td>
<td>34</td>
</tr>
<tr>
<td>PI</td>
<td>0 - 11</td>
<td>0</td>
<td>15</td>
<td>0.252 (0.656)</td>
<td>0.670* (0.333)</td>
<td>4.2</td>
<td>2.6</td>
</tr>
<tr>
<td>SP</td>
<td>0 - 17</td>
<td>0</td>
<td>18</td>
<td>3.737* (0.656)</td>
<td>1.471* (0.333)</td>
<td>4.8</td>
<td>3.2</td>
</tr>
<tr>
<td>OC</td>
<td>0 - 10</td>
<td>0</td>
<td>18</td>
<td>-0.013 (0.656)</td>
<td>1.049* (0.333)</td>
<td>2.8</td>
<td>3.1</td>
</tr>
<tr>
<td>GAD</td>
<td>0 - 15</td>
<td>0</td>
<td>18</td>
<td>0.313 (0.656)</td>
<td>0.634 (0.333)</td>
<td>5.6</td>
<td>3.6</td>
</tr>
</tbody>
</table>

* denotes skewness or kurtosis significantly deviating from normal
On closer examination of the data, the abnormal skewness and kurtosis appear to be due to a higher frequency of zero scores or very low scores.

The correlations between STOT, PA, SA, PI, SP, and OC with the ICC can be examined with a Spearman’s correlation and the difference on these measures between the smooth and stormy groups can be examined using a Mann-Whitney U test. The correlation between GAD and the ICC can be examined with a Spearman’s correlation and the difference on this measure between the smooth and stormy groups can be examined using a t-test.

*Emotionality, Activity, Sociability (EAS)*

EAS yields four sub-scale scores; Emotionality (E); Activity (A); Sociability (S); and Shyness (Sh). Data was available for the EAS for 74 participants.

Table 3, below, summarises the range, possible minimum and maximum, kurtosis, skewness, mean, and standard deviation for the total and subtest scores of the EAS.

<table>
<thead>
<tr>
<th>Scale</th>
<th>Range</th>
<th>Possible Minimum</th>
<th>Possible Maximum</th>
<th>Kurtosis (st.error)</th>
<th>Skewness (st.error)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>E</td>
<td>1-4.8</td>
<td>1</td>
<td>5</td>
<td>-0.867 (0.555)</td>
<td>0.238 (0.279)</td>
<td>2.5</td>
<td>1.0</td>
</tr>
<tr>
<td>A</td>
<td>1.6-5</td>
<td>1</td>
<td>5</td>
<td>0.048 (0.552)</td>
<td>0.302 (0.279)</td>
<td>3.3</td>
<td>0.7</td>
</tr>
<tr>
<td>S</td>
<td>1.8-5</td>
<td>1</td>
<td>5</td>
<td>-0.043 (0.552)</td>
<td>0.399 (0.279)</td>
<td>3.3</td>
<td>0.6</td>
</tr>
<tr>
<td>Sh</td>
<td>1-4.2</td>
<td>1</td>
<td>5</td>
<td>-0.567 (0.555)</td>
<td>-0.549 (0.281)</td>
<td>2.8</td>
<td>0.8</td>
</tr>
</tbody>
</table>
There is no abnormal skewness or kurtosis evident. The correlations between E, A, S and Sh with the ICC can be examined with a Spearman correlation and the difference on these measures between the smooth and stormy groups can be examined using t-tests.

_Behavioural Upset in Medical Patients – Revised (BUMP-R)_

The BUMP yields a unidimensional score for both the home version (BMUNI) and the hospital version (BPUNI), but it also yields scores for several sub-scales. The subscales are Negativity/Agitation (BMNA); Amiability (BMAM); Dysphoria (BMDY); and Non-Compliance (BMNC). In addition, difference scores can be computed for each of these dimensions – Unidimensional (DUNI); Negativity/Agitation (DNA); Amiability (DAM); Dysphoria (DDY); and Non-Compliance (DNC). BUMP-R home data was available for 63 participants, and difference data was available for 59 participants.

Table 4, over, summarises the range, possible minimum and maximum, kurtosis, skewness, mean, and standard deviation for the total and subtest scores of the BUMP-R.
<table>
<thead>
<tr>
<th>Scale</th>
<th>Range</th>
<th>Possible Minimum</th>
<th>Possible Maximum</th>
<th>Kurtosis (st.error)</th>
<th>Skewness (st.error)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>BMUNI</td>
<td>33 - 93</td>
<td>0</td>
<td>112</td>
<td>0.758 (0.595)</td>
<td>0.769* (0.311)</td>
<td>52.4</td>
<td>13.3</td>
</tr>
<tr>
<td>BMNA</td>
<td>0 - 37</td>
<td>0</td>
<td>44</td>
<td>-0.495 (0.595)</td>
<td>0.406 (0.302)</td>
<td>16.7</td>
<td>9.0</td>
</tr>
<tr>
<td>BMAM</td>
<td>17 - 48</td>
<td>0</td>
<td>32</td>
<td>9.540* (0.595)</td>
<td>1.915* (0.302)</td>
<td>52.2</td>
<td>4.5</td>
</tr>
<tr>
<td>BMDY</td>
<td>0 - 12</td>
<td>0</td>
<td>16</td>
<td>-0.050 (0.595)</td>
<td>0.828* (0.302)</td>
<td>3.8</td>
<td>3.3</td>
</tr>
<tr>
<td>BMNC</td>
<td>2 - 13</td>
<td>0</td>
<td>16</td>
<td>-0.916 (0.595)</td>
<td>0.203 (0.302)</td>
<td>7.0</td>
<td>3.0</td>
</tr>
<tr>
<td>DUNI</td>
<td>-22 - 38</td>
<td>-112</td>
<td>112</td>
<td>2.878 (0.613)</td>
<td>0.769 (0.311)</td>
<td>3.0</td>
<td>9.7</td>
</tr>
<tr>
<td>DNA</td>
<td>-15 - 20</td>
<td>-44</td>
<td>44</td>
<td>1.142 (0.613)</td>
<td>-0.358 (0.311)</td>
<td>2.3</td>
<td>6.9</td>
</tr>
<tr>
<td>DAM</td>
<td>-6 - 30</td>
<td>-32</td>
<td>32</td>
<td>21.405* (0.613)</td>
<td>3.791* (0.311)</td>
<td>0.6</td>
<td>4.9</td>
</tr>
<tr>
<td>DDY</td>
<td>-7 - 7</td>
<td>-16</td>
<td>16</td>
<td>1.098 (0.613)</td>
<td>0.390 (0.311)</td>
<td>-1.1</td>
<td>2.5</td>
</tr>
<tr>
<td>DNC</td>
<td>-4 - 13</td>
<td>-16</td>
<td>16</td>
<td>2.931* (0.613)</td>
<td>1.025* (0.311)</td>
<td>2.2</td>
<td>2.8</td>
</tr>
</tbody>
</table>

* denotes skewness or kurtosis significantly deviating from normal

On closer examination of the data, the abnormal distribution for BMDY appears to be due to a high frequency of zero and low scores. The abnormal skewness and kurtosis for BMAM and DNC appears to be due at least in part to, respectively, a bimodal and trimodal distribution.
The correlations between the BUMP-R scale and difference scores with the ICC can be examined with a Spearman’s correlation. The differences on this measure between the smooth and stormy groups can be examined using a Mann-Whitney U test where skewness or kurtosis deviate significantly from normal (BMUNI, BMAM, BMDY, DAM, and DNC), and a t-test can be used where skewness and kurtosis do not deviate significantly from normal (BMNA, BMNC, DUNI, DNA, DDY).

Background Factors

The background factors collected were: age, first language of child; first language of parent; time taken to travel; specialty within which procedure falls; number of previous procedures; child’s reaction to immunisation; whether or not child stayed at the hospital the night before; number of weeks on waiting list; whether child is on the morning or afternoon list; how long child has known the procedure is going to happen; and whether or not the child has received any preparation beyond discussion.

