Experiencing a diagnosis of ADHD in adulthood. A qualitative study using Interpretative Phenomenological Analysis (IPA).
Acknowledgments

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Mary Bond, 2002,
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INTRODUCTION TO THE PORTFOLIO (Vol 1)

The portfolio contains work completed during the three years of the PsychD in Clinical Psychology. It contains the following work:

VOLUME I.

Volume I consists of an academic dossier, clinical dossier and research dossier.

The academic dossier contains five essays for core and specialist placements.

The clinical dossier contains summaries of all core and specialist placements, summaries of five clinical case reports.

The research dossier contains a service related research project (completed Yr 1), literature review (Yr 2) and the major research project (Yr 3).

VOLUME II.

Volume II consists of the clinical dossier of work completed during the PsychD in Clinical Psychology. It contains five case reports for core and specialist placements, summaries of all placements, and documentation from placements undertaken, (placement contracts, placement evaluation forms, logbooks of clinical experience).

Volume II contains confidential clinical material and will be kept in the department of Psychology at the University of Surrey.

The work presented in both Volume I and II is presented in order of placement undertaken. This is to reflect the development of clinical skills over the three years of clinical training.
ACADEMIC DOSSIER

OVERVIEW

The Academic Dossier contains four essays from each of the core placements undertaken in the first two years of training. The fifth essay was on a specialist subject related to a specialist placement undertaken in the third year of training.
Adult Mental Health Essay.

Compare and contrast the effectiveness of cognitive behaviour therapy and systemic therapy in the treatment of eating disorders.

Year 1
Compare and contrast the effectiveness of cognitive behaviour therapy and systemic therapy in the treatment of eating disorders.

1.1. Introduction to eating disorders.

The term ‘eating disorders’ is primarily applied to a group of disorders that are concerned with the “avoidance of fatness and the pursuit of thinness”. (Button, 1993) These can either lead to excessive overeating or a decrease in eating. For the purpose of this essay, I will be focusing on the two major eating disorders; anorexia nervosa and bulimia nervosa.¹

There are varying accounts of anorexia and bulimia and these are accompanied with particular treatment approaches (Fairburn, Shafran and Cooper, 1998). The theoretical orientation and training of the clinician as well as the broader context of the work setting reflects the methods of treatment used. (Wilson, 1995).

This essay sets out to compare two therapeutic approaches in the treatment of eating disorders; cognitive behaviour therapy and systemic therapy. The essay will consider the theoretical rationale behind each treatment approach before focusing on the effectiveness of treatment.²


The first systematic cognitive behavioural applications for anorexia and bulimia came from Fairburn (1981: cited in Vitousek, 1996) for bulimia and Garner and Bemis (1982: cited in Vitousek) for anorexia. Both accounts provide analyses of psychopathology for the two eating disorders and detailed treatment programmes. The basic premise of the models is that “idiosyncratic ideas and beliefs about body weight and shape act to maintain the symptoms of the eating disorder.” The attitudes

¹ These will be referred to as anorexia and bulimia respectively in this essay.
² In the literature on eating disorders, the term family therapy appears to be used as the systemic approach to eating disorders. This essay will continue to use the term family therapy to reflect the literature.
stem from the individuals characteristics and influence the individual to “engage in stereotypical eating and elimination behaviours” (Vitousek, 1996) (p384). An interaction between psychological and physiological aspects serves to maintain the eating disorder.

Since the models were developed, they have been highly influential in the treatment of eating disorders. However, empirical support for the effectiveness of CBT has not been equally demonstrated. Whereas extensive controlled trials have demonstrated the efficacy of CBT for bulimia, the efficacy of CBT for anorexia is not so well highlighted and recommendations for it’s effectiveness have been mainly on clinical grounds (Freeman, 1985). Freeman suggests that the treatment of severe anorexia require major adaptations to the cognitive behavioural model whereas for bulimia only minor changes usually need to be made. Treatment can involve a number of months and there are practical constraints in conducting a controlled study over such a prolonged period.

My essay will briefly consider the application of CBT for anorexia and bulimia before focusing on its evaluation as a treatment approach.

2.2. CBT for bulimia.

CBT has become highly influential in the treatment of bulimia over the last 10-15 years. It has now been defined as the “treatment of choice” for bulimia (Agras 1987; cited in Freeman, 1995).

The most widely evaluated cognitive behavioural treatment for bulimia is by Fairburn, (1981; cited in Wilson, Fairburn and Agras, 1997). This manual based individual treatment has nineteen sessions, is problem focused and time orientated to the present and future. A good relationship between therapist and patient is encouraged and responsibility for change is placed with the patient. There are three stages of treatment. (See table 2.1.)
Table 2.1. The 3 stages of CBT treatment for bulimia

<table>
<thead>
<tr>
<th>Stage</th>
<th>(sessions 1-8)</th>
<th>1. Education about the cognitive view of bulimia and the CBT approach in relation to the clients' individual problems.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td>2. Treatment goals.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>3. Education about weight regulation and the relevance of these in reducing the symptom of the eating disorder.</td>
</tr>
<tr>
<td>Stage</td>
<td>(sessions 9-16)</td>
<td>1. Increased focus on cognitions to identify, examine and modify problematic thoughts and ideas.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2. Cognitive and behavioural methods are used to enhance coping skills to resist binge eating and reduce dietary tendencies.</td>
</tr>
<tr>
<td>Stage</td>
<td>(sessions 17-19)</td>
<td>Relapse prevention strategies are studied which have both cognitive and behavioural elements.</td>
</tr>
</tbody>
</table>

Wilson et al (1997) suggests that these sessions should be adapted to suit individual need. At the end of treatment, individuals will still be ‘symptomatic’, however they are encouraged to draw on skills and review ‘maintenance plans’.

2.3. CBT for anorexia.

Freeman (1995) suggests that CBT for anorexia is “no more the status of a therapeutic style that an individual adopts rather than a complete treatment for anorexia”. (p330). Although there are common features in the use of CBT for anorexia and bulimia (e.g. cognitive restructuring) there are important differences, which distinguish the two (Garner, Vitousek and Pike, 1997). Two of these include motivation for treatment and weight gain as a target symptom. Garner et al (1997) suggest that weight gain should be a main focus of CBT treatment for anorexia, as resistance to it, effects the individuals motivation to begin treatment and to continue with it. This decreased motivation to change could lie in the ego-syntonic symptoms of anorexia (i.e. perceived happiness with current state). Early sessions should focus on engaging patients in treatment to reduce resistance, achieve weight restoration and encourage motivation for change.

Garner et al (1997) present a manual format for anorexia. The effectiveness of the manual has not yet been validated however, it aims to suggest a framework to “facilitate teaching, clinical training and controlled research”. (p95) Like the CBT manual for bulimia (previously described) there are three treatment phases with specific interventions for each phase (see Table 2.2.). Certain therapist and/or patient
variables may make it more difficult to keep to the proposed format, however it provides a coherent structure to follow. Length of treatment is much longer than the recommended nineteen sessions for bulimia and can extend from 1-2 years. This allows for any motivational problems, restoration of appropriate weight gain and potential inpatient care.

Table 2.2. The three phases of CBT treatment for anorexia (Garner, Vitousek & Pike, 1997)

<table>
<thead>
<tr>
<th>Stage 1 (8 sessions in first month)</th>
<th>1. To build trust between patient and therapist.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Assess the main features of the eating disorder.</td>
</tr>
<tr>
<td></td>
<td>3. Provide education about anorexia as a disorder, the cycle of binge eating and purging, medical risks, and psychobiology of starving.</td>
</tr>
<tr>
<td></td>
<td>4. Introduction to the cognitive model and the rational behind the CBT treatment for anorexia.</td>
</tr>
<tr>
<td></td>
<td>5. Self-monitoring and meal planning to help establish regular eating patterns.</td>
</tr>
<tr>
<td></td>
<td>6. Prescribing eating patterns to encourage more normal eating.</td>
</tr>
<tr>
<td></td>
<td>7. Determine the suitability or future family involvement as a potential addition to individual therapy.</td>
</tr>
</tbody>
</table>

This is quite an intensive phase. Garner et al feel that this is necessary in order to increase the chances of the patient remaining in treatment.

<table>
<thead>
<tr>
<th>Phase 2</th>
<th>1. Introduction of more formal cognitive methods e.g. cognitive restructuring to identify problematic thoughts</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2. Focus on the functions and meanings of the anorexia symptoms for the individual.</td>
</tr>
<tr>
<td></td>
<td>3. Identifying alternative ways to achieve goals.</td>
</tr>
<tr>
<td></td>
<td>4. Continued focus on weight gain and establishing normal eating.</td>
</tr>
<tr>
<td></td>
<td>5. Involvement of the family if appropriate.</td>
</tr>
</tbody>
</table>

| Phase 3 | Relapse prevention, review of progress and preparing for end of treatment. |

Fairburn et al (1999) address that a CBT approach for anorexia should address the way in which shape, weight and eating are used as mechanisms of self-control in the individual. They suggest that their approach warrants further research since it could offer a more 'streamlined approach to treatment. However, at present, there is no available data to support its effectiveness.
2.4. Effectiveness of CBT for bulimia.

The effectiveness of CBT for bulimia has been highlighted in a number of controlled clinical studies. The CBT treatment used is typically derived from Fairburns (1981) treatment manual.

2.4.1 Outcome measures for CBT.

Outcome measures for CBT have been summarised in various reviews. These have usually taken the average reductions in binge eating and purging (e.g. Craighead and Agras, 1991; cited in Wilson 1995). The summaries suggest an approximately 80% reduction in binge eating and purging and a 50% remission rate. The effects of CBT on other bulimic features are also documented e.g., improvement in abnormal body shape and weight attributes; (Fairburn, Jones, Peveler, Carr, Solomon, O'Connor and Burton, 1991) as are the wider effects on the related psychopathology of bulimia e.g. on social-functioning and self esteem (Fairburn, Kirk, O'Connor and Cooper, 1986).

CBT has shown quite reasonable effects of durability at the 1-year follow year stage (Fairburn, Jones, Peveler, Hope and O'Connor, 1993). An extended follow up of CBT treatment confirmed that its effects were maintained an average of 5.8 years post treatment (Fairburn, Norman, Welch, O'Connor, Doll & Peveler, 1995).

2.4.2 CBT and other psychological treatments

CBT has been compared with various other psychological treatments and has demonstrated either superior or equivalent effects. Garner et al (1993) in a comparison of CBT and supportive expressive psychotherapy found good improvements in the reduction of binge eating. However, CBT showed significant effects in altering abnormal attitudes towards shape and weight and reducing dietary restraint and purging (Garner, Rockert, Davis, Olmsted & Eagle, 1993). Other outcome studies have shown less difference between CBT and other psychological treatments. Fairburn et al (1986) compared CBT with brief focal psychotherapy and found significant reductions in binge eating and purging for both. CBT was shown to
be more effective on measures of social adjustment and clinical state post treatment and at one year follow up.

A second outcome study by Fairburn et al (1991) compared CBT, behaviour therapy (BT) (consisting of behavioural techniques dismantled from the CBT package) and interpersonal therapy (IPT). IPT was matched with CBT for non-specific factors to attempt to establish if CBT has a ‘specific therapeutic effect’. Post-treatment measures found equal effects for CBT, BT and IPT in the reduction of binge episodes. However, CBT was more effective than IPT in the modification of shape and weight attitudes and the reduction of purging. It was also more effective than BT on the former variable.

A one-year follow up was conducted of this trial (Fairburn et al, 1993) and it revealed interesting results. Out of the original sample of seventy-five patients, twelve (48%) from the BT group had dropped out or were withdrawn due to lack of improvement. This provides further support for the use of standard CBT treatment compared to the dismantled subset used in the BT treatment, (however, it should be noted that a formal analysis of the ‘relative efficacy’ of BT was not possible due to the high attrition rate) (Vitousek, 1996). CBT maintained it’s improvement, although IPT showed consistent improvement and eventually achieved equally successful results on all outcome measures (dietary restrain, bingeing and purging, attitudes to shape and weight, and general psychiatric features). Fairburn et al concluded that despite “temporal differences in the pattern of response”; the two treatments obtained equivalent effects “through the operation of different mediating mechanisms” (p427). They hypothesised that CBT works by refocusing eating patterns and shape and weight attitudes. Wheras, IPT seems to lead to interpersonal changes, which in turn stimulate other important changes.

2.4.3 How does CBT work?

Wilson and Fairburn (1993) suggest that it is important to identify the essential elements of CBT for effective treatment. Some studies have addressed this issue by ‘dismantling’ CBT into its cognitive and behavioural components. Freeman et al
(1988: cited in Wilson, 1995) found equivalent effects for CBT and BT and concluded that it is not necessary to add “cognitive elements to behaviour therapy”. However, there were some problems with the study, which raise doubts about this conclusion (Wilson and Fairburn, 1993). At the time of the study there were no satisfactory measures of attitudes towards body shape and weight and a measure was used which had poor discriminant validity. A central core of CBT is the study of attitudes towards shape and weight, so, it is vital to use appropriate measures to delineate CBT and other treatment. Additionally, follow up measures to determine patterns of responses and temporal changes were not reported (CBT has already shown to be more effective at follow up).

A second ‘dismantling’ study was conducted by Rossiter, Kleifield and Lindholm (1986) who compared a verbal cognitive restructuring method with a full CBT treatment. They found that the CBT treatment was more effective at one year follow up than the restructuring method: patients were completely abstinent from bingeing and purging, had improved eating patterns and modified attitudes towards food. However, the sample used in this study was small and so the generalisability of these results should be treated with caution. Finally, Cooper and Steere (1995) in a comparison of CBT and exposure/response prevention treatment found equal effectiveness for the two treatments at post-treatment stage, however, at the one year follow up, the effects of CBT were maintained and those in the behavioural treatment had relapsed. They concluded that although BT did produce clinical changes, the changes in cognition might be necessary for maintained recovery.

Wilson and Fairburn (1993) concluded that CBT is probably a sufficient but “not necessary condition for the effective treatment of bulimia”. (p265)

2.4.4. Limitations of CBT

Wilson (1996) argues that despite the identification of CBT as an effective treatment for bulimia, it does have its limitations. It is not useful for all patients and for some, there is only partial improvement. There are several options, which can be considered for these “non-responders”. One idea is to expand the current protocol depicted in the
CBT manual (Fairburn 1981) in order to address the individuals needs and enhance the efficacy of the approach. A suggestion by Wilson (1996) was to increase the role of interpersonal issues (e.g. relationship conflicts) or to increase the use of cognitive restructuring. However, this might make the manual more complicated for therapists to use or require more sessions and would in turn contravene the current status of the NHS with its emphasis on cost effectiveness.

Studies are beginning to consider alternative ways of implementing the popular CBT manual with mixed results. Fahy and Russell (1993: cited in Vitousek, 1996) found that 8-10 sessions of individual CBT was less successful than the full package in inducing remission. However, another study obtained more improvement with eight individual sessions. (Thackwray, Smith, Bodfish & Meyers, 1993). Other options considered have been self-help versions of the manual (e.g. Cooper, Coker & Fleming, 1994; cited in Wilson, 1996) who demonstrated a reduction in symptoms comparable to clinician led treatment and a psychoeducational group package which used the CBT manual (Davis, Olmsted & Rockert, 1990; cited in Wilson, 1995). This reported good results for individuals with bulimia.

The approaches need to be evaluated in more detail in a controlled setting to demonstrate their efficacy, however, they suggest that some patients with bulimia might not require more than a group approach or guided self-help (Wilson, 1995). A 'stepped-care' approach, which utilises these more cost-effective methods before individual CBT, might therefore be an option. (Wilson, 1996).

A final point in this discussion of the effectiveness of CBT for bulimia is that many of the reported studies have been conducted in specialist centres by practitioners who utilise a standardised manual based form of CBT. This makes it harder to translate the results into 'normal' clinical practice. Freeman (1995) suggests that in addition to these 'scientific studies', we need "more pragmatic ones which audit the outcome of bulimia treated in ordinary clinics". (p325)
2.5. Effectiveness of CBT for anorexia.