Table 5, overleaf, summarises the range, kurtosis, skewness, mean, standard deviation, and number of respondents for whom data were available for the continuous background variables.
### Table 5: Summary of Descriptive Statistics for Continuous Background Variables

<table>
<thead>
<tr>
<th>Factor</th>
<th>Range</th>
<th>Kurtosis (st.error)</th>
<th>Skewness (st.error)</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>7y0m - 11y11m</td>
<td>-1.171 (0.578)</td>
<td>0.201 (0.293)</td>
<td>9y4m</td>
<td>1.55</td>
<td>67</td>
</tr>
<tr>
<td>Travel time</td>
<td>0.5 - 6.0</td>
<td>0.564 (0.566)</td>
<td>1.222* (0.287)</td>
<td>2.1</td>
<td>1.5</td>
<td>70</td>
</tr>
<tr>
<td>Previous procedures</td>
<td>0 - 35</td>
<td>6.966* (0.574)</td>
<td>2.626* (0.291)</td>
<td>4.9</td>
<td>7.2</td>
<td>68</td>
</tr>
<tr>
<td>Waiting weeks</td>
<td>1 - 130</td>
<td>7.500* (0.574)</td>
<td>2.621* (0.291)</td>
<td>24.2</td>
<td>26.9</td>
<td>68</td>
</tr>
<tr>
<td>Child known</td>
<td>0.5 - 124</td>
<td>9.706* (0.574)</td>
<td>2.888* (0.291)</td>
<td>17.9</td>
<td>24.3</td>
<td>68</td>
</tr>
</tbody>
</table>

* denotes skewness or kurtosis significantly deviating from normal

On closer examination of the data, the abnormal skewness and kurtosis for these data appear to be due to a high proportion of low values coupled with a fairly even distribution of other values, with the exception of age, where the kurtosis appears to be due to a fairly even distribution of children across the age range.

The relationship of the continuous variables (age, time taken to travel, number of previous procedures, number of weeks on waiting list, how long child has known procedure is going to take place) with the ICC can be examined using Spearman’s
Any difference between the smooth and stormy induction groups can be examined using a Mann-Whitney U test.

Considering the categorical data collected, a decision was made not to analyse first language of parent or first language of child since only five children and nine parents did not have English as a first language, resulting in comparison groups of widely different sizes which would render any statistical analysis meaningless. A decision was reached not to analyse ethnicity for similar reasons. Of the remainder, Chi-square tests were considered appropriate since associations were being sought within nominal data. However, data about specialism violated the assumption within Chi-square that no expected cell frequency should be lower than five (Howell, 1997), and data about reaction to immunisation and whether or not preparation was received yielded data where actual cell frequencies were too dissimilar to continue with analysis. Therefore, no further analysis of these two variables will be carried out. Of the remainder (sex, previous night’s stay, and am/pm), 2 x 2 Chi-squared analyses will be carried out.

Results of Statistical Analyses

Children’s Surgical Worries Questionnaire (CSWQ) and Children’s Surgical worries Questionnaire – Revised (CSWQ-R)

The correlations between the CSWQ and the ICC and the CSWQ-R and the ICC were examined using Spearman correlations. The Spearman correlation for the CSWQ revealed that there was a significant positive correlation between scores on the ICC and scores on the CSWQ, $r = 0.630$, $n = 47$, $p < 0.001$. This suggests that children
who express more worries about their upcoming procedure are more likely to have a stormy induction. The Spearman correlation for the CSWQ-R revealed that there was a significant positive correlation between the scores on the ICC and scores on the CSWQ-R, $r = 0.437$, $n = 74$, $p < 0.001$. This suggests that children whose parents consider them to have more worries about their upcoming procedure are more likely to have a stormy induction.

The differences between scores on the CSWQ and CSWQ-R between the smooth and stormy induction groups were examined using Mann-Whitney U tests. Analysis of the CSWQ data revealed that those children who had smooth inductions ($n = 24$, mean rank = 16.50) scored lower on the CSWQ than those children who had stormy inductions ($n = 23$, mean rank = 31.83), $U = 96.0$, $p < 0.001$. This further supports the suggestion that children with higher scores on the CSWQ are more likely to have a stormy induction. Analysis of the CSWQ-R data revealed that those children who had smooth inductions ($n = 41$, mean rank = 29.55) scored lower on the CSWQ-R than those children who had stormy inductions ($n = 33$, mean rank = 47.38), $U = 350.5$, $p < 0.001$. This further supports the suggestion that children with higher scores on the CSWQ-R are more likely to have a stormy induction.

Spence Children's Anxiety Scale (SCAS)

The correlations between the SCAS scores (total, panic and agoraphobia, separation anxiety, fear of physical injury, social phobia, obsessive-compulsive, and generalised anxiety disorder) and the ICC were examined using Spearman correlations. The Spearman correlation for the GAD subscale revealed that there was a significant
positive correlation between scores on the ICC and scores on the SCAS GAD subscale \((r = 0.279, n = 51, p = 0.048)\). The Spearman correlation for the PI subscale revealed that there was a correlation approaching statistical significance between scores on the ICC and scores on the SCAS PI subscale \((r = 0.273, n = 51, p = 0.053)\). The Spearman correlation for the PA subscale also revealed that there was a correlation approaching statistical significance between scores on the ICC and scores on the SCAS PA subscale \((r = 0.275, n = 50, p = 0.054)\). Similarly, the Spearman correlation for the SCAS total score revealed that there was a correlation approaching statistical significance between scores on the ICC and SCAS total scores \((r = 0.266, n = 50, p = 0.062)\). No other significant correlations were identified. This suggests that children scoring highly on the SCAS GAD subscale are more likely to experience a stormy induction. The results approaching significance for the PA, PI, and total subscales suggest that these may be interesting foci for future research.

The differences between scores on the PA, SA, PI, SP, and OC subscales and the SCAS total score between the smooth and stormy induction groups were examined using Mann-Whitney U tests. No significant differences were identified, although the difference on the PA subscale was approaching significance, with those children who had smooth inductions \((n = 27, \text{mean rank} = 22.26)\) scoring lower on the SCAS PA subscale than those who had stormy inductions \((n = 23, \text{mean rank} = 29.30)\), \(U = 223.0, p = 0.082\). Coupled with the result of the Mann-Whitney U test, which was also approaching significance, this suggests that PA may be an interesting focus for future research.
The difference between scores on the GAD sub-scale between the smooth and stormy induction groups was examined using a t-test. The mean SCAS GAD subscale scores for the smooth and stormy induction groups are shown in Table 6, below.

**Table 6: Mean SCAS GAD score for the smooth and stormy induction groups**

<table>
<thead>
<tr>
<th></th>
<th>Stormy Induction (n = 24)</th>
<th>Smooth Induction (n= 27)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean SCAS GAD score</td>
<td>4.70 (3.01)</td>
<td>6.54 (3.99)</td>
</tr>
<tr>
<td>(standard deviation in parentheses)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As can be seen in Table 6, children in the stormy induction group had higher scores than children in the smooth induction group. This difference approached statistical significance, \( t = -1.870, \text{df} = 49, p = 0.067 \) and is not totally incongruous with the significant Spearman correlation found for GAD with the ICC.

*Emotionality, Activity, Sociability (EAS)*

The correlations between emotionality (E), activity (A), sociability (S) and shyness (Sh) and the ICC were examined using Spearman’s correlations. The Spearman’s correlation for the A subscale revealed that there was a correlation approaching statistical significance between scores on the ICC and scores on the EAS (A) subscale \( (r = 0.208, n = 74, p = 0.076) \). No other significant correlations were found. This
suggests that the EAS or other measure of temperament or activity may be an interesting focus for future research in this area.

The differences between scores for E, A, S, and Sh between the smooth and stormy induction groups were examined using t-tests. No significant differences were found for the E, S, and Sh subscales. The mean A subscale scores for the smooth and stormy induction groups are shown in Table 7, below.

Table 7: Mean EAS Activity subscale score for the smooth and stormy induction groups

<table>
<thead>
<tr>
<th></th>
<th>Stormy Induction (n = 33)</th>
<th>Smooth Induction (n = 41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean EAS Activity score</td>
<td>3.47 (0.59)</td>
<td>3.16 (0.74)</td>
</tr>
<tr>
<td>(standard deviation in parentheses)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As can be seen in Table 7, children in the stormy induction group had higher scores on the EAS Activity subscale than children in the smooth induction group. This difference approached significance, \( t = -1.961, \ df = 72, p = 0.054 \). This suggests that the EAS Activity subscale or other measure of temperament or activity may be an interesting focus for future research in this area.

*Behavioural Upset in Medical Patients – Revised (BUMP-R)*

The correlations between the BUMP-R home scale and home-hospital difference scores and the ICC were examined using Spearman correlations. The Spearman
correlation for DNA (difference negativity and agitation between home and hospital) with the ICC revealed that there was a significant correlation between scores on the ICC and DNA, \( r = 0.293, n = 59, p = 0.024 \). This suggests that children whose parents report less child expressed negativity and agitation in hospital compared with home are more likely to experience a stormy induction. No other significant correlations were identified.

The differences between the DDY (home-hospital difference dysphoria), DNA (home-hospital difference negativity and agitation), DUNI (home-hospital unidimensional difference), BMNC (home non-compliance), and BMNA (home negativity and agitation) were examined using t-tests. No significant differences were found for DDY, DUNI, BMNC, or BMNA. The mean DNA scores for the smooth and stormy induction groups are shown in Table 8, below.

Table 8: Mean BUMP-R DNA scores for the smooth and stormy induction groups

<table>
<thead>
<tr>
<th></th>
<th>Stormy Induction (n = 27)</th>
<th>Smooth Induction (n = 41)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean BUMP-R DNA score</td>
<td>-1.30 (2.37)</td>
<td>4.28 (6.78)</td>
</tr>
<tr>
<td>(standard deviation in parentheses)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

As can be seen in Table 8, children in the stormy induction group had significantly lower DNA scores than children in the smooth induction group, \( t = 2.540, df = 57, p = 0.014 \). This further supports the suggestion that children whose parents report less
expressed negativity and agitation in hospital compared with home are more likely to experience a stormy induction.

The differences between the BMUNI (home unidimensional), BMAM (home amiability), BMDY (home dysphoria), DAM (home-hospital difference amiability) and DNC (home-hospital difference non-compliance) scores between the smooth and stormy induction groups were examined using Mann-Whitney U tests. No statistically significant differences were found.

**Background Factors**

The correlations between age, time taken to travel, number of previous procedures, number of weeks on waiting list, and how long the child has known the procedure was going to take place with the ICC were examined using Spearman correlations. A significant positive correlation between number of previous procedures and score on ICC (r = 0.275, n = 68, p = 0.023) was identified. No other significant correlations were identified.

The differences between scores for age, time taken to travel, number of previous procedures, number of weeks on waiting list, and how long the child has known the procedure was going to take place between the smooth and stormy induction groups were examined using Mann-Whitney U tests. A significant difference was found for number of previous operations, where children in the smooth induction group (n = 37) had experienced significantly fewer previous procedures under anaesthetic than children in the stormy induction group (n = 31), U = 385.0, p = 0.019. No further
significant differences between the smooth and stormy induction groups were identified.

These results suggest that children who have experienced a greater number of previous procedures under anaesthetic are more likely to experience a stormy induction.

The nominal data collected on sex of child, whether child stayed in the night before, and whether the procedure was in the morning of the afternoon was analysed with smooth/stormy induction using 2x2 Chi square tests. No significant results were found.
Summary of Significant Results and Trends

Statistically significant results suggest that:

- Children who express more worries about their procedure (higher score on CSWQ) are more likely to experience a stormy induction to general anaesthesia.
- Children whose parents think they are more worried (higher scores on CSWQ-R) are more likely to experience a stormy induction to general anaesthesia.
- Children who report more generalised anxiety symptoms as measured by the GAD subscale of the SCAS are more likely to experience a stormy induction to general anaesthesia.
- Children whose parents report less expressed negativity/agitation in hospital than at home (higher BUMP-R negativity/agitation home-hospital difference) are more likely to experience a stormy induction to general anaesthesia.
- Children who have experienced a greater number of previous procedures under anaesthesia are more likely to experience a stormy induction to general anaesthesia.

Some interesting trends were noted within the data where results were approaching significance, suggesting that these measures may be worthy of closer attention in more targeted studies in future. Trends were found within the panic and agoraphobia, physical injury, and total scales of the SCAS, as well as within the activity subscale of the EAS.
DISCUSSION

Consideration of Amended Hypotheses

Higher trait anxiety will be associated with less compliance at induction to general anaesthesia.

Support was found for this hypothesis in the current study. A significant correlation was found between children’s scores on the GAD subscale of the SCAS and scores on the ICC as well as children’s scores on the GAD subscale of the SCAS approaching statistically significant difference between the smooth and stormy induction groups. Other subscales of the SCAS (PI, PA, and total) had correlations and/or differences approaching significance. Previous research findings have suggested that there is a link between higher child trait anxiety and higher state anxiety immediately prior to and during medical/dental procedures, including induction to general anaesthesia (Holmes & Girdler, 2005; Watson & Visram, 2003).

However, as discussed in the introduction, it does not automatically follow that high anxiety equates to non-compliant behaviour, since an anxious state may equally be behaviourally manifested in over-compliance or heightened alertness. It would have been interesting to have been able to use a measure of anxiety at induction to general anaesthesia, and this could be a consideration for further research, since prediction of non-compliance addresses service issues but not humanitarian issues.
Greater behavioural change between home and hospital will be associated with less compliance at induction to general anaesthesia.

Some support for this hypothesis was demonstrated in the current study. A significant correlation was found between the BUMP-R DNA (difference in expressed negativity/agitation between home and hospital) and the ICC, as well as the BUMP-R DNA scores being significantly different between the smooth and stormy induction groups. Children whose parents reported less expressed negativity/agitation in the hospital environment compared with the home environment were found to be significantly less likely to comply with induction to general anaesthesia.

This finding is concurrent with published literature, where children exhibiting shy, inhibited, or withdrawn personality traits are suggested to be at high risk when exposed to distressing experiences generally (Dadds & Barrett, 2001), and these traits have been explicitly linked with higher anxiety and more disruption during medical procedures including induction to general anaesthesia (Kain et al 2000; Quinonez et al 1997). Published literature suggests an effect for pre-existing behavioural difficulties on levels of anxiety during medical procedures (Diver, Dahlquist & Hilley, 2000; Christiansen & Chambers, 2005), although no effect has been found for the impact of pre-existing behavioural difficulties on compliance (Proczkowska-Bjorklund & Svedin, 2004). The measure of anxiety was excluded from this study at the insistence of the ethics committee. Perhaps if it had been included, an effect for pre-existing behavioural difficulties would have been found.
More self-reported pre-operative surgical worries will be associated with less compliance at induction to general anaesthesia.

Support for this hypothesis was demonstrated in the current study in that children’s scores on the CSWQ were significantly correlated with scores on the ICC, as well as the scores on the CSWQ being significantly different between the smooth and stormy induction groups. It is interesting, however, that worries were more strongly associated with less compliance at induction to general anaesthesia than anxiety. Worrying could be considered the cognitive component of anxiety, in the absence of physiological symptoms, perhaps. The items on the trait anxiety measure used in this study include physiological symptoms of anxiety, such as racing heart or trembling, and it could be that these aspects of anxiety are less related to non-compliance at induction than the cognitive aspects and that general measures of anxiety are less appropriate for use in a paediatric setting. It may also be significant that the children who took part in this study were aged between seven and twelve, broadly falling into the concrete operational phase of cognitive development according to Piaget’s (1952) stage model. At this level of cognitive sophistication, the cognitive process of worry may play a more important part in determining their behaviour than in younger children.

The CSWQ (Quiles, Ortigosa, Mendez & Pedroche, 1999) is a relatively new measure developed with a Spanish-speaking population which has not, to the author’s knowledge, been used with an English-speaking clinical population, its standardisation having been carried out on Spanish school populations. It would be
useful to consider this measure for future use with a paediatric population in Britain, and effort to develop British norms would likely be well spent.

More parent-reported pre-operative surgical worries will be associated with less compliance at induction to general anaesthesia.

Support for this hypothesis was demonstrated in the current study in that parent’s ratings on the CSWQ-R were significantly correlated with scores on the ICC, as well as the ratings on the CSWQ-R being significantly different between the smooth and stormy induction groups.. It is interesting that parent-report of the child’s worries, although significantly related to compliance at induction of general anaesthesia, was less strongly related than child report. Eiser (2000) notes that studies about children with medical conditions too often rely on parent report at the risk of excluding the voice of the child. Carter (1998) describes children as “the silent consumers of healthcare”. The results of this study appear to support the idea that children’s voices should be heard and attended to in medical situations, as it seems they know better than their parents how they are feeling and are able to report this fact.

These findings and considerations add support to the suggestion that the CSWQ (Quiles, Ortigosa, Mendez & Pedroche, 1999) be seriously considered for future use with a paediatric population, both children and parents.
Aspects of the child’s temperament will be associated with less compliance at induction to general anaesthesia.

No clear support was found for this hypothesis in the current study. A correlation statistic approaching significance was found for the activity subscale of the EAS (EAS-A), and the difference in EAS-A ratings between the smooth and stormy induction groups was also approaching statistical significance. Whilst this cannot be taken as supportive of the hypothesis, it perhaps suggests that more targeted research in this area could yield some interesting results.