There is considerably less evidence for the efficacy of CBT for anorexia, despite its widespread use (Vitousek, 1996). Vitousek suggests several reasons for this. The first is that individuals with anorexia are less likely to seek treatment and so assembling samples is more difficult. The second is that the longer period of therapy suggested may raise the chance of participant attrition. This in turn may reduce sample size and cause difficulties with randomisation.

The only controlled study that has been published showed insufficient evidence for the efficacy of CBT in the treatment of anorexia (Channon, de Silva, Hemsley, & Perkins, 1989; cited in Vitousek, 1996). They compared CBT and BT with an unspecified treatment and found significant improvements at follow up periods. However, there were no real differences between conditions. The one finding in support of CBT was increased rates of compliance (an interesting finding because resistance to treatment has been documented for people with anorexia). Vitousek reported a number of problems with the trial:

1. Small sample size meant that there were differences in cell composition. The power of the study could have been increased by having only two treatment modalities instead of three.
2. The treatment length was considerably shorter than the recommended period by Garner and Bemis (1997).
3. It was not obvious how the cognitive components used in the study mirrored Garner and Bemis’ recommendations for CBT for anorexia (despite their claims that it did).

Further controlled studies are needed, to demonstrate the efficacy of CBT for anorexia, which address some of these methodological shortcomings.
3.1. Systemic / Family Therapy.

According to Dare and Eisler (1993) there has long been an awareness of the importance of family interaction in the area of eating disorders, particularly in relation to anorexia. Within family therapy, there is a focus on ‘family factors’ (life cycle processes, system organisation and ways of interaction between the family).

Dare and Eisler (1997) argue that most disorders can be related to a particular paradigm for treatment. Anorexia can be seen as a paradigm for family therapy. Family systems approaches view the family as a ‘complex social system’ where the eating disorder is placed within the context of interacting features of the family (Eisler 1995). Family therapy focuses on an interdependent circular approach to causality instead of linear. Cause and effect are arbitrary and difficult to identify due to continual interaction within the family system. There are considerable variations in family systems accounts, (these vary with their focus on mechanisms of change) and there is a degree of overlap between the models (Eisler, 1995).

Historically, the work of Minuchin et al, (1975) from the Philadelphia group (Minuchin, Baker, Rosman, Liebman, Milman & Todd) and Selvini-Palazzoli (1974) from the Milan group was influential in the development of family therapy in the treatment of eating disorders. Their work, although based on distinct conceptual fields shared some commonalties. Both suggested that there are distinct characteristics in the families where anorexia occurs. These family relationships are particularly close, there is intergenerational ‘blurring’ and an avoidance and fear of conflict or disagreement which the child with anorexia is involved with. Both the Philadelphia and Milan groups developed therapeutic models, which were used in the treatment of anorexia. These focus on changing the characteristic family relationships which are in turn thought to “offer the possibility of helping the patient” (Dare and Eisler, 1995) (p308).

Garfinkel and Garner (1982) argue that the characteristics prescribed by Minuchin et al and Selvini-Palazzoli are not seen in all families with a member who has anorexia. Similarly, the patterns described are not disorder specific, but are believed to occur in
a range of psychosomatic illnesses. They conclude that the characteristics of the family may be “perpetuating rather than predisposing factors to the illness” (p184).

My essay will briefly consider these two models and a more recent model known as the Maudsley model (Dare and Eisler, 1997) before focusing on the evaluation of family therapy as a treatment approach for anorexia.

3.2. Structural family therapy

Minuchin’s approach for the treatment of anorexia developed in the context of possibly the most influential family therapy approach, particularly concerned with family structure. Their model concerns the “psychosomatic family” with anorexia considered to be a representation within it (Dare and Eisler, 1995).

“First, the child is physiologically vulnerable: second, the child’s family has four transactional characteristics: enmeshment, overprotectiveness, rigidity and a lack of conflict resolution. Third, the sick child plays an important role in the family’s patterns of conflict avoidance and this role is an important reinforcement for his symptoms” (Minuchin, et al 1975) (p1033).

The model has certain implications for therapeutic treatment of anorexia. Minuchin et al places the symptom within the family structure and as resting on the patient. They do also note the contribution of other stressors e.g. physiological in the development of anorexia. The focus of therapy is to identify the ‘dysfunction’ in the family (often using the context of the family meal) and to then alter it’s method of organisation by emphasising some forms of interaction and reducing others. The idea behind this is that by ‘improving’ the function of the family, the mechanisms to support the symptom will lesson (Dare and Eisler, 1997).

Evidence for the structural approach in the treatment of anorexia is rather limited, however it does support its effectiveness. Minuchin, Rosman and Baker (1978; cited in Dare and Eisler, 1997) found a good outcome for 80% of their sample of fifty-two adolescents. Similarly, Martin (1985; cited in Dare and Eisler, 1997) reported a
positive outcome for a high proportion of adolescents with anorexia in their follow up study.

3.3 Selvini-Palazzoli and the Milan approach

Selvini-Palazzoli (1974) like Munichen et al (1975) emphasised certain characteristics in families with a child with anorexia. These include:

1. Little conflict resolution.
2. Rigid patterns of interaction between members.

The symptoms of anorexia act as a ‘homeostatic mechanism’ in the family (Dare and Eisler, 1997).

The Milan group initially worked with families who had a child with anorexia (or schizophrenia). The aim of therapeutic intervention was to reframe the principles that ‘govern’ the systems organisation (using a ‘counterparadox’) and so remove the symptom (Partridge, 1992). The therapists’ role was to provide a ‘meta-perspective’ on the organisation in the family and the role of the symptom. The pattern observed is then given a more positive ‘connotated meaning’ (Dare and Eisler, 1995).

The Milan approach has been influential in work with eating disorders. As of yet, there are no control studies which compare it with other therapeutic approaches. However, Stierlin and Weber, (1989; cited in Dare and Eisler, 1997) published a study which utilised this approach. Their study of forty-two families with a member who had anorexia or bulimia showed impressive results. Treatment follow-ups revealed that 2/3 rds had reached normal body weight and there were improvements in the patients’ sociability. However, follow up times ranged from 2-9 years and some of the improvement in body weight may be explained by other interacting variables.
3.4 The Maudsley Model (see below).

Dare and Eisler (1997) describe a more recent family therapy approach of anorexia which is based on an ‘interactional systems model’. The anorexia (‘illness’) is placed outside of the individual to reflect the impact of external sources and the impact of the symptoms on functioning. The influences are not one way but unidirectional. An important component of the model is the organising principle of the life cycle (this interacts with genetic and social factors). Interventions are focused on various sites where the disorder/symptoms are “created and maintained” (p317). They aim to create change in either individual or family functioning and subsequently address the distribution of ‘force’ in the system.

3.5 The evaluation of family therapy as a treatment approach for anorexia.

There have been few controlled studies using family therapy as a treatment approach. This may be due to problems establishing treatment goals, change measurements and the specific therapeutic components. Frude (1980; cited in Dare et al, 1990) argues that controlled outcome trials impose an element of artificiality on the interventions which can influence therapy and interpretation of results. The evaluative methods used in controlled outcome trials are also too reductionist for research in family therapy.

Eisler (1995) suggests that some family therapists would argue that observational studies are the only ways to provide meaningful evidence. There are various methodological problems in other use of observational studies, e.g. reliability and small samples.

As previously discussed, the Philadelphia group and the Milan group have reported good outcomes in their work, however these have not been verified in either controlled trials or systematic follow ups.
3.5.1. **The Maudsley Trials.**

Russell, Dare, Eisler & Grange (1996) reported an extensive set of controlled treatment trials of family therapy at the Maudsley Hospital (See table 3.1.)

**Table 3.1 The Maudsley trials (cited in Dare and Eisler, 1995)**

<table>
<thead>
<tr>
<th>Study</th>
<th></th>
</tr>
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</table>
| **Study 1** | An evaluation of family therapy and individual supportive therapy. 80 patients in four subgroups were randomly allocated to the two treatment modalities. Treatments were compared at the end of one year of treatment. A five-year follow up is reported.  
**Subgroup 1.** Length of illness below 3 years and age at onset less than 18 years.  
**Subgroup 2.** Length of illness more than 3 years and age at onset less than 18 years.  
**Subgroup 3.** Age at onset 19 years or older.  
**Subgroup 4.** Patients with bulimia. |
| **Study 2** | A comparison of family therapy, individual supportive therapy and individual focal psychotherapy. 100 patients from the inpatient unit were randomly allocated to the treatments. |
| **Study 3** | A comparison of family therapy and family counselling. A pilot study (18 patients) and definitive study (40 patients). |
| **Study 4** | A comparison of family therapy, individual focal psychotherapy and standard outpatient treatment for adult patients. |

The results of Study 1 and 3 will be discussed below.

**Study 1. (Russell et al 1987; Dare et al, 1990; Eisler et al, 1997)**

The style of family therapy used, focused on gaining the families active co-operation. The aetiology of the illness was presented neutrally to reduce the opportunity for guilt to develop in family members and to prevent the therapy being undermined in it's effectiveness (Dare et al, 1990). There were three stages outlined in the therapy (see table 3.2.)

**Table 3.2. The three stages of family therapy in Study 1**

<table>
<thead>
<tr>
<th>Stage</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Stage 1</strong></td>
<td>Begins with a family meal and therapy is focused on the eating disorder.</td>
</tr>
<tr>
<td><strong>Stage 2</strong></td>
<td>This phase begins when a steady weight gain in the patient results from the parents' management of the disorder. This is achieved by an emphasis on weight gain without tension within the family.</td>
</tr>
<tr>
<td><strong>Stage 3</strong></td>
<td>The responsibility for further weight gain is resumed within the individual. The focus is now on the therapist and family to discuss other concerns within the family.</td>
</tr>
</tbody>
</table>
The approach has some resemblance to the structural approach (Minuchin et al, 1975; 1978), e.g., in its early focus on more concrete concerns and to the systemic interventions of the Milan school (Selvini-Palazzoli, 1974), e.g., in it’s examination of intergenerational organisations. The individual supportive therapy was used as a controlled comparison. It was not a formalised treatment but was supportive, educational and problem focused.

The results showed that age of illness and illness duration were key variables. Patients whose age of onset was before nineteen years and duration of illness was less than three years responded better at one year with family therapy than the control group and patients with late onset of the disorder in the individual treatment modality had some signs of weight gain. However, there were no other significant differences between treatments in the other sub-groups.

Most of these improvements were supported in a five-year follow up study (Eisler, Dare, Russell, Szmuckler, Grange and Dodge, 1997) using the same outcome measures. Family therapy was favoured for patients in the ‘short history, early onset’ group and individual therapy was favourable for patients with ‘late onset anorexia’. There were several methodological problems reported with the follow up study (Eisler et al, 1997). Some of the information about clinical progress was not complete in the follow up study and was collected by researchers who were not involved in the original treatment programme. Also in the five years after initial treatment at the Maudsley, patients had received other treatments (not reported in the follow up study).

**Study 3.**

This third study compared standard family therapy (involving a systems component and problem solving) with family counselling (involving problem solving). The standard family therapy involved the whole family being seen together whilst in family counselling, parents were seen independently of the patient who was seen individually for counselling and support (Dare and Eisler, 1995).
A pilot study was conducted to evaluate the appropriateness of comparing the two treatments (Le Grange, Eisler, Dare & Russell, 1992). The results at six month follow up revealed similar levels of weight gain for patients in both treatments and similar scores on most of the other outcome measures e.g. self-esteem. However, there were some differences between the two treatments for family measures using Expressed Emotion (EE) ratings (Vaught and Leff, 1976; cited in Le Grange et al, 1992). It was found that more critical comments were made by family members in standard (conjoint) family therapy than those in family counselling.

Le Grange et al argue that it is difficult to establish if change was caused by real differences between treatments or whether “critical parents’ had a negative effect on engagement and outcome in family therapy (p356).

Dare and Eisler (1995) reported preliminary findings for the definitive study which appear to confirm that family counselling was more beneficial than standard family therapy for families who expressed more criticism for their child with anorexia. The results for both studies did not confirm their expectation that conjoint family therapy with its focus on direct observation of interaction patterns in the family and family systems interventions would be more effective. They concluded that long term effects need to be studied and these may produce different outcomes.

3.6. Family therapy for bulimia.

There have been relatively few studies, which have specifically evaluated the effectiveness of family therapy for bulimia. Two of the Maudsley studies had patients with bulimia, but most of these had low weight problems, which warranted admission to hospital. It is more difficult to compare these results with other treatment studies such as CBT where the focus is typically on bulimic individuals with normal weight (Dare and Eisler, 1995).

Dodge, Hodes, Eisler and Dare (1994) suggest that family therapy could be effective in treatment for bulimia. They conducted a small study using this approach with eight adolescent patients with bulimia. The type of family therapy used was similar to that
outlined in the first Maudsley study. The results showed good improvements in two of the major symptoms of bulimia; self induced vomiting and laxative abuse and various changes in the families interactional patterns e.g. 'less discord'.

An interesting finding was the association between improved eating attitudes and family therapy. It has been suggested that for significant changes in symptoms, there needs to be changes in distorted attitudes about eating (Fairburn et al, 1991) and that CBT is the most effective treatment to do this. However, IPT and now family therapy are beginning to suggest their effectiveness in this area.

Overall, the results suggest that family therapy could be beneficial for the treatment of bulimia, however there are several reasons why the above results need to be treated with caution. There was a small sample number in the study, a control was not used and there was no significant follow up period.

3.7. Implications of the results.

Dare et al (1990) suggest that we should not assume that "family change is always necessary to achieve individual change" (p54). They now advocate a mixture of individually focused therapy and family therapy (conducted either simultaneously or in sequence) but they do not elaborate on whether their individual work is systemically orientated. Jenkins and Asen (1992) argue that systemic interventions do not dictate that the whole family should attend. Individual systemic work differs from other psychotherapies with an individual focus as it supports the "openness of the therapeutic system" (p3). It is useful if there is resistance to a whole family approach or if the individual has no 'immediate' social system. However, it should not ideally be used with a child as it may lead to a 'covert alliance' between therapist and child. Individual systemic work may be a useful extension for treatment and research in eating disorders and its effectiveness could be compared with conjoint family work.

4.1. Conclusion.

The aim of my essay has been to compare and contrast the effectiveness of CBT and systemic therapy in the treatment of eating disorders. Both therapeutic approaches
have been widely applied in treatment with anorexia and bulimia but research tends to reflect its identification with one of the two eating disorders. For CBT, its effectiveness has been widely acknowledged in the treatment of bulimia. Despite, its widespread use in the treatment of anorexia, there is considerably less evidence for its efficacy and several reason have been suggested for this (Vitousek, 1996). Family therapy has been widely used in the treatment of anorexia, however there has been limited research into the effectiveness of the approach for its treatment and the focus has been predominantly on particular subgroups of patients.

Jenkins and Asen (1992) suggest that IPT bears a similarity to “systemic therapy with an individual” (p11) and the effectiveness of this approach has been well documented in its comparison with CBT. However, at present, there are no studies, which directly compare CBT and systemic therapy in the treatment of eating disorders. Both approaches have been primarily identified with separate eating disorders and so for practical reasons this means comparative studies are difficult to implement. Similarly, both approaches vary in terms of intensity and duration of sessions, severity of the patient’s symptoms and whether treatment is conducted in a family or individual format. Finally, in order to objectively compare treatment approaches, the evaluation of CBT as a ‘pure’ treatment, (using the manual format) has been more accessible, however, systemic therapy does not form an entirely unified approach and any comparisons would be more difficult and need to specify a particular theoretical orientation.

Garner et al (1997) suggest that there is a role for the integration of cognitive and family approaches, which implies that there are similarities in the two approaches. These may form the basis of future comparative studies. Both agree that ‘meaning’ is a primary concern and also that “symptoms are adaptive on one level of meaning and dysfunctional on another” (p134).

Garner and Needleman (1997) support the move towards an eclectic approach in the treatment of eating disorders by forming treatments into an integral and sequential model. The model grades treatment from the least disruptive, most cost-effective approach to the most expensive, intrusive approach. The aim of this is to ensure that
individuals are matched with treatment (and vice versa) and both CBT and systemic therapy have demonstrated the effectiveness of their roles.
References:


Learning Disability Essay.

What is the impact of others expectations on the communicative abilities of people with learning disabilities and how might a Clinical Psychologist work with these issues?

Year 1
What is the impact of others expectations on the communicative abilities of people with learning disabilities and how might a Clinical Psychologist work with these issues?

1.0 Introduction to communication

Communication is of key importance to an individuals quality of life (Van der Gaag, 1998). Coupe and Joliffe (1988) define it as an “intentional transmission of meaning in a formal code between people who share that code” (p104). Additionally, communication has been defined as the transmission of a message that the communicator has and its subsequent interpretation by the ‘addressee’. The expectation surrounding the ‘listener’ or ‘speaker’s’ role in the communication setting influences the function of that communication and the way in which the communication occurs (Van der Gaag, 1998). Both of these definitions imply that communication is a two way collaborative process, involving a communication partnership and interaction in a social context. The roles of both participants are equally valuable in the exchange and imply that discourse is co-constructed with the contribution of both people (Perkins, 1995: cited in Bartlett, 1997).

1.1 Communication in people with learning disabilities.

Bradshaw (1998) argues that individuals with learning disabilities consistently experience problems in communication, although it is difficult to ascertain the true extent of the problem. These include initiation and response difficulties to messages of a verbal and non-verbal nature, reception, speech production and pragmatics of language. Hallas (1982) suggests that communication disorder is the most common ‘problem’ in individuals with a learning disability. Surveys have indicated a high prevalence of identifiable problems in communication. Blackwell (1989) found that 62% of a proportion of residents in various settings (e.g. hospitals and day centres) had communication problems with 33% of the sample having difficulty with verbal communication. A different survey conducted in an education centre found that 81% of individuals with a learning disability needed support with communication skills,
with 9.5% of this sample unable to communicate verbally (Law and Lester, 1991). Bartlett (1997) suggests several reasons for variation in the results of surveys. These include population differences and methods of data collection.

Price, Williams and Sabsey (1979: cited in Van der Gaag, 1989) separated 'communicative competence' into two groups: namely, linguistic and pragmatic competence. Linguistic competence refers to syntactic and phonological qualities, whereas, pragmatic competence is defined as the use of language as a means of social influence (Remington, 1997). This takes into consideration the individuals characteristics and aspects of the environment, which can effect the persons communicative abilities. Guyette (1978: cited in Van der Gaag) devised the phrase 'communication environment' to explain this. It includes aspects of the physical environment, the individuals chances to utilise communication and the demands placed on them in order to communicate (Bradshaw, 1998). Finally, it includes the relationship between communication partners.

Leudar (1988) provides evidence to support the influence of the communication environment on the way an individual with a learning disability will utilise communication skills. Leudar argues that the communication environment is often 'distorted' and does not create the same amount of opportunities as a 'non learning disabled' environment. A study by McGarry and West (1975) in a residential home, found that staff had less interactions with residents who had communication difficulties compared with residents who did not. This may lead to a 'distorted' communication environment for the residents with communication difficulties.

The above studies support the relationship between the communication environment and the communicative competence of individuals with a learning disability. They also indicate the possible impact of others attitudes and expectations on the communicative abilities of people with learning disabilities. Van der Gaag (1998) argues that this does not imply that the individuals needs should be neglected but that the role of the social environment should be acknowledged in the individuals communication experience. This implies that there is an onus on others to adapt their own communication behaviour and accept increased responsibility for change.
This essay sets out to examine the extent of others' expectations on the communicative abilities of people with learning disabilities and to then examine the possible impact of this. The essay will further consider how a Clinical Psychologist might work with these issues. The context of the essay will initially be set in the development of language and communication in individuals with a learning disability.

1.2 Language and communication acquisition.

Price (1989) notes an important paradigm shift in the focus of communication and language as an ‘abstract structural system’ to a belief that it is essentially a ‘social phenomenon’ in which joint activity and physical and social contexts are integral. (p186) This reflects an increased focus over the last thirty years on pragmatics and the idea that verbal language is only one part of communication (Warren and Yoder, 1997).

Chomsky (1957: cited in Price, 1989) saw language as genetically predetermined and obtained through the ‘language acquisition device’ by a natural process. He limited the impact of pre-linguistic experiences and social interaction in the acquisition of language. Piagetian theory (cited in Warren and Yoder, 1997) considers language skills to have a cognitive prerequisite. The role of social communicative abilities is not readily apparent. Vygotsky in contrast (1962; cited in Messar, 1996) uses culture and social interaction as a basis for understanding development. His work suggests that social communication stems from adult interaction. The ‘social responses’ of the adult to infant actions and words” leads to the beginning of an intent to communicate with others, to influence adults and to gain new communication methods (Messar, 1996) (p28).

As previously discussed, theories of language and communication have evolved. A focus on the social and pragmatic basis of communication has led to a transactional model formulation, which interacts “cognitive, linguistic and social factors”. It further states that if children do not have a reason to communicate and a meaningful, interactive communication audience, they will find difficulty learning to communicate (p188).
1.3 **The development of communication in people with learning disabilities, caregiver interaction and parental expectations.**

A number of researchers have looked at the process of interaction between primary caregivers and children with a learning disability to establish if it is different from that of 'normally developing' children. The possible impact of parental/child interaction and expectations of the person with a learning disability will be considered in relation to this.

Research into interaction between caregivers and children with a learning disability has been generally inconclusive. An initial concern was for maternal speech with children with a learning disability. Cunningham et al (1981) found that mothers with a learning disabled child initiated less interactions and despite being more directive, they responded less positively to the child's resulting compliance. Bricker (1981: cited in Price, 1989) found that mothers consistently spoke at a faster rate and spoke too often which meant that the child was not given the same opportunity to respond or that the conversation overlapped. This overstimulation could lead to feelings of confusion and over intrusiveness in the child. Similarly, Clark and Seifer (1983) have shown that primary caregivers of children with a learning disability have "overriding behaviours" and a more directive, controlling interactive style. (p33)

However, Beveridge (1989) argues that greater levels of directiveness and stimulation are an acceptable response to the difficulties the child is encountering. The problem, however, is that the carers directive style remains, despite the child's increases in communicative competence (Beveridge, 1989). This may eventually lead to poor initiation skills and withdrawal, which may in turn impact on others expectations of the individual and so a cycle may begin.

Evidence suggests that the picture is considerably more complex than it might appear. It seems possible that there is a bi-directional effect between primary caregiver and child, so that primary caregiver behaviour may impact on the child and similarly child characteristics may impact on primary caregiver behaviour (Price, 1989). Nind and Hewitt (1994) would agree with this and suggest that there is an 'ambiguity' about
which occurs first “with both infant and caregiver behaving atypically each affecting the other” (p32). Bakeman and Brown (1980: cited in Nind and Hewitt) suggest that the caregivers response to some of the characteristics of poor communication (for e.g. less responsiveness) may mean that they carry more of the ‘interactive burden’. This suggests that as the caregiver works harder with the increased expectation that the child is not responding (i.e. reduced expectations) the child may become increasingly frustrated and withdrawn, leading to a negative spiral and potential communication breakdown.

A further interesting point is that caregivers will all bring their own expectations about caring for a child with a learning disability into the communication environment, which is likely to influence interaction between themselves and their child. Societal expectations about learning disabilities, combined with levels of support/education received and personal experiences and encounters with individuals with a learning disability are all likely to impact.

Price (1989) has considered the important methodological problems from dyadic communication research. Price argues that it is difficult to compare results between studies when a range of populations with different age groups and stages of development are used. In addition, data has been collected using different methods in a range of settings (e.g. a laboratory setting versus a familiar setting at home). Finally, Conti-Ramsden (1989) argues that the assumption that the communication abilities of people with a learning disability are a homogenous set and develop similarly is a wrong one. Methodologically therefore, it is impossible to generalise the findings of ‘parent-child dyads’ to all children with a learning disability. Instead, the form should be on both parent and child having specific characteristics and looking at how these interact. Important caregiver characteristics to consider are expectations concerning the degree of learning disability, motivation and acceptance of the disability. All of these are likely to impact on the caregiver's expectations of the communicative abilities of their child and their subsequent interactional style.
1.4 Staff expectations and its impact on the communicative abilities of people with learning disabilities.

With the recognition that communication is an ongoing, social interactive process, researchers have begun to look at the impact of others expectations on the communicative abilities of people with learning disabilities beyond the early years.

In particular, researchers have looked at staff expectations of client's in a range of settings and its impact on communicative abilities and exchanges. Barlett (1997) argues that increased focus on communication between support staff and adults with learning disabilities has occurred due to several reasons. The first is that for the learning disabled individual, the transference from one situation to another of acquired communication skills cannot be assumed and staff can provide assistance in supporting this transference. Secondly, recent work on communication development emphasises the role of 'carer responsiveness'. This suggests that in order for communication abilities to develop and be maintained, staff need to support the individual (Ware, 1996: cited in Bartlett). Finally, the focus on a 'medical' based approach in old residential institutions has shifted with the move towards community based services. Van der Gaag and Dormandy (1993) argues that this has caused an increase in staff working with people with a learning disability who have limited 'specialist training' in communication for this client group. They also suggest that little training in communication skills could lead staff to have false expectations and make 'inappropriate judgements' about an individuals communicative repertoire. These may involve underestimating or overestimating the individuals' competencies.

Bartlett (1997) linked these potential misinterpretations of competence into the philosophy of 'normalisation' (Wolfensburger, 1972: cited in Bartlett) which was later redefined as Social Role Valorisation (Wolfensburger, 1983). Bartlett argued that staff are trained in an environment of service delivery that values the roles of people with learning difficulties in daily life. A misinterpretation from this could be the 'normalising of communicative acts to people with a learning disability”, despite the possibility it might overestimate their skills (p148). More specifically, a belief in a 'normal adult life' for the individual could result in overly high expectations of the
person's communication skills and the provision of opportunities, which are unrealistic for him/her. This could lead to failure and subsequent "diminished experiences" which may in turn cause "more restricted communication skills use" (p149). The likely outcome is isolation of the individual, low self-esteem and exclusion from communicative exchange or partnerships.

Conversely, the risk of having low expectations and underestimating the individuals communicative abilities has been illustrated by O'Brien's Vicious Circle (1981; cited in Bartlett, 1987). This suggests that an individual may have prejudiced beliefs about the learning disabled individuals competence, which will result in low expectations about that individual, exclusion of opportunities and 'diminished experiences'. This may lead to an enhancement of difficulties in the communicative competence of the individual.

Other researchers have considered interactional styles between support staff and clients with a learning disability. They imply that staff may have certain expectations, which may impact on the individuals communicative abilities. Landesman (1988) found that care staff in various residential settings spent only 10-15% of their total work hours interacting with clients. The social interactions that did occur tended to be infrequent, brief and directive. Shane and Shane (1985: cited in Calculator, 1988) argued that the discourse, staff members share with learning disabled individuals contained certain characteristics. These seem to cluster around low expectations of the clients' communicative abilities. Staff tended to 'fake' comprehension of the individuals communication, to constantly interrupt the person, to obtain answers to their own questions and to consistently anticipate the clients communication needs, therefore pre-empting the individuals opportunities to communicate. Leudar (1988) on a similar note, found that individuals consistently tried to validate communication by learning disabled individuals, which was 'obviously true or indisputable' (p296). These may all serve to reduce the opportunities for the individual to initiate and engage in communication and to feel valued as a communicator. The result may be withdrawal, low self-esteem and continued frustration.
Purcell, Morris and McConkey (1998) suggest that if staff expectations of an individual's communicative competence is 'inaccurate' they may not adjust their own communication to "maximise their partners ability to contribute to the dialogue" (p17). Their study of support staff with varying years of experience identified some difficulty in assessing an individual's communicative competence accurately. In particular, they found that staff encountered some difficulty interpreting the clients' non-verbal signals, they tended to overestimate the individual receptive verbal language skills and underestimated the impact of hearing difficulties. The implication from this is that staff expectations of the client's receptive skills may not be accurate and they may be unaware of additional communication needs indicated by non-verbal responses. Purcell et al concluded that staff "may need to adjust their perceptions of individuals communicative needs and their own communication skills to optimise communication with the individual" (p23). Bartlett (1997) would agree with this and concludes that a good communication environment for the individual who has communication difficulties should involve a match between the individual's competencies and the "output of significant others".

Finally, several studies have suggested that staff may view attempts to improve clients communication as consisting of "changes in the client rather than changes on their part" (Purcell et al, 1999) (p22). Their study suggested that staff perceived the issue as "fixing the person" instead of considering the impact of their own expectations and responses to communication difficulties. Similarly, Hodgkinson (1997) in a small scale study of staff members in a variety of learning disability services found that although staff accepted a role in the promotion of communication, they felt "powerlessness in their ability to bring about change" (p6). These points both imply that staff training needs to reflect on communication as a two way process and incorporate opportunities for staff to reflect on their own impact on the communicative exchange.

1.5 Professional expectations and their impact on the communicative abilities of people with a learning disability.
Professionals need to be aware of the impact of their expectations on the communicative abilities of people with a learning disability. This may lead them to overestimate or underestimate their communicative abilities. It is also important to consider that from the learning disabled persons point of view, they are “strangers, officials, visitors and very often testers, who demand conversation, words, answers” (Van der Gaag and Dormandy) (p96). A perceived power imbalance may result which may result in or impact on the individuals communicative abilities.

Bull (1995) has reviewed research in the area of interviewing people with learning disabilities in a legal context (although the general guidelines produced for professionals interviewing clients in this area will generally be applicable to all settings). The guidelines imply that professionals need to be aware of their own expectations about clients' communicative abilities and that their questioning may be influential in the clients’ responses. Sigelman, Budd, Spankel and Schoenrock (1981) argue that professionals need to consider the issue of acquiescence when interviewing people with a learning disability (i.e. answering yes, regardless of the question). They suggest that interviewers could utilise picture questions to reduce ‘response bias’ and increase the opportunities for individuals to reply honestly and appropriately.

Other issues for professionals to consider when interviewing individuals with a learning disability include: avoiding leading questions, not constantly questioning on a particular point which may cause the individual to deviate from their response, not placing pressure on the individual to respond (which could lead to confabulation), being aware of non-verbal behaviour and using an appropriate level of communication for the individual to understand (Cahill, Grebler, Baker and Tully, 1988: cited in Bull, 1995). This implies that professionals may have certain expectations about the communicative abilities of people with a learning disability, which may impact on their communicative exchange. It suggests that the professional needs to be aware of these issues when conducting interviews to build up an accurate representation of the clients’ abilities and information imparted.
2.0  What is the impact of others expectations on the communicative abilities of people with learning disabilities?

Van der Gaag (1988) argues that there are serious repercussions for the individual with a learning disability who has communication difficulties, which link in with the expectations that have been placed on the client. These may include social withdrawal and isolation, poor self esteem, feelings of frustration, anger and years of compliance (Flynn, 1989: cited in Van der Gaag, 1998). Another impact of others expectations on the communicative abilities of people with a learning disability may be challenging behaviour. Ceci (1986) has suggested a connection between communication difficulties and challenging behaviour. Other researchers have argued that challenging behaviour has a function of communication, as a communicative expression when other methods of communication are considered ineffective or unavailable (Chamberlain, Cheung Chung and Jenner, 1993).

It could be suggested that inaccurate expectations by others of an individuals communication skills (e.g. overestimation or underestimation etc.) may lead the person to feel frustrated, angry, isolated and demonstrate challenging behaviour as a means of communicating when other options are not effective. McLean, Brady and McLean (1996) for example, in a study of individuals with severe learning disabilities, found that those who had more advanced symbolic communication forms had higher rates of aggression. They suggested that this might imply greater frustration “when individuals in their daily environment do not respond to communication in ways that are sought or expected by those more able communicators” (p588).