Previous research findings suggest that there is a link between shy or inhibited temperament traits and non-compliant behaviour at induction to general anaesthesia (Proczykowska-Bjorklund & Svedin, 2004) rather than a link between highly active traits, although it has been proposed that hyperactivity correlates significantly with qualitatively observed distress during venepuncture in paediatric oncology patients (Diver, Dahlquist & Hilley, 2000). However, it should be noted that the majority of research into temperament and its effect in medical situations concentrates on children who are younger than those who took part in this study. Equally, the EAS (Buss & Plomin, 1984) is only validated with children up to the age of 8 years, although a very similar version is available for use with adults. It could be that the measure used was not appropriate for the age group, or that, as children grow older and their behaviour becomes governed less by instinct and more by reason that temperament becomes less predictive of their behaviour.
Children who reacted badly to their immunisations will be less compliant at induction to general anaesthesia.

This hypothesis could not be supported or disputed statistically, since data yielded cell frequencies which were too dissimilar to continue with analysis. Proczkowska-Bjorklund and Svedin (2004) found that negative emotional response to childhood vaccinations predicted non-compliance at induction to general anaesthesia, and other authors (e.g. Kotiniemi, Ryhanen & Moilanen, 1997) have reported associations with negative past medical experiences and high anxiety/distress at induction to general anaesthesia. Qualitative experience of past medical experiences seems worthy of future investigation with regard to compliance at induction to general anaesthesia.

It is possible that other background factors will be associated with level of compliance at induction to general anaesthesia. In addition to these specific hypotheses, and in the light of limited research evidence focussing on compliance with induction to general anaesthesia, the relationship between all background factors assessed and the ICC will be explored.

Of the background factors assessed, one was found to be associated with less compliance at induction to general anaesthesia. Children who have experienced a greater number of previous procedures under anaesthesia were found to be less likely to comply with induction to general anaesthesia. Many authors have demonstrated that there is no effect simply due to previous experience of surgery, but that it is the qualitative experience of previous procedures that is a predictor for anxious or non-
compliant reaction to induction (e.g. Kotiniemi et al, 1997; Lumley et al, 1993; Proczkowska-Bjorklund & Svedin, 2004). It could be that, due to a sampling artefact, the children involved in this study have, in the main, experienced previous procedures as aversive.

It is encouraging that no significant effect was found for age, since this further supports the choice of 7-12 years as a developmentally cohesive sample. That no effect was found for gender fits with the research findings around medical and dental procedural compliance, but not with general understanding of differences between boys and girls on measures of anxiety and fear. Again, perhaps if the originally proposed anxiety measure had been included as an outcome, a difference would have been evident.

**Original hypotheses which could not be addressed**

*Children who themselves, or whose parents, do not have English as a first language will likely be less compliant and more anxious at induction to general anaesthesia.*

The ethics committee prevented the researchers from including families who did not speak English in this study. As a result, only four children and nine parents did not have English as a first language, resulting in comparison groups of widely different sizes which would render any statistical analysis meaningless.
As discussed in the introduction, culture, ethnicity and language are factors which are noticeably absent from consideration in the body of the published literature and it would be valuable to consider these factor in any future research, as well as consideration of ethnicity and culture. In an increasingly multi-cultural society and a health service in which provision of culturally competent practice is increasingly emphasised, it would be inexcusable to fail to provide appropriate services as a result of omissions in the evidence base.

Limitations and Potential Solutions

Characteristics of the Data

Due to the characteristics of the data, the planned regression analysis could not be carried out, and as such, a large number of individual statistical analyses were carried out, increasing the chance of a type one error. A larger sample size would solve this problem, since, even if the outcome measure was distributed in the same way as in this study, leading to a categorical outcome measure, a logistic regression could be performed if the sample size were large enough. However, due to the difficulties in accessing the population discussed later, gaining a large enough sample size would have been well beyond the resources or available time of the researcher. Regression analysis is important in a study of this type, since it is likely that some of the variables interact with one another, and regression analysis would allow these interactions to be examined and, in the case of step-wise regression, be controlled for. Additionally, regression analysis would allow statements of causality to be made with some
confidence, as opposed to correlations and tests of difference, which only allow associations to be reasonably discussed, although some inference can be made about causality when the results are considered in conjunction with the published literature.

The split in the outcome measure into smooth and stormy induction groups is an interesting consideration. The proportions falling in the smooth (54%) and stormy (46%) groups in this study are not dissimilar to the satisfactory (52% intravenous an 42% inhalation) and unsatisfactory (48% intravenous and 58% inhalation) proportions of inductions reported by Meyer and Lakheeran (2002) in a study carried out at the same hospital as this research. However, it should be noted that the smooth induction group consisted of children who were rated as displaying no problematic behaviour whatsoever, whereas the stormy induction group consisted of children who were rated as displaying one or more problematic behaviours. Another, slightly lengthier, label for the stormy induction group would be the less-than-perfect-group.

The distribution of the data for some of the categorical variables limited which could be examined using Chi squared tests, since the assumptions of minimum expected cell frequency and reasonably even distribution amongst the cells were violated, meaning that some data could not meaningfully be analysed. In some cases, such as specialty, this difficulty could be addressed by using stratified sampling, picking equal numbers of children from the different specialty surgical lists. To have done this for the study in its current form would have created even more difficulties in collecting data from a large enough sample, since the volume of children on the different lists varies
enormously. Additionally, some lists (such as plastic surgery) would be more likely to be cancelled to make way for emergency operations than more necessary lists (such as urology). However, if similar research is carried out, it may be useful to consider stratified sampling in this way to allow data about specialty to be meaningfully analysed.

Gaps in the Data

Fewer child-completed measures were collected than parent completed measures. The reason for this is that many families were happy for their child to be included in the research, and were happy to complete the parent-rated measures, but did not want their child to complete that child-rated measures. Many parents expressed the belief that by asking their child about worries and anxieties, they would become more upset. This desire to protect their children from additional worry is understandable, although the fact that this data was unavailable is a difficulty.

This difficulty may have been overcome had the completion of questionnaires been more removed from the surgical procedure. In practice, although the questionnaires were posted to families well in advance of the procedure, only two families returned the questionnaires – the remainder completed them on the day of their child’s procedure. Had the researcher been available full-time at the hospital, as opposed to one or two days a fortnight, attendance at pre-surgical assessment appointments would have been possible, and families could have been asked to complete the measures at this appointment.
Exclusion Criteria

The exclusion criteria of not having fluent English which was imposed on this study by the research ethics committee led to a number of people being excluded on this basis, and meant that the hypothesis regarding having English as a first language could not be addressed in the data analysis. As already discussed, the factors of first language and ethnicity are noticeably absent from the published literature, and it would have been valuable to investigate these here. These factors should be considered a priority for future research.

Children undergoing procedures associated with life-threatening conditions were excluded from this study for a number of reasons, including illness-specific factors such as frequency of invasive procedures under general anaesthetic, motivations for surgery, and the high levels of stress and worry associated with living with a life-threatening or chronic condition. It was felt that these children constituted a distinct population when compared with children undergoing non-life saving, elective, day surgery. Had time allowed, it would have been informative to have sampled, for example, an oncology or cardiology population to seek differences or similarities between the populations.

Methodological Considerations

The most significant methodological consideration is the fact that the study carried out was not the original study proposed. Due to the insistence of the ethics committee the
m-YPAS, a observer-rated measure of situational anxiety was excluded from the study. This meant that humanitarian issues surrounding alleviation of anxiety immediately prior to and during medical procedures could not be addresses, although operational service issues related to managing non-compliant children were addressed through the inclusion of a measure of compliance.

It became clear as this research progressed that surgical lists for a particular day four to seven weeks prior to the scheduled date bore little resemblance to the surgical lists for that day on the scheduled date. Reasons for this included non-attendance without warning on the part of the family, rescheduling by the family or hospital, arrangement of procedures at short notice, cancellation by the hospital to clear the elective lists for emergency lists, and, mid-way through the research, reduction of allowable numbers of elective procedures as a budget control exercise. This is responsible in the main for the small sample size of the study. In retrospect, approaching families on the day would have been a better strategy, as it would have increased the accessible population approximately five-fold. It was, however, made clear to the researchers that this would not be acceptable. Stalker, Carpenter, Connors and Phillips (2004) report similar difficulties in gaining access to children in NHS settings.

*Individual Differences*

Marteau and Johnston (1987) point out that a major flaw with much research into children's experiences of medical procedures is the underlying assumption that all care given by health professionals is consistent. This criticism applies equally to this
study – who was in the room at induction to anaesthesia was not recorded, nor was any note made of experiences on the ward prior to entering the operating suite. This was not an oversight on the part of this study. These factors were considered as potential factors which could affect compliance with induction to general anaesthesia. However, who was in the room at induction was not recorded due to sensitivities amongst the anaesthetists. Co-operation from the anaesthetic department was essential in order for this study to be carried out, and the author was advised by a consultant anaesthetist that recording which staff were present would not be well received as the anaesthetists may feel they were being evaluated. Experiences on the ward prior to entering the operating suite were not recorded as it simply would not be possible – several children were included in the study on each day of data collection and only one researcher was present.