Similarly, the expectations of others towards an individual with challenging behaviour might be that they are unable to communicate with the individual or understand what the individual is attempting to communicate. It may also mean that the ‘behaviours’ themselves become seen as the ‘problem’ instead of a “symptom of underlying difficulties” (Stansfield and Cheseldine, 1994) (p11). Stansfield and Cheseldine argue that if an individual has challenging behaviours, the expectation by others of that person becomes “coloured by this knowledge” (p11). They also suggest that others may become withdrawn from the person (perhaps due to fear) and eventually the
opportunities available to them for communication may be reduced. This may lead to a vicious circle in which the challenging behaviours increase as the individuals communication needs may not be met.

Bradshaw (1998) demonstrated the role of expectations by others of individuals communicative abilities and the link with challenging behaviour. Bradshaw illustrated this with a case study of a male client who presented various challenges to the service and who had profound hearing loss. Prior to any intervention, expectations of the clients' communication was limited — staff perceived that their messages were not received by him and this led to limited attempts for a communicative exchange. This in turn led to few demands being placed on him to respond, reduced expectations that his communication could develop and possible low expectations of his own skills. After the intervention (staff training, development of alternative forms of communication and challenging behaviour analysis) staffs' expectations of the clients' communicative abilities changed. Communication became more meaningful and interactive between staff and client that in turn led to more successful communication experiences and more chance for skills development. The level of challenging behaviour reduced and staff had an increased understanding of the possible role of the challenging behaviour as a communicative function. Bradshaw, did however, point out that the conclusions should be treated as tentative, as staff attitudes and expectations were anecdotally recorded and the reduction in challenging behaviour was not systematically evaluated.

Stansfield and Cheseldine (1994) argue that staff and carers working with individuals with challenging behaviour may have different expectations of the 'behaviours' demonstrated, which may in turn lead them to be 'labelled' in different ways. Their study of therapists working with client's with a learning disability found that certain types of challenging behaviour were seen as 'distracting behaviours' (e.g. withdrawal, swearing), whilst others were seen as 'disruptive behaviour' (e.g. scratching, biting). Although both may fulfil a communicative function, it indicates that the interactor has a role in defining and labelling the behaviour which may in turn implicate how any further intervention is conducted and whether the behaviour is seen as having a communicative function or some other function.
Nind and Hewitt (1994) suggest that others expectations that an individual with a learning disability should engage in “adult styles of interaction” (p177) could lead to an overestimation of that persons communicative abilities (see previous section for more detailed discussion of this). This may in turn lead to challenging behaviour as a reaction to the inappropriate expectations and demands placed on the individual. The challenging behaviour serves a function of communicating needs and feelings. Nind and Hewitt argue that intervention techniques should incorporate realistic expectations of the individuals present communicative ability. They suggest that if communicative exchanges with the individual appropriately respond to and respect “signals of negativity”, the challenging behaviour (and the communicative function it holds) often reduces.

This approach therefore supports the idea that if an individuals expectations of the learning disabled person leads them to make an inappropriate or inaccurate representations of that persons communicative abilities, this could contribute to challenging behaviour. By adjusting attitudes and expectations of the person, which are reflective of their present communication level, this could lead to a reduction in the challenging behaviour.

3.0 How might a Clinical Psychologist work with these issues?

There are several ways in which a Clinical Psychologist might work with these issues. These may take place either directly or indirectly with individuals with a learning disability.

3.1 Working with parents/carers.

Bott et al (1997) suggests that early intervention and support should be offered to parents and carers who may be experiencing difficulties in communication with their child. The work of a Clinical Psychologist could be to support the carer in identifying the reason why the difficulties are occurring, to provide education about communicative difficulties, to discuss issues surrounding communicative expectations
of the child (are they appropriate or realistic for the child’s current abilities, where did the expectations stem from etc?) and to suggest strategies to aid the continued development of communicative abilities. It might also be the role of the Clinical Psychologist to decide if a Speech and Language Therapist should be involved to provide specific input (for e.g. communication assessment) and to work conjointly with the other professional.

McConkey (1980: cited in Price, 1989) would agree and argued that parents or caregivers have a central role in the facilitation of language and communication in the learning disabled child. The professionals' role is to enhance parental knowledge about "how this early learning takes place to enable them to help their child more effectively" (p207).

Bott et al (1997) conclude that "the earlier that strategies for pre-empting behaviour problems are introduced, the more likely they are to succeed" (p5). As previously discussed, challenging behaviour has been identified with a communicative function and opportunities for it to develop may be reduced if the person’s communicative needs/abilities are being met from an early age. The impact of unrealistic expectations from the carers perspective might need to be discussed with the parents in this respect as they could impact on the communicative abilities of the person.

Alternatively, the Clinical Psychologist may be able to provide input in a group setting for relatives and/or carers of an individual with a learning disability. The topics could include the role of communication and the facilitation of communication skills, verbal versus non-verbal communication, communicative difficulties and how to approach them, challenging behaviour and its communicative function. The group might additionally focus on the impact of expectations about the communicative abilities of people with a learning disability and help challenge or confirm some of these ideas and their origins.
3.2 **Staff training.**

The role of the Clinical Psychologist in staff training may be as a consultant for more localised delivery of a course or as a training provider. Staff training can be seen as a vital factor in raising awareness of the communication needs of people with a learning disability and the role of staff’s expectations or perceptions of individuals communicative abilities in encouraging successful communicative exchange. Van der Gaag (1998) suggests that staff training in communication with people with a learning disability should be flexibly adapted to meet the needs of the individual staff group and be sensitive to “managerial and environmental factors” within the service (Cullen, 1988: cited in Van der Gaag). It should also provide opportunities for staff to be self-reflective on their beliefs and expectations about communication in people with a learning disability, on how they use communication with this client group and on how this may impact on others communication. The Clinical Psychologist may provide ‘one off’ training as a response to identified need, e.g. difficulties working with challenging behaviour, new staff members etc. but it should encourage the generalisation of skills and knowledge to working practice and therefore should be reviewed on an ongoing basis.

3.3 **Challenging behaviour interventions.**

The role of the Clinical Psychologist can be to work with staff and client’s to look at the role of the individuals challenging behaviour and to provide proactive and reactive intervention strategies. Chamberlain et al (1993) suggest that there is “a case for intervention with a communicative focus when behaviour is used in a communicative way or as a result of communication difficulties “ (p124). The role of the Clinical Psychologist may be in four areas: assisting staff in preventative work, early detection of potential problems, crisis management and in specialised long term support (Emerson, McGill and Mansell, 1994).

Applied behavioural analysis is based on the premise that challenging behaviour has a function, (for example, communication, access to desired events (Emerson et al, 1994). The functional analysis should take into consideration the relationship between
the clients' needs, the environment and it's possible impact on behaviour. One
difficulty is that the behaviour could be attributed entirely to the individual, however,
the role of the psychologist is to consider the role of all communicative partners and
the impact of the environment in the maintenance of the challenging behaviour.
Strategies can then be put into place, which take account of the interaction between
these variables and consist of an integrated approach.

Stansfield and Cheseldine (1994) suggest that the professional needs to work
sensitively with staff, to ensure that they "continue to see clients’ as people, who are
attempting to communicate regardless of the severity of their challenging behaviour"
(p14). Work with staff should consider the role of their attitudes, expectations and
responses to the individual's challenging behaviour and/or communicative acts and
make the link with the possible impact that this may have on the client's
communicative abilities and the communicative exchange. Staff support should be an
ongoing process to ensure that the process of intervention is being maintained and
supported.

3.4 Direct work with people with learning disabilities.

Direct work with the individual might involve one to one input or group work. The
aim here would be to consider the role of communication in the clients' lives, how
they use communication and the perceived impact of other expectations on their
communicative abilities. The individual might be feeling frustrated and/or low in self
esteem due to the belief that their communicative needs are either not being heard or
met. The role of the psychologist might be to consider assertion skills and the
development of interaction skills to help to reduce the perceived vulnerability of the
individual and to develop strategies for managing the impact that it has had on their
communicative abilities.

4.0 Conclusion.

The aim of my essay has been to demonstrate the role of others expectations on the
communicative abilities of people with learning disabilities. It has considered the
impact of these expectations and the way in which a Clinical Psychologist can become involved to work with these issues.

The role of communication is an integral part of all individuals lives. Yet, Hallas (1982) has suggested that communication disorder is the most common ‘problem’ in individuals with a learning disability and a number of survey studies have indicated a high prevalence of identifiable problems in communication, such as initiation and response difficulties.

An important paradigm shift has occurred from the concept of communication and language as a structural, rigid system to the idea that it is an interactive ‘social phenomenon’ in which joint activity between communicative partners is integral (Price, 1989). This implies that it is the “communication environment, the opportunities a person has to use his/her communication skills and the knowledge and experience of the ‘communication partner’ which will have a major influence on whether or not an individual is or becomes a successful communicator” (Van der Gaag, 1998) (p89). It also implies that the impact of others attitudes and expectations on the communicative abilities of a person can have a detrimental or positive impact and that there is an onus on others to adapt their own communication behaviour and accept increased responsibility for change.

This essay has considered the early impact of primary care givers interactions and expectations of the communicative abilities of children with a learning disability. It also considered how professionals might make certain expectations, which may impact on the working relationship between professional and client. Later on it looked at the impact of staff expectations on the communicative abilities of people with learning disabilities, with the recognition that communication is an ongoing social, interactive process. Van der Gaag and Dormandy (1993) suggested that staff who had received little opportunity for training could have false expectations and make inappropriate judgements about an individuals communicative abilities. These may involve underestimating or overestimating the individuals competence. Both sets of expectations were linked within a circular process, whereby a mismatch between staff expectations and the present communicative abilities of the person led to
difficulties coping with excessive demands, frustration, diminished opportunities and low self esteem (Bartlett, 1997). The impact of these expectations suggests an enhancement of difficulties in the communicative competence of the individual.

As previously outlined, there are serious repercussions for the individual with a learning disability who has communication difficulties. These may include social withdrawal and isolation, frustration, anger and compliance. It was also suggested that inappropriate expectations by others of an individual's communication skills may lead the person to feel so frustrated, angry and isolated that challenging behaviour becomes a means of communicating when no other options are effective, in other words it has a functional communicative role.

The diverse role of the Clinical Psychologist was demonstrated in various ways of working with these issues. These included staff training, direct work with people with learning disabilities on an individual or group basis, work with carers and proactive or reactive intervention for clients' who challenging a service.

Communication is a two way process, which is ever evolving and influenced by so many different variables. The consideration of perceptions and attitudes of others which may in turn lead to certain expectations of the individuals communication, could have a vital role in "breaking the cycle of negativity which colours many communicative experiences for individuals with learning disabilities (Van der Gaag, 1998) (p98).
References:


Child Essay

Psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. Discuss.

Year 2
Psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. Discuss.

1.0 Introduction to classification.

According to Cantwell and Rutter (1994) classification is a means for information to be grouped in a logical phenomenon. Classification "reflects a general human tendency to use concepts in order to make sense of the world" and as such is a mechanism to form some degree of order on "psychological disturbance, personality characteristics, levels of adaptive functioning and types of psychosocial situations" (p3).

Carr (1999) discusses three functions of classification in general, in the field of clinical child psychology. The first is that information about different childhood problems can be arranged in an ordered way to enhance the growth of knowledge. The second function of classification is to encourage the development of information about the prevalence and occurrence of different problems. This information is useful in decisions regarding service planning, particularly where resources are more sparse. The final function of classification is to supply a method of meaningful communication for researchers and clinicians alike. Clark, Watson and Reynolds (1995) would support this and highlight the role of classification in the facilitation of clinical practice and communication, as well as stimulating research and enhancing scientific understanding. Sonuga-Barke (1998) argues that clinical situations put the clinician in a position where he or she ultimately has to decide between children or adolescents who "need help" and "those who don’t". Additionally, the clinician needs to distinguish between what type of help is needed for the child and in order to relate "therapeutic responses" to different clinical problems diagnosis serves a practical benefit (p117).

Mezzich and Mezzich (1987) state that "diagnosis is epitomised by classification" and that the diagnosis is traditionally seen as the "point of thought" in working forwards
towards treatment (p34). However, classification and the systems used to classify are imperfect systems, which aim to categorise often complex, highly individualised behaviour. As such, the adequacy of them needs to be considered in order to understand their contribution to the understanding and treatment of mental health problems in childhood and adolescence. Carson and Garber (1986) would agree and suggest that it is important to consider the reason for classifying as well as the potential risks.

This essay aims to discuss the idea that psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. It will initially be set in context with a discussion of the history and development of psychiatric classification, its utility, problems with the use of classification in children and finally in its contribution to the assessment and treatment of this group. The final part of the essay will consider how psychology as a profession may be ideologically opposed to the construction of psychiatric classification (which provides support for the idea that psychiatric classification is irrelevant to the understanding and treatment of mental health problems). Also that psychological formulation may be a more useful way of understanding and treating child and adolescent mental health problems.

1.1 History of child and adolescent psychiatric classification systems and current systems.

According to Cantwell (1996), traditional psychiatric classification systems, for e.g., the Diagnostic and Statistical Manual (DSM-1: American Psychiatric Association, 1952) and International Classification of Diseases, 8th revision (ICD-8; World Health Organisation, 1967) (both cited in Cantwell) focused almost entirely on adult disorders. However, there were few references to child and adolescents.

The first system which sought to classify child and adolescent disorders, was based on psychoanalytic ideas and was developed by Anna Freud (1965: cited in Cantwell). However, according to Cantwell and Rutter (1994), a number of investigations suggested that the way forward for psychiatric classifications was a focus on
symptomatology rather than on "theories that lacked empirical substantiation" (p3). As they stood, the systems of classification in use at the time did not enable a clear distinction to be made for clinical purposes and there was a proliferation of subjective, biased diagnoses made which reduced clinical utility (Sonuga-Barke, 1998). This led to the development of a diagnostic system, which could be used in a similar way by both clinicians and researchers. The DSM-III, 1980: cited in Cantwell and Rutter) was the first system to incorporate this approach followed more recently by DSM-III-R (American Psychiatric Association, 1987) and now DSM-IV (American Psychiatric Association, 1994) (both cited in Cantwell and Rutter, 1994).

1.2 Current psychiatric classification systems.

Currently, the two main psychiatric classification systems in use are the DSM-IV and the tenth version of the International Classification of Diseases (ICD-10) (World Health Organisation, 1992: cited in Carr, 1999). The ICD-10 is used predominantly although not exclusively in Europe whilst the DSM-IV is used predominantly in North America (Carr, 1999).

Both systems are categorical in nature which means that "patients either meet or do not meet criteria for a diagnosis" (Clark et al, 1995) (p124). The actual diagnoses made in Axes I are in categorical terms. However, there are some dimensional axes within both systems in which psychosocial stress and psychosocial functioning are included. They are also both multi-axial, which means that individuals are coded on a number of axes. Carr (1999) suggests that the aim here is to reduce the oversimplification obtained from a single axis system. As such, they include medical conditions, intellectual functioning and psychosocial/ environmental situations in an attempt to consider more complex facets of children and their families. Also, in both systems, the principal diagnoses are provided in Axis I and other "facets of the case are described on the remaining axes" (Carr) (p66).
1.3 Dimensional approaches to childhood psychological problems.

Clark et al (1995) suggest that we should be moving towards dimensional frameworks in the assessment and understanding of childhood problems. They argue that dimensional frameworks are a more efficient alternative to categorical psychiatric classification systems as they assume that "symptomatology is assessed on a linear continuum of graded severity" (p144). As such they are more closely linked with clinical utility than a categorical approach. An example of the dimensional approach is the Child Behaviour Checklist (Achenbach, 1991; cited in McConaughy and Achenbach, 1994). This forms the premise that behavioural problems can be placed along two behavioural dimensions. The first is externalising behaviour problems (overt actions such as drug abuse) and internalising behaviour problems, which reflect levels of internal emotional distress.

They suggest two main advantages of dimensional systems. The first is that it replaces a large number of diagnostic categories with a smaller number of basic dimensions. The second is that places a stronger emphasis on the severity of the disorder. Carr (1999) also argues that dimensional frameworks can be used more comprehensively in the assessment process. A number of behaviour checklists and tests can be used in clinical practice to identify the position of children along the dimensions and compare the child with other children using established norms. Additionally, any changes (whether showing improvements or deterioration) can be determined by comparing to score changes along the dimensions.

However, Clark et al, (1995) argue that the dimensional approach needs a large amount of work in order to be considered a viable alternative to categorical classification systems. Indeed, they argue that even the word "dimensional" is used inconsistently among clinicians and researchers. A study by Kasius, Ferdinand, Van der Berg and Verhulst compared the Child Behaviour Checklist with the DSM-111 criteria. They found that it would be difficult for one approach to take over from the other, as they do not really converge. They suggested that it could be useful to combine them to capture information from them both.
Carr (1999) suggests that the dimensional approach is more able to identify common problems, which contain a number of symptoms such as anxiety with depression and somatisation. The DSM and ICD categorical approach is more appropriate for the conceptualisation of “pervasive developmental disorders, tic disorders and single-symptom presentations such as pica” (p75).

1.4 Classification and the medical model.

Wilson (1993), suggests that although classification enables clinicians to make certain distinctions between children, it does not mean that the distinctions are always right or that they are made consistently. Mirowsky and Ross (1989: cited in Sonuga-Barke, 1998) suggests that classification wastes information about important differences within and between groups by grouping people together on possibly significant characteristics. They argue that an increased understanding about mental health problems and other disorders has developed despite of, instead of, the categorical approach.

Sonuga-Barke (1998), suggests that the use of classification as a practical clinical mechanism, is different from actually following the ideology that the categories are grounded in reality. The psychiatric classifications outlined above are based on a medical model of psychological problems and as such, they may be unacceptable to those who view psychology in an alternative way. Cantwell and Rutter (1994) argue that “there is the query on the parallel between mental and physical disorders”. It follows from this that mental health problems may not form distinct conditions as those suggested by medical diagnoses.

Similarly, those clinicians who view the idea that children’s problems “have an existence within the nature of the troubled child” are likely to view the concept of classification in a different way to those who do not (p117). Hobbs (1975: cited in Gibbs, 1982) suggests that the implication of psychiatric classification systems is that the problems reside like a “tumour or virus within the child” and that by classifying the child as the central unit for classification and description has extreme limitations (p16). This area will be discussed in more detail later on.
Following on from this, Knoff (1986), argues that the clinicians personal attitudes towards classification per se, influence its use. Overall, the clinician needs to balance the strengths and weaknesses of the classification system and identify if it improves the “quality of problem identification, problem analysis, intervention and evaluation method” (p18). If the use of classifying enhances the field of communication between those involved in working with the child it may have a purpose. However, if it only serves to bias the views of those involved, which may in turn reduce the commitment towards a positive way of working with the presenting difficulties, it may not be a useful system.

2.0 Problems with psychiatric classification.

2.1 Labelling and other ethical problems involved in psychiatric classification.

Carr (1999), argues that the diagnosis formed from psychiatric classification can serve to “pathologise youngsters who are relatively powerless to resist this process” (p77). The process of labelling the child or adolescent with a diagnosis may lead to them being perceived as different, disturbed etc. Psychiatric classification can also be seen as a method of placing the child in a ‘pigeonhole’ in order to make sense of them, instead of focusing on their relative strengths and coping resources (Carlson and Gerber, 1986).

Gibbs (1982) discussed the possible repercussions of labelling in children and adolescents. She felt that children and adolescents are more dependant on their environment which means that labelling has a more profound effect. As such, they may not be able to disagree with the individual who labels them and may be less able to actively make changes to their label. Adults may be able to “create a new environment” in response to labelling, whereas children are unlikely to have the practical or emotional resources to do so (they may in turn be given a new label for attempting to recreate or change their environment, e.g. school refusal or emotional withdrawal).
In addition to this, labelling in children and adolescents has been linked with poor self-esteem and self-image and rejection from friendship groups (e.g. Macmillan & Meyers, 1981; cited in Gibbs, 1982). The idea of a self-fulfilling prophecy, whereby children's perceptions of themselves are shaped and reinforced by others has also been discussed in relation to labelling (Carlson and Gerber, 1986). Finally, Kessler (1971; cited in Carlson and Gerber, 1986) suggests that labelling is problematic in children anyway because they are changing and growing. The somewhat rigid outcome of psychiatric classification may not reflect developmental changes in the child or adolescents mental health problems.

Although the negative side of labelling children or adolescents with a diagnosis has been well documented, the more positive side has also been considered. Carr (1999) suggested that it "may only be justifiable to the extent that the diagnoses given, lead to treatment which ameliorates the problems described by the label" (p77). Mash and Terdel (1988) suggest that labelling may help to increase communication between the professionals involved with the child or adolescent and the family network. Cantwell and Rutter (1994) suggest that it may help parents or family to make sense of the difficulties the child (or adolescent) is experiencing and may act as a vehicle to help the family to work with the issues involved. Finally, they suggest that the label may provide a 'passport' to accessing the necessary mental health services, the child or adolescent my need.

2.2 Developmental issues.

Cantwell and Rutter (1994) argue that it is important to remember that if a diagnosis is going to be made, it should be recognised that "diagnoses apply to disorders and not to people". They suggest that classification may imply that the 'disorder' is static and fixed and this goes against considerable evidence. Indeed, Newman and Garfinkel (1992) suggest that the majority of childhood disorders have the same name as adult disorders. This gives the impression that they are the same and implies that they form a continuum from childhood to adulthood.
However, it seems likely that psychological symptoms will present in some areas of the life span or age group rather than others. Cantwell (1994), for example, commented that obsessive compulsive disorder increases much more in females than males with the onset of puberty. Whilst, Kendall, Cantwell and Kazdin (1989) suggest that depression in children and adolescents may be associated with problems thought predominately to occur in childhood e.g. separation anxiety. As the child or adolescent grows older the symptoms may change. Indeed, Cantwell argues that the classification of psychological problems using the DSM and ICD classifications in infants and young children is not even useful. The overall picture is one of maturation and change and provides evidence against the provision of an inflexible label provided by psychiatric classification.

2.4 Technical problems with psychiatric classification systems.

In any discussion of psychiatric classifications, technical issues such as reliability and validity should be included. According to Sonuga-Barke (1989), a system of classification can be deemed reliable, if it enables different individuals at different times to make the "same distinctions between problems" and categorise these in a consistent way. It can be deemed valid if it enables clinicians to make a distinction between children who "differ in clinically significant ways" (p117).

An assumption from this would be that the use of psychiatric classification may be undermined if there are demonstrably poor levels of reliability and validity (and indeed other technical problems such as co-morbidity discussed below). Similarly, if psychiatric classification systems have such a number of technical problems, how meaningful are they in their ability to enhance our understanding of child and adolescent mental health problems?

2.4.1 Reliability.

Concerns about poor interrater reliability were identified for earlier DSM psychiatric classification systems and it was hoped that the introduction of a more explicit, observable set of diagnostic rules would increase reliability co-efficients in the DSM-
111 (Carr, 1999). However, Kirk and Kutchins (1992), found that even when DSM-111 and DSM-11 were compared in controlled studies, relatively no improvement was noted.

Hodge, Cools and McKnew, (1989)) reviewed seven major studies, which incorporated structured interviews with a total of 750 children. They noted that a fair degree of reliability was found for four childhood psychological disorders (namely, conduct disorder, Attention Deficit Disorder, major depression and anxiety disorders). However, Carr (1999) notes that despite the use of strict diagnostic criteria, structured interviews and computer algorithms to reach a diagnosis, the reliability co-efficients still only fell within the fair range.

A further reliability issue may come from the way symptoms are interpreted by a clinician. These may vary according to the situation the judgement is made in, the child they are classifying, the relationship between the clinician and client and the theoretical approach of the clinician (Mumma, 1993).

Cantwell (1996), concludes that although the aim of improving reliability is to utilise diagnostic rules in a precise way, this can only be true “if there are precise rules for how the symptom is determined to be present, rather than just rules for what symptoms need to be present for the diagnosis to be made” (p6).

2.4.2 Heterogeneity.

The move towards improving reliability and reducing within-category heterogeneity in psychiatric classification has led to narrowing of the definitions of disorders. Carr (1999), suggests that the aim to reduce within category heterogeneity actually resulted in the problem of poor coverage (whereby individuals referred for clinical input cannot be placed into defined categories).

Clark, Watson and Reynolds (1995) argue that the purpose of classification as a means to inform treatment can be undermined by either within-category heterogeneity or poor coverage. In the case of substantial within-category heterogeneity, this
"challenges the basis for classification" (p132). Clark et al suggest that if the categorical approach to psychiatric classification is undermined by problems such as heterogeneity, (and co-morbidity) the clinical utility of classification systems is also undermined.

Clark et al (1995) argue that heterogeneity problems have been addressed by adding new categories and subtyping. They conclude that although the aim has been to improve coverage for individuals who were previously without a diagnosis, it has simply served to "replace old areas of diagnostic confusion with new boundary or residual cases" (p142). Sonuga-Barke (1998) also suggests that with the attempt to improve one problem, so another one becomes more problematic. By subtyping categories in an attempt to reduce heterogeneity, the risk of comorbidity increases.

2.4.3 Co-morbidity.

Studies of childhood disorder suggest that the prevalence of co-morbidity is high, whereby more than one disorder is thought to exist in the same person (McConaughy and Achenbach, 1994).

The extent of co-morbidity has been assessed in both clinic and community based studies. One population based study whereby structured interviews were conducted using the Diagnostic Interview Schedule for children (DISC-C) (Costello, 1982; cited in Anderson, Williams, McGee and Silva, 1987) found that out of the 219 children diagnosed, 55% had more than one diagnosed disorder using DSM-111 criteria (Anderson, Williams, McGee and Silva, 1987). A second study using 943 adolescents aged 15 years found that 25% of the adolescents had more than one diagnosed disorder. The most common disorders found to occur co-morbidly included, depression, anxiety, attention deficit hyperactivity disorder and conduct disorder (Carr, 1999).

McConaughy and Achenbach, (1994) argue that co-morbidity can have important ramifications for severity, expected outcomes and responses to treatment. For example, one study found that children with diagnoses of conduct disorder (CD) and
depressive disorder had poorer outcomes and a greater risk of adult criminality than children who had a depressive disorder in isolation of CD (Harrington, Fudge, Rutter, Pickles & Hill, 1991; cited in McConaughy and Achenbach).

In terms of research which aims to increase understanding of mental health problems in children, the issue of co-morbidity could “challenge the meaningfulness of a research paradigm in which investigators identify a group of individuals who share a common diagnosis and then examine them on variables hypothesised to be relevant to the aetiology, course or treatment of the disorder” (Clark et al, 1995) (p140). The problem here being that those children in an identified diagnostic group can share a complex pattern of problems which do not fit neatly into a psychiatric classification. Cantwell and Rutter (1994) suggest that in the case of co-morbidity, the combination of the problems may change the overall meaning of them. So for example, in studies of depression (which is often co-morbidly linked with other psychological problems such as anxiety) it is important to attend to the “co-morbid combination in order to determine whether or not it has a special meaning” (p16).

Clark et al conclude that it might be the case that it is not adequate for a categorical system to classify “psychopathology” and that psychiatric classification cannot capture natural variations in different problems (Kirmayer, 1994; cited in Clark et al). Our understanding of child and adolescent mental health problems may be better understood by examining the relative influence of co-morbid conditions that reflect the complex interactions presented.

2.4.5 Validity.

Carr (1999) suggests that in order for psychiatric classification systems to be validated, it needs to be shown that individuals who fulfil the criteria for one diagnostic category share common characteristics and that they in turn differ from individuals who share the characteristics of another diagnostic category. Some of these include predisposing factors, precipitating factors and protective factors. Similarly, the onset of the disorder and responses to treatments should also be largely shared by individuals who all fulfil the same diagnostic criteria.
However, Carr argues that no research has established validity on all these criteria and that there is little specificity in the relationship between child and adolescent psychological problems and aetiological factors. A high degree of the predisposing, precipitating and protective factors are common to a number of psychological problems, e.g. social disadvantage, parental separation etc. Finally, Carr argue that treatment responses are extremely variable and are impacted by risk factors and co-morbidity issues.

Volkmar and Schwab-Stone (1996) suggest that the problems outlined above may be due to the fact that often children present with complex “clinical pictures” which are accompanied by a large range of other problems such as developmental difficulties. As such, they do not tend to fall neatly into “current syndrome boundaries and usual syndrome pictures” (p782). This may reflect the interaction and complexity of the parent-child relationships and indeed other members of the child (and adolescents) networks.

Carr (1999) would agree with this and argues that childhood psychological problems are not “disease like categorical entities” but should be seen as “interactional problems” between children and others and between children and their environments (p74). Similarly, Mash and Terdel (1988) argue that psychiatric classification systems fail to take enough account of contextual influences and attempt to apply static categories to a developing child. Although psychiatric classification may imply treatment for some medically based disorders, the majority of classifications for psychological problems have a “lack of demonstrated relevance for treatment” (p17).

It would seem to follow that psychiatric classification systems are not believed to reflect the complex, subtleties of child and adolescent psychological problems. As psychologists we would seek to identify and formulate these on the basis of our assessment and integrate interactional relationships and other contextual influences. Due to the large number of problems identified with psychiatric classification, it would also suggest that their contribution to the understanding and treatment of child and adolescent mental health problems should be treated with caution.
3.0 An interactional approach to understanding mental health problems in children and adolescents.

Cox (1994) suggests that the assessment of children and adolescents is likely to reveal problems, which are relatively specific to certain situations, so for example, a child who is anxious at school may not be anxious at home. The implication of situation specificity is that child and adolescent mental health problems should be considered in interactional terms. Whereas, a psychiatric classification system would imply that the problem lies just within the child, an interactional approach would suggest that the problem "lies in the interaction between a child and it's environment and not just within the child" (p25). This environment would typically involve immediate and extended family members as well as other social networks in the child’s environment. The suggestion has important consequences for formulation and plans for therapeutic interventions, as the focus of change would not just be on the child’s characteristics.

Carr (1999) argues that psychiatric classification systems such as the DSM and ICD may obscure the interactional nature of the majority of child and adolescent problems. Carr acknowledges that there is an opportunity to code psychosocial and contextual factors on these systems, however they are positioned on a lower axis. As such they may not be particularly helpful for a clinical psychologist as it is the "system of relationships around the child which has the greatest implications for management and prognosis" (p76). Systemic therapists would be more likely to see the "problem" as part of the complex interactions within the family system (or wider system) that the child or adolescent is placed in. As such they would not focus on psychiatric classifications or single-factor models (i.e. child characteristics, parent characteristics etc.) but on more complex interactional processes.

Families may vary on a range of parameters which all need consideration in the formulation and treatment of child and adolescent mental health problems (Mikesell, Lusterman and McDaniel, 1996; cited in Carr, 1999). Amongst these, include, families who are at different stages in the lifecycle process and families who are chaotically organised, versus families who are organised more adaptively (Carr, 1999).
4.0 Formulation versus classification?

Cantwell and Rutter (1994), argue that in clinical practice, classification must be supplemented with additional assessment and formulations which enable the individual to be considered in the context of their own individual situation and their own individual strengths and weaknesses. As such they suggest that classification has its place as a vehicle of communication, but is only a part of that communication.

May (1982: cited in Carlson and Gerber, 1986), would agree and argues that a clinical decision cannot be made regarding treatment with a diagnosis alone. Assessment should incorporate a large range of information about the aetiology, maintenance and nature of the problems. This should then underlie the basis for intervention and treatment. Even if the existence of particular problems or symptoms imply a particular diagnosis, this is not sufficient to aid the understanding and treatment of the individual child (Newman and Garfinkel, 1992).

Cox (1994) suggests that formulation is more useful in the understanding and treatment of mental heath problems in child and adolescents than psychiatric classification. Formulation enables the drawing out of “qualities that are different and distinctive about the child and family” (p26). The process of formulation enables the construction of hypotheses about factors which may predispose children to develop problems (predisposing factors), possible causes of the problems (precipitating factors), the factors causing the problems to continue (maintaining factors) and factors that may help the child in terms of therapeutic intervention and/or preventing the problems from getting worse (protective factors). As previously discussed, the child or adolescent cannot be considered in isolation of his or her environment and the interaction between the two need to be considered in relation to the predisposing, maintaining and protective factors.