**Strengths and Contribution to the Evidence Base**

This study considered a large number of factors in relation to the clinical end-point of induction to general anaesthesia as opposed to separation from parents or the unsatisfactorily defined “peri-operative period”. Although the limitations discussed above mean that this research must be considered as exploratory rather than confirmatory, the findings are indicative of useful directions for future research.

The CSWQ (Quiles, Ortigosa, Mendez & Pedroche, 1999), although not without its limitations as discussed in the method section, was used with a clinical population for
the first time in the author’s knowledge, and it was found to be significantly associated with non-compliance at induction to general anaesthesia. This has highlighted its potential usefulness in future studies with a paediatric population.

Carter (1998) and Eiser (2000) highlight the importance of hearing the voice of the child within medical settings. Inclusion of the child-completed surgical worries measure as well as the parent-completed surgical worries measure does mean that the voice of the child was heard. It is particularly interesting that the child’s report of their pre-surgical worries was more predictive of non-compliance at induction to general anaesthesia than the parent’s report. This supports the assertion that children’s voices should be heard, although there are ethical considerations in considering the reluctance of some of the families for their children to complete the measures.

Although research focussing on procedural distress has been evident in the psychological literature for some time (Watson & Visram, 2003), much of the research focussing on compliance at induction to general anaesthesia has been carried out by medical researchers. This research, hopefully, provides a psychological perspective on a medical issue.

The received wisdom amongst the anaesthetic community that children will be more compliant as they get older mentioned by Mellor (2004) has resulted in the majority of studies investigating factors associated with procedural distress or non-compliance focusing on younger children than those involved in this study. Moreover, the
children who participated in this study broadly fell within Piaget's concrete operational stage of cognitive development. Arguably, more attention should be paid to developmental level in this type of research.

**Implications for Practice**

This study suggests that screening for non-compliance/distress at induction to general anaesthesia is possible, and it is arguably desirable, since the current situation where preparation is not targeted, but rather offered to those children who are in the right place at the right time is less than ideal. With more chronic conditions, such as cancer or cardiac problems, the child's journey through the health system is more planned and organised, and access to appropriate preparation is usual. Within the elective day surgery population, however, access to preparation is not planned and not targeted to those children most in need, and this may cause difficulties for some children at induction or in the future if they need further procedures.

Pen-and-paper measures such as the BUMP-R (Rodriguez & Boggs, 1994) and the CSWQ (Quiles, Ortigosa, Mendez & Pedroche, 1999) are worthy of consideration as screening measures for non-compliance at induction to general anaesthesia.

Attention should be paid to non-clinical factors, such as how far the child has had to travel, and background clinical factors, such as number of previous procedures when considering which children are most at risk of high distress/low compliance at induction to general anaesthesia.
Standard practice and procedure would need to change in order for screening and subsequent targeted preparation to be effective. The current practice of allocating children to either morning or afternoon lists on the basis of when the consultant’s operating list is held would not allow for children whose consultant only operates in the morning to receive preparation if it was indicated as a result of screening. In these cases, it might be possible for the child to be admitted the afternoon before, and to receive preparation that afternoon, or for that child to be allocated to the latest slot on the morning list and to receive preparation in the morning. Another possibility would be for screening to take place weeks before the planned procedure, and a preparation session scheduled in the time between the screening and the procedure.

Further research in this area is essential. A randomised trial where children are either allocated to a screening condition in which preparation would be offered if indicated or a non-screening condition in which standard practice would apply would allow the benefits of screening to be objectively evaluated, and would further establish which factors are most indicative of non-compliance at induction to general anaesthesia.
REFERENCES


Dear Parent/Guardian,

Identification of Factors Contributing to Difficult Anaesthetic Induction in Children

We are currently doing a study which aims to investigate difficult inductions to general anaesthetic in children aged between 4 and 11 years.

The aim of this study is to develop a clearer picture of the level and frequency of difficult induction to anaesthesia, and to begin to develop an insight into pre-operative factors which could contribute to this.

In order to do this, we are asking the families of all children who are coming into Great Ormond Street Hospital for a general anaesthetic on data collection days if they would take part.

Before you and your child decide if you would be willing to take part, please read the information sheets enclosed with this letter. There are three; one for the parents, one for children aged between 8-11 years, and one for children aged under 8 years. Please decide which sheet it would be most appropriate for your child to read/have read to them.

If you and your child decide that you would be willing to take part, we would be grateful if you could sign the consent and assent forms, complete the enclosed questionnaires, and bring them all with you when you attend the hospital for your child’s procedure.

If you decide that you would not like to take part, that is fine. It will not affect the way you or your child are treated at the hospital. If you decide now that you would like to take part, but change your mind later, that is also fine. Again, this will in no way affect how you or your child are treated at the hospital.

If you have any questions, please get in touch.

Yours faithfully,

Caroline Haigh and Jenny Cropper
Trainee Clinical Psychologists

Contact telephone number: 01483 689441

The researchers regret that they will be unavailable to answer any calls directly, but if you call, you will be able to leave a message and the researchers will return your call as soon as possible, although this will probably not be on the same day.
9th December 2004

Dear Dr,

We are conducting a research study with the aim of identifying some of the factors that may contribute to a difficult induction to anaesthetic in children aged 4-11. We hope to begin a process which will identify which children are likely to find the process of having a procedure under general anaesthetic more distressing than others, with the aim of more appropriately targeting preparatory interventions.

This study has received approval from the research ethics committee and research and development department.

As part of this study we will be approaching the parents of your patients in the above age bracket who are awaiting a planned procedure, asking if they wish to take part. Involvement in the study comprises the parents and some of the older children completing postal questionnaires, and some basic pen and paper measures on arrival at the ward on the day of their procedure.

The final part of the study is for an Operating Department Assistant to complete a quick measure following the child’s induction to anaesthetic. This measure quantifies the ease of the induction. We are assessing the child and not the anaesthetist, therefore we are not recording the name of the anaesthetist and we are not comparing anaesthetist to anaesthetist.

Please contact us via Dr Lindsey Edwards in the cochlear implant department if you require any further information, or if you do not wish a child under your care to be involved in the study.

Many thanks

Yours faithfully,

Jenny Cropper
Trainee Clinical Psychologist

Caroline Haigh
Trainee Clinical Psychologist
Please rate each of the items for your child on this scale

<table>
<thead>
<tr>
<th>Rating</th>
<th>Item Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Child tends to be shy</td>
</tr>
<tr>
<td>2</td>
<td>Child cries easily</td>
</tr>
<tr>
<td>3</td>
<td>Child likes to be with people</td>
</tr>
<tr>
<td>4</td>
<td>Child is always on the go</td>
</tr>
<tr>
<td>5</td>
<td>Child prefers playing with others rather than alone</td>
</tr>
<tr>
<td>6</td>
<td>Child tends to be somewhat emotional</td>
</tr>
<tr>
<td>7</td>
<td>When child moves about, he usually moves slowly</td>
</tr>
<tr>
<td>8</td>
<td>Child makes friends easily</td>
</tr>
<tr>
<td>9</td>
<td>Child is off and running as soon as he/she wakes up in the morning</td>
</tr>
<tr>
<td>10</td>
<td>Child finds people more stimulating than anything else</td>
</tr>
<tr>
<td>11</td>
<td>Child often fusses and cries</td>
</tr>
<tr>
<td>12</td>
<td>Child is very sociable</td>
</tr>
<tr>
<td>13</td>
<td>Child is very energetic</td>
</tr>
<tr>
<td>14</td>
<td>Child takes a long time to warm up to strangers</td>
</tr>
<tr>
<td>15</td>
<td>Child gets upset easily</td>
</tr>
<tr>
<td>16</td>
<td>Child is something of a loner</td>
</tr>
<tr>
<td>17</td>
<td>Child prefers quiet, inactive games to more active ones</td>
</tr>
<tr>
<td>18</td>
<td>When alone, child feels isolated</td>
</tr>
<tr>
<td>19</td>
<td>Child reacts intensely when upset</td>
</tr>
<tr>
<td>20</td>
<td>Child is very friendly with strangers</td>
</tr>
</tbody>
</table>
These are some of the thoughts that other children and young people have had about going to hospital for an operation. We would like to know if your child has the same thoughts. Please tell us how worried you think your child is about each of the following situations, using the scale below:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all worried</td>
<td>A little worried</td>
<td>Quite worried</td>
<td>Very worried</td>
<td>Extremely worried</td>
</tr>
</tbody>
</table>

I'M WORRIED ABOUT..........