Cox (1994) also suggests that formulation should be constructed in a way that will guide therapeutic treatment. As such, it should include information obtained from the range of informants involved and both short and long term treatments that are
intended in view of a possible prognosis. Finally, part of the formulation process should include feedback to the child and family in order to establish a mutual understanding of the mental health problem and agreed treatment goals.

Pilgrim (2000) would agree with this. He argues that psychological formulation "assumes a continuity between the normal and the abnormal", whereas psychiatric classification creates a line between the well and the unwell (p302). As such, formulation which is based on established psychological theory, enables psychologists to account for a persons experiences and actions in the specific context of his or her surrounding. Pilgrim argues that psychiatric classifications are "atheoretical and descriptive" and do not offer sensitivity or a good understanding of the complexities of the psychosocial problems concerned.

Pilgrim argues that there are three main reasons why classification and diagnosis should be rejected in place of formulation. The first is that we should be focusing on "the understanding of psychological differences" instead of trying to reduce problems into pre-emptive categories. The second is that by focusing on situation specific explanations of behaviour, it should enable more responsive approaches to the understanding and treatment of mental health problems in the individual. This should in turn, enable the development of more sensible service planning, which can respond to the needs of the individual.

5.0 Conclusion.

The aim of my essay has been to discuss the idea that psychiatric classification is irrelevant to the understanding and treatment of mental health problems in children and adolescents. This essay has set the context of the discussion by looking at the history and development of psychiatric classification, it’s utility, problems with the use of classification in children and finally at the way it has contributed to the assessment and treatment of children and adolescents. The end of the essay considered the idea that psychological formulation is a more relevant and meaningful way of understanding and treating child and adolescent mental health problems.
Psychiatric classification of children and adolescents was developed with the aim to provide clinicians with a clear distinction between childhood disorders. The focus on symptomatology and observed symptoms was felt to be a more systematic and subjective way of defining difficulties (Sonuga-Barke, 1998). A further aim of psychiatric classification was to facilitate communication amongst clinical practitioners as it hoped to provide a mechanism for shared understanding of childhood problems. However, the use of classification and other systems to classify is an imperfect system. As such, the adequacy of them needs to be considered in order to understand the meaningful role they actually have in the contribution to the understanding and treatment of mental health problems in childhood and adolescence (Mezzich and Mezzich, 1987).

This essay has considered the problems of the current psychiatric classification systems in use, with a focus on the two main categorical psychiatric classification systems (the DSM and ICD-10). A suggestion was that psychiatric classifications are based on a medical model and as such, they may be unacceptable or ideologically opposed to a psychological way of working. Issues of labelling, a poor consideration of developmental issues and a range of technical problems, such as reliability, heterogeneity and co-morbidity were discussed in the essay. It was suggested that these problems all question the clinical utility and application of classification to the understanding of psychological problems in children and adolescents.

The essay moved on to the idea that psychiatric classification systems are not believed to reflect the subtleties of child and adolescent psychological problems. Children often present with complex “clinical pictures” which are accompanied by a large range of other problems. As such they do not fall neatly into the boundaries installed by the confines of psychiatric classification systems. It was argued that an interactional approach, which places the emphasis on the interaction between the child and the environment, enables a more detailed understanding of mental health problems in children and adolescents.

The essay considered the idea that a clinical understanding of the mental health problems presented by children cannot be made with a diagnosis alone. The child or
adolescent must be considered in the context of their own individual situation and their own individual strengths and weaknesses (Cantwell and Rutter, 1994). It was therefore argued that psychological formulation, which seeks to construct hypotheses about the causes, maintaining factors and protective factors is a more effective way of understanding childhood mental health problems. The process of formulation enables psychologists to account for an individual's experiences and actions in the specific context of his or her surrounding, in a way that psychiatric classification systems are currently unable to do.
References.


Older Adults Essay

Discuss the use and effectiveness of CBT for emotional disorders in people with dementia.

Year 2
Discuss the use and effectiveness of Cognitive Behaviour therapy (CBT) for emotional disorders in people with dementia.

1.0 Introduction to dementia.

The term 'dementia' is used to refer to a “syndrome of acquired loss of cognitive function, behavioural changes and loss of social function” (Feldman and O’Brien, 1999) (p232). The majority of dementias are progressive and lead to a decline in the individuals level of functioning. The most important goal in terms of psychological and more recently pharmacological intervention is to accurately diagnose and assess each individual to help them achieve at a level appropriate to their current level of functioning (Feldman and O’Brien).

The two most common causes of dementia are Alzheimer’s Disease and Vascular Disease. Alzheimer’s Disease is probably the most common out of the two and leads to a progressive global deterioration in the person’s intellectual and cognitive functioning (Cherry and Plauche, 1996). The progression of the disease is often variable in terms of its decline, although with some individuals, there can be a plateau of time, during which there is no substantial loss of ability (Cheston and Bender, 1999). Vascular dementia accounts for approximately 10-20 per cent of dementia diagnoses (Cheston and Bender). It is caused by the occurrence of infarcts of small strokes, which leads to an abrupt deterioration in the individual following the stroke, which is typically followed by varying recovery. This means that decline is often stepwise and leads to some areas of functioning being more affected than others. In addition, the individual will usually be accompanied by physical paralysis or weakness (Feldman and O’Brien, 1999).

1.1 Emotional disorders in people with dementia.

The use of psychotherapeutic work with people with dementia has been cited as far back as forty years ago (Gilewski, cited in Cheston, 1998). However, a more recent shift which reflects a new emphasis in dementia care recognises the ideas that people
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with dementia have a range of emotional and psychological needs as well as a range of physical needs (Cheston, 1998). The process of dementia, as well as the experience of having the disease is often likely to elicit strong emotional reactions in the person, such as depression, anger, grief, anxiety and fear. Each person will encounter their own experience of these feelings and the way in which they are expressed (Cheston and Bender, 1999).

This essay sets out to examine the use of CBT as a therapeutic approach for emotional disorders in people with dementia. For the purpose of this essay and to reflect the available literature, the main focus will be on the treatment of depression and anxiety using CBT. Discussion will also be made on the use of CBT as a treatment approach for emotional disorders in carers of people with dementia.

1.2 The prevalence of depression in people with dementia.

Depression occurs in a substantial proportion of people with dementia and is increasingly recognised as a “common concomitant of dementia” (Woods and Bird, 1999) (p320). The average prevalence rate for depression in people with dementia is 20 per cent (Ballard, Bannister and Oyebode, 1996). The study by Ballard et al (1996) found that depression was more common in people with milder cognitive impairment. This may be due to a greater awareness of the decline in cognitive functioning or it may be that depression may be expressed in a different way in people with more advanced cognitive impairment and so is more difficult to detect (e.g. behavioural disturbances).

Depressive symptoms in people with dementia appear to be similar to those who have depression without dementia. As such they may include difficulty sleeping, feelings of guilt and worthlessness, dysphoric mood, loss of interest in previously enjoyed activities etc. (Teri, 1994). Reifler and Larson (1990) argue that depression in dementia serves to further impair the person’s level of intellectual function. It may also impact on the person’s quality of life in terms of daily activities (Fitz and Teri, 1994: cited in Ballard and Eastwood, 1999), and cause extreme distress to the individual as well as to those around him or her. The treatment of depression may
enable people with dementia to "function at a more optimal level for a longer time" (Thompson, Blake, Zeiss, Gallagher, 1990) (p385).

The diagnosis of depression is made more difficult by the often coexistence of depression and dementia. Use of standardised measures may be difficult as answers to some questions (e.g. reduced interest in activities) may be due to the dementia or the depression. If depression is not recognised in the person with dementia then this can lead to unnecessary distress in the individual (Kasniak, 1996).

An interesting finding is that there is a high rate of resolution of symptoms of depression, particularly in people with Alzheimer's disease with mild to moderate dementia (Ballard, Patel, Solis, Lowe and Wilcock, 1996). This may have implications for the delay of treatment (psychological or pharmaceutical), although it is important to consider the devastating impact of depression and unnecessary suffering on the individual and his or her family at the time. Clinical discretion is therefore likely to be needed and as will later be discussed, a thorough assessment of the person's needs at the time, which needs to take into consideration the ongoing depression, it's relevant precipitants and it's impact on the individual needs to be made.

1.3 The prevalence of anxiety in people with dementia.

Anxiety is also common in people with dementia and may occur in the absence or presence of depression. The comorbidity between anxiety and dementia has been reported to be as much as 38 per cent (Wands, Merskey, Hachinski, Fisman and Fox, 1990: cited in Koder, 1998). As with depression, it seems that individuals with mild dementia are more likely to experience symptoms of anxiety (Ballard, Mohan, Patel and Graham, 1994). This again may be due to the person being aware of certain changes occurring, such as a decline in their cognitive abilities or that anxiety in people with severe dementia may be expressed in other ways.

The issue of diagnosing anxiety in people with dementia is often a contentious one. The rate of co-morbidity with depression is high and it is important to make a detailed
assessment in order to ascertain which “elements predominate” and require treatment (Koder, 1998) (p180). The diagnosis is also made difficult by the lack of standardised anxiety schedules to assess people with dementia, as no measure has been validated in this population (Ballard and Eastwood, 1999).

2.0 A conceptualisation of cognitive therapy with people with dementia.

A conceptualisation of distress in individuals with dementia has recently been developed by James (1999). The framework draws on Beck’s (1976: cited in James) cognitive model as well as Kitwood’s (1997: cited in James) work on personhood and aims to provide an explanation of the person’s difficulties in order to guide the process of intervention.

The model explains that the way a person perceives a situation is dependent on the interaction between a range of components, such as premorbid personality, culture and mental health status. For the person with dementia, information processing is also affected in the decline of cognitive function which results in “some abnormal interpretations” (p23). If the person additionally has emotional disorders such as anxiety or depression their perception will also be influenced by biases consistent with their mood (such as overgeneralising, negative thinking etc.). Thompson et al (1990) suggest that for people with dementia two common cognitive distortions are overgeneralising and catastrophising. These may be more powerful “when individuals have difficulty with such cognitive processes as remembering, reasoning, abstracting and sustaining focused attention” (p387), particularly when they have a level of insight into their cognitive decline.

The present model suggests that the products of information processing can be viewed through Beck’s cognitive triad, which provides a conceptual basis for depression and anxiety (1976: cited above). The cognitive triad suggests that the individual’s feelings and behaviour will be influenced by their cognitions. These are based on the person’s beliefs about themselves, their world and the future. James argues that the way that the person with dementia acts and behaves can “often be interpreted as coping
strategies” e.g. aggression (p23). The way that other people react to some of these behaviours may influence the person’s psychological well being.

The model enables the therapist to formulate a good understanding of the individual's distress in view of their dementia (James, 1999). It also forms the outline for intervention, which is consistent with the cognitive triad, either on an individual, or other/environment led basis.

2.1 **CBT and the importance of assessment with people with dementia.**

As previously discussed, there has been a shift in emphasis on work with people with dementia. According to Woods and Bird, (1999) this is reflected in more psychological work in the area of anxiety and depression in people with dementia.

In order to make a decision about the suitability of the individual for CBT (and other psychological intervention), a thorough assessment needs to be carried out. This needs to include an assessment of the individual's cognitive, behavioural, physical, emotional and environmental needs (Kasniak, 1996). In addition, Woods and Bird (1999) suggest that factors such as the person’s premorbid characteristics should be considered in order to provide such information as previous coping styles. Other factors such as the person’s social network and perception of difficulties should also be considered with the overall aim to gain an understanding of the person’s perspective.

According to Cheston (1998) assessment also needs to consider the potential aims of working with the individual. Some clinicians would argue that psychological work with the person with dementia should help the person to make sense of the experience of dementia (this implies that all individuals with dementia could benefit from intervention) (e.g. Stokes and Goudie, 1990: cited in Cheston). However, other clinicians would argue that psychological interaction with people with dementia should be restricted to those who experience distress by the disease. This approach would generally focus on a definite clinical problem such as depression and/or anxiety and is more likely to be addressed in the context of CBT.
One important area of assessment is the persons' cognitive function as it may help to highlight the person's strengths, which can be built on in the process of therapeutic intervention. As such, neuropsychological testing is often appropriate (Thompson et al 1990). There is also some suggestion that CBT may only be appropriate for individuals with a certain level of cognitive function. One stance is that cognitive therapy, which places a priority on the use of verbal skills, may only be suitable for individual's whose cognitive function is relatively intact. This may be the case for people who are in the early stages of dementia and who retain a level of insight and self-awareness into their difficulties (e.g. Solomon and Szwabo, 1992).

Thompson et al (1990) would agree with this idea and suggest that people with dementia are most likely to benefit if their level of cognitive capability enables them to learn the use of basic coping strategies. They suggest that “as a general guideline, this might include patients in the mild dementia phase on the Clinical Dementia Rating Scale” (Hughes, Berg, Danzinger, Coben & Martin, 1982: cited in Thompson et al, 1990) (p389). In situations where the dementia is more advanced and the extent of the cognitive losses has led to a significant reduction in pleasurable events the use of a behavioural approach may be more suitable (Teri and Gallagher-Thompson, 1991).

2.2 The application and adaptation of CBT with people with dementia.

A number of characteristics within CBT have been described as particularly useful for people with mild dementia (Thompson et al, 1990). In particular, CBT is generally presented as a more accepting approach, it is well structured with goals, which can be adapted to the individual needs of the client, and it is time limited. It also focuses on problems that are currently occurring, which may be important when working with people who are disorientated with time and in a confused state (O'Donovan, 1996: cited in James, 1999). Finally, CBT has some evidence of effectiveness with older adults, particularly in the area of depression (e.g. Thompson, Gallagher and Breckenridge, 1987). However, the effectiveness demonstrated in these outcome trials might not necessarily translate to an older adult population with depression and dementia.
The use of CBT as a treatment approach typically requires that the individual is able to develop some level of realistic insight into their difficulties and to learn to use various cognitive and behavioural strategies during the course of intervention. The intervention also emphasises the importance of a collaborative approach between client and therapist, where work focuses on challenging negative cognitions and finding more adaptive interpretations of situations and events. However, a person with dementia may not possess all or some of these abilities. This could mean that certain adaptations to therapy may need to be considered (James, 1999). As previously discussed, each person will come to therapy with their own set of cognitive strengths and weaknesses and a comprehensive assessment needs to be carried out in order to determine these. Knowledge of the persons strengths and weaknesses also enables the therapist to decide if a self-appraisal or negative thought is a reflection of "true deficits" or whether it is a cognitive distortion (Thompson et al, 1990) (p389).

A review of the relevant literature surrounding adaptations for the use of CBT reveals very few differences between older adults in general and older adults with dementia (e.g. Hughes, 1991). The main emphasis is on the accommodation of cognitive changes in the individual, which may impair short-term memory and the capacity for abstracting and reasoning with information as well as learning new information. This seems to reflect the normal process of ageing or can be part of the dementia process (Zeiss and Steffen, 1996). Difficulties in abstract thinking (and judgement difficulties) may mean that the person with dementia finds difficulty using and generalising from record sheets (Church and Bennet, 1982: cited in Bradbury, 1991). Similarly, the abstract concept that emotional reactions may follow thoughts about a situation may be more difficult to conceptualise (Steuer and Hammen, 1983: cited in Hughes, 1991).

In view of this information, various modifications to the process of CBT can be made. Some of these include: the use of shorter sessions, setting a slower pace, frequent repetition, frequent summaries of the session, perhaps in the form of handouts, cue cards or audio-tapes (Teri and Gallagher Thompson, 1991) and the use of concrete examples to provide structure for record sheets. Providing structure in sessions also
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seems to be important as it may also help to "engender hope and positive expectancies in patients who often belief that Alzheimer's Disease is a death knell for their ability to function and participate adequately in relationships" Thompson et al, 1990 (p390). Similarly, the way that structure is used to organise and compartmentalise problems in CBT may offer a model that can be generalised outside of the therapy session (Thompson et al). Thompson et al also suggest the use of other concrete techniques such as 'priming' which is the concrete task of writing down a number of positive thoughts which can then be either prominently displayed or carried around with the person.

Depending on the individual, the work may need to focus more on behavioural elements than on cognitive elements, e.g. relaxation. The role of the therapist may be at times need to be more directive (e.g. to get therapy back on track) which is slightly different to the Socratic approach normally emphasised in CBT (Thompson et al, 1991). Additionally, the context of the sessions may need to be more flexible and informal depending on the person's place of residence and this may imply a consideration of boundary issues in therapy (Cheston, 1998). Sessions might also need to incorporate carers and family members either as part of the therapeutic process or additional to it (Wilkinson, 1997). This may be to encourage generalisation outside of sessions and to work on themes together outside of sessions.

Finally, the therapist needs to be continually aware of the reality of the dementia for the individual. CBT cannot alter the course of the underlying dementia disease or bring about permanent changes (Thompson et al, 1990). For people in the earlier stages of dementia, the reality is that they have experienced a number of losses and may be aware of the losses that are likely to come. This could mean that the cognitive characteristics of emotional disorders such as hopelessness, need to be reviewed in light of the person's realistic appreciation of limitations caused by the dementia and/or the ageing process. It could also mean that the use of "catastrophisation" is "a legitimate cognitive response" to the situation (Cheston, 1998) (p217). However, what CBT can hope to do is to enable the individual to "recognise and deal with the cognitive distortions which may prevent or relieve a devastating depression" (Thompson et al) (p392).
2.3 The use of CBT for depression in people with dementia.

Indirect support for the use and efficacy of CBT for the treatment of depression in people with dementia can be taken from research in the elderly without dementia (Thompson et al 1990). However, there has only been a small amount of systematic research in this area. One outcome trial compared group CBT with group psychodynamic therapy (Steuer, Mintz, Hammen, Hill, Jarvik & McCarley, 1984). The study found that participants in both groups showed some improvement in terms of symptoms of depression, although more significant improvement was found in the CBT group. However, this study did not include a control group and the participants themselves were an atypical group, as they had a high academic achievement level and were recruited via the media (Wilkinson, 1997).

An earlier study looked at the effectiveness of therapeutic intervention for depression in older adults on a more long-term basis (Gallagher & Thompson, 1982: cited in Wilkinson, 1997). The study compared three intervention groups: a behavioural group, cognitive group and insight orientated therapy group. Results showed good improvement in the three intervention groups, however at follow up this was only maintained in the cognitive and behavioural groups. An interesting question to raise here is whether a combined CBT group would have made a difference to the outcome results?

Even less research has examined the use of CBT for older people with depression who also have dementia. One of the exceptions is research by Teri and Gallagher-Thompson (1991). They described two approaches based on Beck’s theory of cognitive therapy for depression (Beck, Rush, Shaw & Emery, 1979: cited in Teri and Gallagher-Thompson, 1991) and Lewinsohn’s behavioural theory for depression (Lewinsohn, Antonuccio & Steinmetz, 1984: cited as above).

The first approach is for older adults with mild dementia, whilst the second approach is for older adults with a moderate to severe dementia. The cognitive approach takes place over 16-20 individual sessions and consists of identifying and challenging
'dysfunctional thoughts' using daily records and activity schedules. The behavioural approach is based on the theory that depression in people with dementia is caused by a reduction and withdrawal from activities previously enjoyed. The approach consists of behavioural management techniques e.g. relaxation exercises, increasing involvement in pleasant activities and decreasing aversive experiences. The behavioural approach includes the person with dementia and their caregiver, who was actively involved in the treatment.

The researchers suggest that the cognitive intervention is clinically more relevant when the person's depression centres on "perceived cognitive losses" and their implications for the future (p416), whilst the behavioural intervention is more suitable when the person's activity level and abilities impacts on their "pleasurable events". They also suggest that whilst the cognitive and behavioural treatment approaches are suitable for individuals with 'milder dementia' the cognitive treatment approach is not suitable for those with more advanced dementia. Although the title of the research indicates that CBT is used as a combined treatment approach, the researchers have presented the cognitive and behavioural elements separately. As such there is no indication of the effectiveness of a combined approach. They do however, suggest that clinicians may decide to integrate them according to the needs of the individual. This would seem to be an important consideration for future research as it seems apparent that considerable more work needs to be done in the adaptation of these approaches (Cheston, 1998).

According to the researchers, both approaches have been used in clinical settings and treatment outcome has suggested a reduction in depression scores (as measured by the Beck Depression Inventory: Beck, Ward, Mendelson, Mock & Erbaugh, 1961: cited in Teri and Gallagher-Thompson). However no real explanation has been given of this process. At the time of the article the researchers explained that they were in the process of conducting controlled clinical trials to evaluate the effectiveness of the approaches. However, a recent literature review by the author of this essay has only identified preliminary data for a controlled clinical trial in behavioural treatment (Teri, 1994). This provided initial support for the efficacy of behavioural treatment in reducing depression in people with Alzheimer disease. Interestingly, the research also
provided results to suggest that the involvement of careers in the treatment process led to a reduction of depression in this group as well.

A later study evaluated a CBT group for males with a diagnosis of probable dementia (Kipling and Bailey, 1999). The aim of the CBT group was to “address maladaptive memory-related beliefs” with the hope that this would encourage more adaptive behavioural changes, an increased understanding of memory function and a reduction in negative affect. This was based on a “generic cognitive therapy model” (Padesky and Mooney, 1990: cited in Kipling and Bailey). Although the main aim of the study was to address memory difficulties, it also identified positive changes in mood and reduced anxiety. The researchers argued that the study provided evidence for the efficacy of CBT, however the limitations of the study included a small number of participants and the absence of a control group. Use of measures which directly address the issues of cognitive and behavioural change may also have been useful to consider the impact of CBT.

2.4 The use of CBT for anxiety in people with dementia.

Research suggests that the treatment most commonly used for the treatment of anxiety in older adults is pharmacological (Radley, Redston, Bates. Pontefract & Lindesay, 1997). However, the use of CBT may be a suitable alternative, as it does not have the same risks as medical intervention e.g. physical side effects and physical dependence. Similarly, the learning of new more adaptive coping skills in relation to anxiety management may enable the transfer of these skills to other difficult situations (Koder, 1998).

There has been little systematic research in the use of CBT as a treatment approach for anxiety in the older adult age group. A single case study reported by Haley (1983: cited in Koder 1998) demonstrated the use of cognitive coping self-statements in helping a client to challenge the thoughts that led to agitation. Haley reported that the person gradually learnt to replace the negative cognitions with a list of alternative statements, which led to a decrease in incidents of agitation. The list of statements
had been rehearsed daily which could suggest that the person was unable to generalise the strategies learnt beyond those that had been taught.

A later outcome study for individuals with anxiety symptoms (generalised anxiety disorder, panic disorder and agoraphobia) found that CBT was successful in reducing symptoms of anxiety. Results were maintained over the six months in which the study was conducted (King and Barrowclough, 1991). The study did not include a control condition and caution should be used in interpreting the results, as sample sizes were small. However, Koder (1998) suggests that the within-subject design used in this study is still extremely important as it might help to identify the “crucial variables in the treatment of anxiety in older adults, especially where change may be greatest for cognitive symptoms of anxiety” (p174).

Even less research has examined the use of CBT for older people with anxiety who also have dementia (Koder, 1998). Koder reported another single case study by Haley (1983) who used graded exposure, basic relaxation techniques and environmental cues in the treatment of an 87 year old female with moderate dementia who had anxiety about being on her own. At the end of the treatment sessions, the client was able to remain for a longer period of time on her own without being anxious. Although Koder described this as a CBT intervention, the intervention seems to reflect a more behavioural treatment approach.

Koder (1998) described two single case studies where she used CBT for the treatment of anxiety in two older adults with dementia. A description of the assessment procedure, intervention and progress was included for both case studies. Of interest, the description of the assessment for the first case-study revealed that the person was not suitable for cognitive therapy, however on reading the intervention it seems that some cognitive techniques had been used, e.g. cognitive restructuring and coping self-talk. As such, justification for the use of these techniques was not demonstrated and their relative efficacy was not highlighted. The bulk of the intervention in the first and second case study was biased towards more structured behavioural techniques such as relaxation and graded exposure. The inclusion of the caregiver in the role of a “co-therapist” was deemed helpful to support the client both during and between sessions.
Koder (1998) concluded that the intervention did improve the quality of life for the two clients and their families, however, the interventions did not appear to provide sufficient explanation or support for a combined CBT approach. Similarly, the use of single case studies meant that it was difficult to generalise the results and the contribution of other factors in the client’s lives may well have led to the changes occurring (e.g. support from the client-therapist relationship). Further research in this area needs to utilise more rigorous research designs as well as the inclusion of an appropriate control group, and dependant measures to assess where and what changes are occurring (Koder).

3.0 CBT for caregivers of people with dementia.

Carers of people with dementia often have to fulfil a number of difficult roles in caregiving. Some of these roles are likely to be in areas for which they are not equipped for emotionally or physically (Hepburn and Warsaw, 1986: cited in Gendron, Poitras, Dastoor, & Perodeau, 1996). The uncertain nature of the dementia illness, deterioration of a loved one, difficulties in obtaining diagnosis, financial worries and social isolation may all combine to make the carers role burdensome and emotionally stressful (Kaplan & Gallagher-Thompson, 1995). An early study found that spousal caregivers are particularly at risk for the development of emotional disorders. (Cantor 1983). Consequently, spousal caregivers may report a cluster of symptoms including: depression, anxiety, grief and anger (Gallagher et al, 1989).

Some evidence for the efficacy of CBT individual and group interventions for caregivers has been found and these will be reported below. Group interventions are increasingly used in services as they are deemed to be cost-effective in the current climate of the National Health Service. However, a key aim in the development of any group intervention is to ensure that the type of intervention being used is effective in meeting the needs of the client and is proven to be effective (Gendron et al, 1996).

A study by Gendron et al (1996) described the use of a CBT approach for spousal caregivers of people with Alzheimer’s disease. The research aimed to evaluate the use
of a CBT group approach, which utilised cognitive-restructuring, assertiveness and problem-solving. The group was compared with a general support group. Various measures were taken prior to the intervention and afterwards which included a measure of assertion, marital adjustment, coping styles and psychological distress. The researchers suggested that the results indicated the potential benefit of CBT with caregivers, particularly in relation to assertion training and cognitive restructuring. However interestingly the results showed that there were no significant differences between the two groups in terms of negative thoughts, coping styles, psychological distress and burden following treatment.

A later study by Chang (1999) compared an eight week CBT group intervention with an attention only group for caregivers of people with Alzheimer’s disease. Participants were allocated randomly to the two groups and various measures were taken at intervals throughout the group, which included measures of coping, physical health, emotional health and caregiver burden. The results showed a reduction in depression in the CBT group compared to the attention only group and a significant reduction in anxiety for both groups. This would seem to provide partial support for the efficacy of CBT in the treatment of depression in caregivers of people with dementia. However, the intervention described as CBT could be questioned, as it consisted of a video-assisted modelling programme for modelling eating and dressing behaviour in the person with dementia and nursing support to enable the carer to build on coping strategies.

Several studies have looked at individual CBT with depressed carers of people with dementia. A single case study by Kaplan and Gallagher-Thompson (1995) described the use of a 17 session of combined CBT and grief counselling. The client consisted of a 69 year old spousal caregiver with major depression. Intervention was based on the cognitive theory of depression (Beck, 1979: cited in Kaplan and Gallagher-Thompson) and Worden’s grief counselling (1991: cited in Kaplan and Gallagher-Thompson). Results were positive and at the end of the treatment, the client was described as “asymptomatic” and her symptoms of depression were found within the normal range. Although the study was a single-case design it does appear to demonstrate support for the efficacy of the combined approach. Intervention was
clearly linked to its respective theoretical approaches, which was another strength of the study as it demonstrated good theory-practice links. The researchers concluded that modification of the CBT approach might be useful in view of the contribution of certain factors such as unresolved, difficult grief reactions. However, it may also be useful to set up a group study, which compares the relative efficacy of these two approaches. This would also enable the evaluation of their individual contributions.

One study has compared the relative efficacy of two therapeutic approaches for depressed caregivers, namely CBT and brief psychodynamic therapy (Gallagher-Thompson, Lovett & Rose, 1991: cited in Adkins, 1999). It found that although there were no differences between the two approaches for carers who had been in their role for approximately four years or below, those who had been in their role for longer, appeared to benefit from CBT. The relative benefits of CBT for carers seemed to be that they were able to utilise more adaptive ways of coping which in turn led to increased feelings of internal control and less emotional distress. Psychodynamic therapy however, led to the carer confronting the extent of their loss and consequently having to deal with issues around loss and bereavement.

4.0 Conclusion.

This essay has set out to examine the use and effectiveness of CBT as a therapeutic approach for emotional disorders in people with dementia. The essay has placed the main focus on the treatment of depression using CBT, although it has also considered the treatment of anxiety using CBT. Some discussion has also been made on the use of CBT as a treatment approach for carers of people with dementia, which reflects the high level of emotional distress often created by the caring role, as well as the interactive relationship between carer and cared for.

There has been limited research into the effectiveness of the CBT approach for the treatment of emotional disorders in people with dementia, although it is acknowledged that the approach is increasingly being used in clinical settings (Cheston, 1998). Thompson et al (1990) suggest that indirect support for the use and efficacy of CBT for the treatment of depression in people with dementia can be taken from research in
older adults who do not have dementia. However, research in this area is still extremely limited and any comparisons should be treated with caution as the results might not necessarily translate to an older adult population with depression and dementia.

So far, research, which has evaluated the use of CBT in the treatment of people with dementia, has produced mixed, inconclusive results. As the essay has discussed, some of the research has been based on single case studies and small samples, which mean that the results are difficult to generalise. The research studies described in the context of this essay have illustrated a wide variation in the use of CBT and the way in which it is evaluated. In some studies, there has been a greater emphasis on behavioural techniques and in others, the cognitive element has not been utilised at all. This makes any comparisons difficult to make as well as any claims about its relative effectiveness. Similarly, some of the studies have not always demonstrated the link between CBT as a theory and it's application in clinical practice. The suggestions for the modifications of the CBT approach have largely been based on clinical experience and anecdotal evidence and again need to be treated with some caution.

Cheston (1998) suggests that the inconclusive results produced by research so far are not surprising. He argues that generally, clinical practice will “precede outcome research on treatment approaches” Similarly, the evaluation of the effectiveness of therapeutic treatment in controlled research can be “compounded by the deteriorating cognitive deficits of dementia patients” (p220). There is now a need for more structure in the research process if the use of CBT as a treatment approach is to develop in this area (Cheston, 1998). This may mean that CBT needs to be developed into a “purer form” so that comparisons can be made between different treatment approaches. Other suggestions include: the selection of relevant outcome measures to distinguish between symptoms caused by the dementia process and symptoms of depression or anxiety and more research into the impact of CBT on the well being of caregivers (Thompson et al, 1990). Similarly, more controlled research needs to be carried out to evaluate the adaptations suggested in this essay for the application of CBT to this client group and to consider the adequacy of CBT for people who have progressed further into the process of dementia (Teri & Gallagher-Thompson, 1991).
Despite these criticisms, the publication of single case studies and clinical practice has been useful in its illustration of the process of CBT as a therapeutic treatment with people with dementia (Department of Health, 1996: cited in Cheston, 1998). James' (1999) conceptualisation of distress in people with dementia has led to theory guided interventions which are now being evaluated using single case methodology. The studies also demonstrate the potential value of working with people to improve the quality of their life however, short term it may be (Koder, 1998). Similarly, the use of CBT as a treatment approach may have certain economic as well as psychological consequences, as it may help to reduce emotional distress not only in the person with dementia but also in their carer. This may in turn delay the use of inpatient services (Thompson et al, 1990).
References.


Specialist Essay

Discuss the role and effectiveness of Narrative Therapy (NT) in work with children and their families.

Year 3
Discuss the role and effectiveness of Narrative Therapy (NT) in work with children and their families.