1. Not getting completely better from the illness after the operation

2. Feeling a lot of pain

3. Injections

4. Having a needle in their arm for a long time

5. Having blood taken

6. How they'll be anaesthetised

7. What they'll feel during anaesthesia

8. Waking up before the operation is over

9. How they'll wake up after the operation

10. What the operating room will be like

11. Being separated from their parents during the operation

12. What they'll feel during the operation

13. The operation not being a success

14. Having scars left after the operation

15. Who's going to do the operation

16. What they'll be able to do while they're in hospital

17. If the doctors and nurses will be kind to them

Thank you very much for taking the time to complete this questionnaire.
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
APPENDIX SIX

These are some of the thoughts that other children and young people have had about going to hospital for an operation. We would like to know if you have the same thoughts. Please tell us how worried you are about each of the following situations, using the scale below:

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all worried</td>
<td>A little worried</td>
<td>Quite worried</td>
<td>Very worried</td>
<td>Extremely worried</td>
</tr>
</tbody>
</table>

I'M WORRIED ABOUT..........

1. Not getting completely better from the illness after the operation ( )
2. Feeling a lot of pain ( )
3. Injections ( )
4. Having a needle in my arm for a long time ( )
5. Having blood taken ( )
6. How they'll anaesthetise me ( )
7. What I'll feel during anaesthesia ( )
8. Waking up before the operation is over ( )
9. How I'll wake up after the operation ( )
10. What the operating room will be like ( )
11. Being separated from my parents during the operation ( )
12. What I'll feel during the operation ( )
13. The operation not being a success ( )
14. Having scars left after the operation ( )
15. Who's going to do the operation ( )
16. What I'll be able to do while I'm in hospital ( )
17. If the doctors and nurses will be kind to me ( )

Thank you very much for taking the time to complete this questionnaire.
IDENTIFICATION OF FACTORS CONTRIBUTING TO DIFFICULT ANAESTHETIC INDUCTION IN CHILDREN

Information Sheet for Parents

The doctors taking care of your child have decided he/she needs to have a procedure under general anaesthetic. We are currently doing a project looking at how often children have a difficult induction to general anaesthesia, and to see how difficult this is for those children. We would like to ask your permission to include your child in this project. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

The aim of the project
The aim of this project is to try to identify how many children have a very difficult induction to anaesthesia, and to try to identify some of the pre-operative factors which might contribute to this.

Why is the project being done?
We know that some children find induction to general anaesthetic more upsetting than other children. We hope that if we identify some of the factors associated with this, a questionnaire could be used to check which children this is likely to be. These children could then be given extra preparation for the procedure, which might help them be less upset. We also want to know the number of children who are having a difficult induction to general anaesthesia.

How will the project be done?
The project will be carried out during your child’s stay at the hospital. If you agree to take part, a researcher will come to see you whilst you and your child are waiting on the ward and will ask you to answer some questions. Then, when your child is being inducted to anaesthesia, a member of staff who would normally be present will complete a checklist to assess how difficult the induction to anaesthesia is.

What are the risks and discomfort?
Some parents may find it upsetting to think about their child being upset, and some children may find it upsetting to think about induction to anaesthesia, although children often find it helpful to talk about their worries. If you or your child find it too
distressing, you can ask the researcher to stop. This will not affect the care or attention you receive from the hospital staff.

What are the potential benefits?
Some parents and children find it helpful to talk about their worries and feelings before surgery, possibly better preparing the child for the procedure. It may also provide you both with an activity to complete during the time they are waiting to go to the operating room.

Who will have access to the information you get?
The information we get over the course of this study will be kept confidential to the research team. The 1988 Data Protection Act safeguards the use of some types of personal information. This places an obligation on those who record or use personal information, but also gives rights to people about whom information is held. If you have any questions about data protection, please contact the Data Protection officer via the switchboard on 020 7405 9200 Ext 5217.

The results from our project will be published as papers in professional journals. No personal identifying details will be revealed in these publications.

What are the arrangements for compensation?
This research project has been approved by an independent Research Ethics Committee who believe that it is of minimal risk to your child. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely vent that any harm should occur as a result of taking part in this project.

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

Do I have to take part in this project?
No. If you decide not to take part in this project, this is entirely your right and will not in any way affect your child’s present or future treatment.

Who is organising and funding the project?
This is a joint project between Great Ormond Street Hospital and the University of Surrey. It has received no special funding.

Who do I speak to if I have further questions or worries?
Please contact Jenny Cropper or Caroline Haigh at the University of Surrey. You can contact them by leaving a message with the Clinical Psychology department at the University of Surrey (01483-686887). The researchers regret that they will not be available to answer calls, but will do their best to return any messages within the shortest time possible.

If you have any complaints about the way in which the project is being or has been conducted, in the first instance please discuss them with one of the researchers. The researchers are Jenny Cropper, Caroline Haigh, Dr Daniela Hearst and Dr Lindsey Edwards. If the problems are not resolved, or you wish to comment in any other way please contact the Chairman of the Research Ethics Committee by post via The University of Surrey, Guildford, Surrey, GU2 7HX or, if urgent, by telephone on 01483 689041, and the Secretary to the Ethics Committee will put you in touch.
Information Sheet for Children Aged 8-11

Your doctors have decided you need to have an operation under general anaesthetic. A general anaesthetic is a type of medicine that will let you have a special sleep. When you are having this special sleep you won't feel any pain. We are interested in knowing how children feel about having an operation under general anaesthetic. Therefore, we would like to ask you and your parent or guardian to fill in some questionnaires before your operation. A questionnaire is a name for a piece of paper with questions on it. There are not any right or wrong answers to these questions, they are just about how you feel. We would also like to ask your permission for a member of staff to do an observation rating of you. An observation rating is when a member of staff notices what you are doing and writes it down.

Take time to decide if you want to say YES or NO to this. Please read, or have someone to read for you, this information. Don't worry if you don't understand it straight away. Your parents have also been told about this, and you can ask them to help you understand.

1) Why are we doing this?

We want to find out how children feel about having an operation under general anaesthetic. We also want to see if we can find out why some children might be worried about having an operation under general anaesthetic. If we can find this out we might be able to help these children.

2) What will be different for you?

Before you come to hospital, you and your parents will be sent some questionnaires to fill in. When you are already in the hospital, one of the researchers will ask your parent or guardian to answer some questions. This will take about ten minutes. Nothing else will be different for you.
3) Why do we ask you?

We ask the children who are coming to Great Ormond Street Hospital for an operation under general anaesthetic to take part.

4) Do I have to take part?

No. It is up to you and your parents to decide. If you decide you don’t want to, that’s absolutely fine. The doctors and nurses will look after you as best as they can anyway.

5) What will you ask me to do?

When you are already at the hospital, one of the researchers will ask your parent or guardian to answer some questions.

6) Is it dangerous?

No, but some of the questionnaires will be asking questions about your fears and worries. Some children might find this upsetting.

7) Will it help me and other children like me?

You might find it helpful to talk about how you feel about having an operation under general anaesthetic.

Once we have finished the research, it will be easier to know which children might be worried, and so it will be easier to help them.

8) Who will know about what I say?

Only the researchers will know what answers you give. If the researchers think that you are very upset, they will tell the ward staff, but only if that is OK with you.

9) Who can I speak to if I have any questions?

You can speak to your parents who have also been given information about this project. You can also speak to the doctors or nurses on the ward.

The people involved in this research are Jenny Cropper, Caroline Haigh, Daniela Hearst and Lindsey Edwards. You and your parents can always speak to one of them if you have any more questions. Your parents also have some further contact details of people to speak to if they have any complaints or worries.
IDENTIFICATION OF FACTORS CONTRIBUTING TO DIFFICULT ANAESTHETIC INDUCTION IN CHILDREN

Information Sheet for Children Aged Under-8

Your doctors have decided that you need to have an operation. Your operation will happen under general anaesthetic. A general anaesthetic is a type of medicine. A general anaesthetic will let you have a special sleep. When you are having this special sleep you won't feel any pain.

We know that this can be scary or worrying. We want to find out what makes this more or less scary or worrying. We would like to ask you and your parent or guardian to answer some questions before your operation. We would also like to do an observation rating of you. An observation rating is when someone notices what you are doing and writes it down.

Think about whether you want to say YES or NO to this. Please read this information, or ask someone to read it to you. Don't worry if you don't understand straight away. We have told your parents about this too, and they can help you understand.

1) Why are we doing this?

We want to find out how many children find it very scary or worrying to have an operation under general anaesthesia. We are also trying to work out which children get most scared or worried about having an operation under general anaesthetic. If we work this out, we might be able to help these children be less scared or worried.
2) What will be different for you?

Before you come to hospital, your parent or guardian will be asked to fill in some questionnaires. When you are in hospital, a researcher will ask your parent or guardian to answer some questions. This will take about 10 minutes. Nothing else will be different for you.

3) Why do we ask you?

We are asking all children who are having an operation under general anaesthetic at Great Ormond Street Hospital to take part.

4) Do I have to take part?

No. It is up to you and your parent or guardian to decide. If you say no, that is fine. The doctors and nurses will look after you in the same way.

5) What will you ask me to do?

When you are already at the hospital, one of the researchers will ask your parent or guardian to answer some questions.
6) Is it dangerous?

No, it is not dangerous. Some of the questionnaires you will look at at home are about your fears and worries. You might find this upsetting.

7) Will it help me and other children like me?

It might. If it seems that you are very scared or worried, we can let other people know if that is OK with you.

When we have spoken to lots of children, it might be easier to know which children will be very scared or worried. This would make it easier to help them.

8) Who will know about what I say?

Only the people who ask the questions to your parent or guardian will know what you say.
9) Who can I speak to if I have any questions?

You can ask your parent or guardian. You can speak to the doctors or nurses on the ward.

The people involved in this research are Jenny Cropper, Caroline Haigh, Daniela Hearst and Lindsey Edwards. You and your parents can always speak to one of them if you have any more questions. Your parents also have some further contact details of people to speak to if they have any complaints or worries.
Participant identification number:

Identification of Factors Contributing to a Difficult Anaesthetic Induction in Children

Consent form to be signed by the parent or guardian of the child who will undergo general anaesthesia at Great Ormond Street Hospital.

- I have read the information sheet about the above project and have had the opportunity to ask questions about the project.

- I agree that my child can take part in the project as described in the information sheet.

- I understand that my consent is entirely voluntary and can be withdrawn at any time, without giving a reason, and that if I should do this, it will not in any way affect the way my child is treated at the hospital.

Name of Child...........................................................................................................................

..............................................................................................................................................
Name of person giving consent  Date  Signature

..............................................................................................................................................
Name of researcher  Date  Signature
Identification of Factors Contributing to a Difficult Anaesthetic Induction in Children

Assent form to be signed by the child who will undergo general anaesthesia at Great Ormond Street Hospital.

- I have read, or someone has read to me, the information sheet about this project.

- I agree that I will take part in the project.

- I understand that I can change my mind at any time without explaining why. If I do change my mind, I understand that the doctors and nurses will care for me in exactly the same way as before.

Name of Child.............................................................................................................

Signature....................................................................................................................

Date.........................................................................................................................

Name of Researcher                         Date                         Signature
The Induction Compliance Checklist - Intravenous

Please read each of the statements below and tick whichever applies to the child. Please note, you may tick more than one description if more than one applies.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perfect Induction (does not exhibit negative behaviours, fear or anxiety</td>
<td>✓</td>
</tr>
<tr>
<td>Crying, tears in eyes</td>
<td>✓</td>
</tr>
<tr>
<td>Pulls arm away from needle</td>
<td>✓</td>
</tr>
<tr>
<td>Verbal refusal, says 'no'</td>
<td>✓</td>
</tr>
<tr>
<td>Verbalisation indicating worry or fear, e.g. “where’s mummy?” or “will it hurt?”</td>
<td>✓</td>
</tr>
<tr>
<td>Pushes needle away with hands, pushes nurse/anaesthetist away with hands/feet</td>
<td>✓</td>
</tr>
<tr>
<td>Tries to cover IV site</td>
<td>✓</td>
</tr>
<tr>
<td>Hysterical crying, may scream</td>
<td>✓</td>
</tr>
<tr>
<td>Kicks/flails legs/arms, arches back, and/or general struggling</td>
<td>✓</td>
</tr>
<tr>
<td>Requires physical restraint</td>
<td>✓</td>
</tr>
<tr>
<td>Complete passivity, either rigid or limp</td>
<td>✓</td>
</tr>
<tr>
<td><strong>INDUCTION NOT COMPLETED</strong></td>
<td>✓</td>
</tr>
</tbody>
</table>
The Induction Compliance Checklist - Inhalation

Please read each of the statements below and tick whichever applies to the child. Please note, you may tick more than one description if more than one applies.

<table>
<thead>
<tr>
<th>DESCRIPTION</th>
<th>TICK</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perfect Induction (does not exhibit negative behaviours, fear or anxiety</td>
<td></td>
</tr>
<tr>
<td>Crying, tears in eyes</td>
<td></td>
</tr>
<tr>
<td>Turns head away from mask</td>
<td></td>
</tr>
<tr>
<td>Verbal refusal, says ‘no’</td>
<td></td>
</tr>
<tr>
<td>Verbalisation indicating worry or fear, e.g. “where’s mummy?” or “will it hurt?”</td>
<td></td>
</tr>
<tr>
<td>Pushes mask away with hands, pushes nurse/anaesthetist away with hands/feet</td>
<td></td>
</tr>
<tr>
<td>Covers mouth/nose with hands/arms or buries face</td>
<td></td>
</tr>
<tr>
<td>Hysterical crying, may scream</td>
<td></td>
</tr>
<tr>
<td>Kicks/flails legs/arms, arches back, and/or general struggling</td>
<td></td>
</tr>
<tr>
<td>Requires physical restraint</td>
<td></td>
</tr>
<tr>
<td>Complete passivity, either rigid or limp</td>
<td></td>
</tr>
<tr>
<td>INDUCTION NOT COMPLETED</td>
<td></td>
</tr>
</tbody>
</table>
## BEHAVIOURAL UPSET IN MEDICAL PATIENTS – REVISED (BUMP-R) BEHAVIOUR AT HOME

Please describe how your child typically behaves at home.

My child at home........

0 = NEVER  
4 = ALWAYS

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>is demanding</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>2</td>
<td>is manipulative</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>has to be reminded what to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>4</td>
<td>tries to be friendly</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>5</td>
<td>looks depressed and sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>6</td>
<td>refuses to speak</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>7</td>
<td>is stubborn, negativistic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>8</td>
<td>becomes upset easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>9</td>
<td>accepts advice or instruction easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>10</td>
<td>looks worried and tense</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>11</td>
<td>is incredibly passive</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>12</td>
<td>says he or she feels blue or depressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>13</td>
<td>is irritable or grouchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>14</td>
<td>complains</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
My child at home........

0 = NEVER  

4 = ALWAYS

15 is pleasant to be with 0 1 2 3 4
16 laughs or smiles at funny events or comments 0 1 2 3 4
17 has sleep problems 0 1 2 3 4
18 takes the initiative 0 1 2 3 4
19 gets angry 0 1 2 3 4
20 starts conversation 0 1 2 3 4
21 has to be told what to do 0 1 2 3 4
22 is uncooperative 0 1 2 3 4
23 is clinging and needs lots of reassurance 0 1 2 3 4
24 does what he or she is told 0 1 2 3 4
25 sleeps unless directed into activity 0 1 2 3 4
26 is able to ask for help 0 1 2 3 4
27 cries 0 1 2 3 4
28 is impatient 0 1 2 3 4
BEHAVIOURAL UPSET IN MEDICAL PATIENTS – REVISED (BUMP-R) BEHAVIOUR IN HOSPITAL

Please describe how your child is behaving in hospital.

My child in hospital...........

0 = NEVER 4 = ALWAYS

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>is demanding</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>is manipulative</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>has to be reminded what to do</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>tries to be friendly</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>looks depressed and sad</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>6</td>
<td>refuses to speak</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>7</td>
<td>is stubborn, negativistic</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>8</td>
<td>becomes upset easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>9</td>
<td>accepts advice or instruction easily</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>10</td>
<td>looks worried and tense</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>11</td>
<td>is incredibly passive</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>12</td>
<td>says he or she feels blue or depressed</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13</td>
<td>is irritable or grouchy</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14</td>
<td>complains</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
My child in hospital........

0 = NEVER 4 = ALWAYS

<p>| | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>is pleasant to be with</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>16</td>
<td>laughs or smiles at funny events or comments</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>17</td>
<td>has sleep problems</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>18</td>
<td>Shows interest in recovery</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>19</td>
<td>gets angry</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>20</td>
<td>starts conversation</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>21</td>
<td>has to be told to follow hospital routine</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>22</td>
<td>is uncooperative</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>23</td>
<td>is clinging and needs lots of reassurance</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>24</td>
<td>does what he or she is told</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>25</td>
<td>sleeps unless directed into activity</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>26</td>
<td>is able to ask for help</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>27</td>
<td>cries</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>28</td>
<td>is impatient</td>
<td>4</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>
Demographic data

About the Child and Family

Age

Sex

Ethnicity

Main care-givers’ occupation(s)

Child’s first language

Parent’s first language

How long has it taken the family to travel to GOSH?

Is the child or family involved with other health or social care services?

About the Procedure

Type of procedure

Number of previous surgical procedures (of any type, general or local anaesthetic)

How did the child react to his/her immunisations?

1=well; 2=neutral; 3=badly

Did the child stay in the night before the procedure?

How long has the child waited for the procedure?

Is the child on the morning or afternoon list?

How long has the child known that the procedure is going to take place?

Has the child received any preparation for the procedure? If so, what? Please include any sort of preparation, whether provided by GOSH, parents or someone else.

Are there any other fears or worries?
RESEARCH LOGBOOK

Below is a summary of the research skills and experience gained over the three years of the training course, including a description of how they were gained, and the approximate date on which the skills were used.

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>How research skill/experience acquired</th>
<th>Date acquired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conduct a literature search</td>
<td>1. Conducted a computerised literature search for each essay submitted.</td>
<td>Throughout training.</td>
</tr>
<tr>
<td></td>
<td>2. Conducted computerised literature searches for various pieces of clinical work throughout placements.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Conducted computerised literature searches for service-related research, qualitative research, and major research project.</td>
<td></td>
</tr>
<tr>
<td>Critically review the literature</td>
<td>1. Literature critically reviewed within each piece of work submitted.</td>
<td>Throughout training.</td>
</tr>
<tr>
<td>Formulate a specific research question</td>
<td>1. After discussion with department, formulated research questions and carried out research around working with people with a personality disorder in CMHT's.</td>
<td>December 2002</td>
</tr>
<tr>
<td></td>
<td>2. In collaboration with two other trainees, formulated research question and carried out research around trainee clinical and counselling psychologists' concepts of mental health.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. After discussion with department, formulated research question and carried out research around factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia.</td>
<td>April 2004</td>
</tr>
<tr>
<td></td>
<td></td>
<td>November 2004</td>
</tr>
<tr>
<td>Write a brief research proposal</td>
<td>1. Prepared a brief research proposal to carry out audit/research into professionals' experiences of working with people with a personality disorder in a CMHT.</td>
<td>December 2002</td>
</tr>
<tr>
<td>Write a detailed proposal/protocol</td>
<td>1. Prepared several versions of a detailed research proposal to carry out research into factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia.</td>
<td>June 2004 to March 2005</td>
</tr>
<tr>
<td>Obtain appropriate supervision/collaboration for research</td>
<td>1. Sought and obtained appropriate supervision and collaboration for research into factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia. University supervision was achieved by approaching a research tutor with similar research interests, who agreed to supervise me. NHS supervision/collaboration was achieved by approaching clinical psychologists who had made their research interests known through the University research bulletin, who agreed to collaborate with, field supervise, and provide resources for this research. Collaboration and sharing of data collection was established with another trainee who was conducting similar research.</td>
<td>Summer 2004</td>
</tr>
</tbody>
</table>
| Write a participant information sheet and consent form | 1. Wrote participant information sheet and consent form for research around trainee clinical and counselling psychologists' concepts of mental health.  
2. Wrote three versions of participant information sheets (young child, older child, parent) and consent and assent forms for research around factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia. | April 2004 November 2004 |
| Judge ethical issues in research and amend plans accordingly | 1. Judged ethical issues and amended plans accordingly for research around working with people with a personality disorder in CMHT's. Main ethical considerations were around client confidentiality and gathering potentially controversial opinions from my colleagues.  
2. Judged ethical issues and amended plans accordingly for research around trainee clinical and counselling psychologists' concepts of mental health. Main ethical considerations were around drawing participants from our own peer group.  
3. Judged ethical issues and amended plans accordingly for research around factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia. Main ethical issues included dealing with distress and intruding on family privacy. | December 2002 April 2004 November 2004 |
<p>| Obtain approval from a research ethics committee | 1. Ethical approval was obtained from the Great Ormond Street/Institute of Child Health REC for research around factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia. | November 2004 |
| Collect data from research participants | 1. Data collected by questionnaire and interview from participants for research around working with people with a personality disorder in CMHT's. | January and February 2003 |</p>
<table>
<thead>
<tr>
<th>Activity</th>
<th>January 2004 - May 2005</th>
<th>April 2004</th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Data collected through focus group for research around trainee clinical and counselling psychologists’ concepts of mental health.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Data collected from participants by questionnaire and interview for research around factors that may be predictive of high distress/low compliance in children at induction to general anaesthesia.</td>
<td></td>
<td>January to May 2005</td>
</tr>
<tr>
<td><strong>Set up a data file</strong></td>
<td>1. SPSS data file set up for data collected in respect of the major research project.</td>
<td>June 2005</td>
</tr>
<tr>
<td><strong>Analyse quantitative data</strong></td>
<td>1. SPSS analysis carried out with data collected in respect of the major research project.</td>
<td>June 2005</td>
</tr>
<tr>
<td><strong>Analyse qualitative data</strong></td>
<td>1. IPA analysis carried out with transcript of focus group in respect of qualitative research assignment.</td>
<td>April 2004</td>
</tr>
<tr>
<td><strong>Summarise results in figures/graphs</strong></td>
<td>1. Pre- and post- intervention data summarised in graphs and tables in case reports.</td>
<td>Throughout training</td>
</tr>
<tr>
<td></td>
<td>2. Psychometric data summarised in tables in clinical reports.</td>
<td>Throughout training</td>
</tr>
<tr>
<td></td>
<td>3. Results summarised in tables in respect of the service-related research project.</td>
<td>March 2003</td>
</tr>
<tr>
<td></td>
<td>4. Results summarised in tables in respect of the major research project.</td>
<td>July 2005</td>
</tr>
<tr>
<td><strong>Interpret results from data analysis</strong></td>
<td>1. Results of data analysis interpreted in respect of service-related research project.</td>
<td>March 2003</td>
</tr>
<tr>
<td></td>
<td>2. Results of data analysis interpreted in respect of qualitative research.</td>
<td>April 2004</td>
</tr>
<tr>
<td></td>
<td>3. Results of data analysis interpreted in respect of major research project.</td>
<td>July 2005</td>
</tr>
<tr>
<td><strong>Present research findings/plans to an audience</strong></td>
<td>1. Service-related research project presented to first year clinical trainees.</td>
<td>Autumn 2003</td>
</tr>
<tr>
<td></td>
<td>2. Plans for major research project presented to second year clinical trainees.</td>
<td>Summer 2004</td>
</tr>
<tr>
<td></td>
<td>3. Research in progress presented to psychology department at the Royal Marsden.</td>
<td>September 2004</td>
</tr>
<tr>
<td></td>
<td>4. Research findings presented to psychology department at Great Ormond Street Hospital.</td>
<td>August 2005</td>
</tr>
<tr>
<td><strong>Produce a written report on a research project</strong></td>
<td>1. Written report submitted of service-related research project as part of requirements of clinical course.</td>
<td>March 2003</td>
</tr>
<tr>
<td></td>
<td>2. Brief written report of service-related research project provided for the service which supported the research.</td>
<td>April 2003</td>
</tr>
<tr>
<td>1. Research examined by viva.</td>
<td>September 2005</td>
<td></td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------</td>
<td></td>
</tr>
<tr>
<td>2. Poster presentation of major research project at conference.</td>
<td>September 2005</td>
<td></td>
</tr>
<tr>
<td>3. Plan to prepare and submit paper from major research project to <em>Paediatric Anaesthesia</em>.</td>
<td>After training.</td>
<td></td>
</tr>
</tbody>
</table>

| 3. Written report submitted of qualitative research as part of requirements of clinical course. | April 2004 |
| 4. Written report submitted of major research project as part of requirements of clinical course. | July 2005 |
| 5. Poster prepared of major research project for presentation at conference. | July 2005 |

<table>
<thead>
<tr>
<th>Defend research project at an oral examination</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>2. Poster presentation of major research project at conference.</td>
<td>September 2005</td>
</tr>
<tr>
<td>3. Plan to prepare and submit paper from major research project to <em>Paediatric Anaesthesia</em>.</td>
<td>After training.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Apply research findings to clinical practice (give examples of three papers published during your training which influenced your practice)</th>
<th></th>
</tr>
</thead>
</table>