1.0 Introduction.

NT is a therapeutic approach which is becoming increasingly recognised in the field of clinical psychology and family therapy (Carr, 1998). A number of authors are beginning to write about its incorporation into clinical work and mental health practices (e.g. Weston, Boxer & Heatherington, 1998, Dahlgren Daigneault, 1999) and it has been suggested that NT is an approach that is useful among a wide range of specialist difficulties including anorexia, child abuse and schizophrenia (Carr, 1998).

The use of NT with children and families has been documented by a variety of authors (e.g. White and Epston, 1990, Zimmerman & Dickerson, 1994, Freeman, Epston & Lobovits, 1997). Narrative work with this client group appears to offer an innovative, sensitive and collaborative approach, which may potentially be useful on a wider scale in the NHS. However, despite the apparent attractiveness of this approach there is little evidence for its utility. As such it may not demonstrate its viability in the current NHS climate of clinical effectiveness (Etchison & Kleist, 2000).

This essay sets out to consider the use of NT in working with children and their families. It will first consider the theoretical rationale of NT before considering its potential usefulness in work with this client group. ¹

1.1 The theoretical rationale of NT.

NT is placed within a social constructionist perspective, which assumes that knowledge is socially constructed. The deconstruction of the person’s experience of the world forms the basis of a narrative therapeutic approach since experiences are

¹This essay will largely focus on the re-authoring approach used by White & Epston (1990), although the author appreciates that there are a number of different narratively orientated approaches, e.g. hermeneutic approaches (Anderson & Goolishian, 1988, 1992: cited in Smith, 1997).
broken down into narrative frameworks (Cowley & Springen, 1995). Two other relevant factors to be addressed by the narrative therapist include the person’s language use and the social structure or power relationship that the person is positioned within (Carr, 1998).

The use of a narrative therapeutic approach stems largely from the work of White & Epston (1990) whose ideas are drawn from the work of the French intellectual Foucault on knowledge and power (1979, 1980, 1984: cited in White & Epston, 1990). A key difference in NT from other therapeutic approaches (e.g. psychoanalytic) is that it encourages the separation of the problem from the person (White & Epston, 1990). Labels or diagnoses are seen as part of a wider societal “pathologising narrative” and only serve to increase the burden on the client’s attempt to deal with the problem (Carr, 1998) (p487). The beginning of the separation of the problem from the person is the first stage in the therapeutic change process. The change can either occur by renegotiating the person’s relationship with the problem in a different way or by forming a protest against or resisting the problem (Etchison & Kleist, 2000).

NT aims to create an alternative story with the client which highlights aspects of lived experience which “fall outside” of the problem saturated, dominant story (White & Epston, 1990) (p15). This is defined as the process of re-authoring (Myerhoff, 1982, 1986: cited in White & Epston, 1990). The alternative story is created by the exploration of occasions where the person has resisted the “damaging stories or depictions of self and relationships”. The act of externalising the person from the problem serves to strengthen the reclamation of the person’s life from the problem (Etchison & Kleist, 2000) (p61). Carr has summarised the central practices in the re-authoring narrative approach (see below).

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<thead>
<tr>
<th>Practice 1</th>
<th>Adopt a collaborative position for co-authoring with the client.</th>
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<tr>
<td>Practice 2</td>
<td>Use externalising conversations to begin to separate the person from the problem.</td>
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<td>Practice 3</td>
<td>Look for unique outcomes by identifying points where the person has not been oppressed by the problem.</td>
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<td>Practice 4</td>
<td>Thicken the description of the unique outcomes by using specific question techniques.</td>
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<td>Practice 5</td>
<td>Connect unique outcomes to the past and future to create an alternative story where the problem is viewed as less powerful.</td>
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<td>Practice 6</td>
<td>Invite other members of the client’s network to witness the alternative story.</td>
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<td>Practice 7</td>
<td>Document the new story and the journey towards this new story with the use of letters, documents (narrative means to therapeutic ends) (Malone, 2001).</td>
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<td>Practice 8</td>
<td>Share this new knowledge and practice which forms the alternative story with other people with similar problems.</td>
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</tbody>
</table>

### 2.0 How NT differs from other approaches in work with children and their families.

NT as a social constructionist approach is disparate from the idea that there is a universal truth that is objective and unbiased. Freeman and Combs (1996) suggest that these modernist assumptions inform more traditional therapies. NT also moves away from the idea of pathologising labels or diagnostic categories and does not conform to the idea that the therapist is the expert on either the cause of the client’s problems or the best way to solve them. Finally, NT does not conform to other modernist assumptions that the client has various ‘deficits’ which bias or distort their perceptions and as such their own ideas about the problem are less reliable and biased by these distortions (Smith, 1997).

The implications of these modernist assumptions in working with children is that their perception may be inadvertently discredited in favour of the therapists ‘expert theoretical lens’ or professional opinion (Lobovits & Freeman, 19.97). A child’s views may be seen as ‘irrational’ in the therapists domain but may in fact be entirely ‘rational’ when considered in relation to the underlying sociocultural influences in their lives. Similarly, the implication that the therapist is the expert on the cause of the child’s problems implies that the child’s interpretation is less valid or relevant which could further reinforce an already existing power differential between the adult therapist and the child. This could in turn make it difficult for the child to find a voice in the therapeutic sessions, may inspire self-blame and reduce opportunities for effective treatment (Freeman & Combs, 1996). The possible long-term implications of this is that individuals could begin to mistrust their own perspectives and unique
solutions and may need to turn to ‘experts’ in the future whenever problems arise (Smith, 1997).

2.1 Why NT might be useful for work with children and their families.

A number of authors suggest that NT with children and their families provides the opportunity for the child’s ‘voice’ to be valued in equal terms to other’s voices (e.g. Freeman, Epston & Lobovits, 1997, Stacey, 1997, Malone, 2001). This is a factor that is likely to significantly influence the outcome of therapeutic intervention in work with children as it can guard against the imposition of meaning from other individual’s working with the child (Stacey & Lopston, 1995). A narrative therapist places a primary importance on the children’s experience of the problem, which is used to gain an understanding of “what children want for their lives and how this connects to what they want from therapy”. Since the therapist does not assume the expert role, the therapy attempts to be non-prescriptive and moves away from the implication of blame in either the child or it’s family (Smith, 1997) (p27).

The overall aim of treatment in a narrative framework is not to determine what needs to be corrected or challenged or to provide an interpretative framework based on ‘what the child really means’. (Neimeyer, 1993). Instead, the focus of intervention takes place in “the world of experience” by helping young people and their families to create “more preferred stories” based on their everyday lived experiences (Adams-Westcott & Dobbins, 1997) (p201).

For younger children who may have more difficulty expressing their voice in a verbal context, narrative therapists utilise a range of play modalities e.g. drama, drawings etc. in order to enable the child to express their experiences. Narrative therapists suggest that it is the focus on lived experience rather than the ability to use verbal language that is important (Adams-Westcott & Dobbins, 1997) (see later for a more detailed discussion of this area).
2.2 Playfully working in a narrative approach with children and their families.

A playful approach to working narratively with children and their families has been introduced by several authors (Freeman, Epston & Lobovits (1997, Lobovits & Freeman, 1997). The authors suggest that the narrative therapist will encounter a number of different versions of stories by each family member, which are influenced by age, gender, sociocultural influences and sex. They suggest that playful communication between adults and children induces a “common language to express the breadth and depth of thoughts, emotions and accounts of experience” (Lobovits & Freeman, 1997) (p174). It is largely inclusive of all ages and levels of cognitive development (Freeman, Epston & Lobovits, 1997).

The authors suggest that by the time that the child and family have entered the therapy session, the seriousness of the problem may have included despair and worry to the degree that the family is ‘oppressed’ by the problem. Working in a playful way to resolve problems is an approach that children are likely to feel more at ease with than adult based discussion or systematic problem solving (Stacey, 1995). The authors suggest that playful communication may also be beneficial for the therapist who is working with the child and family as it enables them to remain curious, to think on a lateral level and to retain the belief that the situation can be resolved (Freeman, Epston & Lobovits, 1997).

The playful approach may involve working with humour, games, role play, fantasy and magical plots but above all the emphasis appears to be on working creatively and collaboratively with the various narratives (Lobovits & Freeman). The aim of this collaboration is to inspire both children and their families to utilise their resources to provide solutions in the face of the problems and move away from the focus of the ‘child as the problem’ to the relationship with the problem (Freeman, Epston & Lobovits, 1997).
2.3 Does assessment have a role in NT?

Whereas many other psychological approaches emphasise the role of formal assessment at the beginning of therapy to arrive at tentative formulations of the problem (e.g. developmental history, family background, problem triggers etc), NT does not emphasise these in the same way (Smith, 1997). NT as a social constructionist approach does not assume that the therapist is able to unearth a singular objective definition of the problem. This is not to say that narrative therapist’s do not use information about developmental theory or consider historical questions. Instead these will be discussed in relation to the concerns brought forward by the parent’s or child. Any exploration of this area is carefully discussed to ensure that it is relevant and ‘fits’ for the family concerned (Smith, 1997).

The initial focus of NT is to create a safe and comfortable environment for conversation and to explore the meanings of the family and child involved (Smith, 1997). Freeman, Epston & Lobovits (1997) suggest that in the initial stages of therapy, it is also important to gain an understanding of the child apart from the problem. Many children will enter the therapy room ‘dominated’ by the effect of the problem and at times their identify as a person is overly merged with the ‘symptoms’ of the problem. One approach they have used is to initiate discussion or description of the child, which does not include the problem. This approach may inspire an atmosphere of hope as well as providing a connection with the child and family and information about their special abilities and resources. Freeman & Combs (1997) illustrated this in their work with a ‘quiet’ nine year old girl who was referred for ‘depression’. They began by asking the girl to discuss her interests and special skills which included swimming, rollerblading and skating. Similarly, Fristad, Gavazzi & Soldano (1999) discussed their approach to working with children who were referred with ‘mood disorders’. They designed a technique whereby the children were asked to write down their ‘positive attributes’ on one side of the page and the effects of the ‘mood disorder’ on the right hand side of the page.

2.4 The ‘passage of change’ in narrative work with children and families.
Specialist essay

Lobovits and Freeman (1997) support the idea of a 'passage of change' or transformation occurring in narrative work with children and their families. They divide the process of change into three parts.

1. **Harbingers of change.**

This is marked by a position of readiness to accept that change is needed. It is often marked by the acknowledgement of pain and discontentment. Lobovits and Freeman (1997) discussed this part in relation to the problem of fighting in a family. They suggested that if fighting has taken over life in the family, the initial step would be to identify the 'fighting interactions' and acknowledge the pain that occurs with these. The family members could then be invited to consider their preferences for communicating within the family and identify interactions which occur without fighting. This initial move towards discussing past and present life experiences, combined with exceptions to the problems can inspire further transformation of narrative change.

2. **Meeting the challenge.**

This stage is marked by experimentation with the new ideas and experiences and observing incidents of these changes. At this stage it is important that the changes observed are meaningful and are strong enough to achieve change. Lobovits and Freeman (1997) continued with their example of fighting and suggested that if a family recounted a recent outing where peace was present instead of fighting, the therapist could inquire how fighting was resisted by each member and how it could have caused damage to the outing if it had occurred.

3. **Celebration and confirmation.**

This stage is marked by the 'celebration of a new identity', confirmation that meaningful change has occurred and reincorporation of old with new to redefine the different relationship with the problem (Freeman & Lobovits, 1997) (p176). It may
well be that the child or family may decide to keep the problem in the new narrative (e.g. now that peace is the main way of interacting, what role should fighting continue to play?). Or that the family decide that the problem should be left behind or rehabilitated (e.g. fear can be an ally when the child dives into the deep end of a swimming pool).

2.5 Working narratively with the problem saturated stories.

White and Epston (1990) suggest that when a child and family enter therapeutic intervention their focus is on the problem and the narrative that surrounds it. The problem saturated story limits resources and the potential to take control of the problem (Freeman, Epston & Lobovits, 1997). A discussion with the family aims to map the effects of the problem on the child and family and how their choices and life experiences are being limited by the story. Nylund and Ceske (1997) found that depression had effected a young girl’s life by making her stay in the house and have arguments with her family and friends. The influence of the family on the problem is then mapped to begin to draw out existing strengths, competencies and resources. White (1984; 1997) found that a family were able to ‘outsmart’ a young boy’s ‘sneaky poo’ on several occasions. This marks the beginning of the discovery of unique outcomes (White & Epston, 1990) as exceptions to the overwhelming influence of the problem-saturated story are discovered.

As the unique outcomes are drawn out with the child, the development of an alternative story will begin to emerge which weaves in the newly found special skills, abilities and strengths of the child (Epston, 1997). The development of the alternative story has a slightly different focus when working with children as the counterplot usually contains a heroic or virtuous strength with a magical or fantasy element (e.g. bear-like-strength (Epston, 1997), tiger strength (Freeman, Epston & Lobovits, 1997).
2.6 **Externalisation.**

A family may often become ‘silenced’ by shame and blame created by a problem such as encopresis or anorexia. Similarly, if the problem has begun to be viewed as part of or integral to the child, it may have lead to difficulties instigating change (Freeman, Epston & Lobovits, 1997; Stacey, 1997). Sanders (1997) discussed the difficulties of some adolescents who were referred with the label ‘addictive personality’. He argued that this label served to paralyse or immobilise the young person from exerting any change in their life as the problem definition created the belief that their personality had been genetically determined. The practice of externalisation aims to separate the relationship between the child and the problem. The aim of this is to relieve the child from self-blame as they are free to have a ‘relationship’ with the problem. The child can then discover their own strategies and resources to ‘revise their relationship’ with the problem (Freeman, Epston & Lobovits, 1997) (p8).

Freeman, Epston & Lobovits (1997) suggest that the narrative approach of externalisation provides a good fit for work with children as it reflects their ‘learning environment of play’ (p10). For the child, externalisation may be seen as a playful game of ‘pretend’ in which “any identity is possible and secret thoughts can be safely revealed” (Paley, 1990) (p7). Externalising conversations with children and families occur largely with words, however conversation can be enhanced with the use of a wide range of expressive stimuli (e.g. Barragar-Dunne, 1997).

White (1984, 1997) externalised soiling (or encopresis) in his work with a six year old boy and his family. The soiling was externalised as ‘sneaky poo’ and externalising conversations were used such as looking at how ‘sneaky poo’ had become a friend, or the way that ‘sneaky poo’ was ‘sneaking’ into the child’s life. White argued that the externalisation of ‘sneaky poo’ enabled the child and family to ‘free themselves’ from the problem. It was only at this point that they were able to identify ways of dealing with it.

Stacey (1997) suggested that there are two main categories of externalising conversations, both of which can be used to increase the influence of a ‘non-
problematic feature’ or to reduce the influence of a ‘problematic feature’. The first category is defined as outer externalisations. These are used when the problem is mainly seen as a feature that is negative and able to be removed from the child’s life (e.g. tempter, fears or worry). The second category is defined as inner externalisations. These are used when the problem may not be reviewed as removable from the child’s life, perhaps due to the presence of neuropsychological or biological reasons. Externalising conversations used in this category focus more on the development of a collaborative relationship with the problem or the development of a balance in the relationship with the problem so that it does not dictate the child’s life. Stacey (1997b) discussed the narrative work she had done with children with language based learning difficulties. Stacey utilised an externalising conversation which used the concepts ‘ears thinking’ and ‘eyes thinking’ to separate the learning difficulties from the child in a meaningful way. The externalising metaphors focused on the development of a collaborative relationship between the child and his or her learning difficulty.

2.7 Use of questions.

In NT, the therapeutic process tends to move forward via a question and answer approach instead of statements or interpretations made by the therapist (Freeman, Epston and Lobovits (1997). The types of questions used are predominately ‘reflexive’ in nature as they facilitate views, experiences and choices for the family concerned (Tomm, 1988). The questions are also used as a ‘linguistic resource’ to help the child to consider different ways to talk about the situation and to help them provide a framework for co-authoring a new narrative (Freeman, Epston & Lobovits, 1997). Stacey and Lopston (1995) argue that the therapist should always remain aware of the ways that their questions may influence their work with the child, particularly when working in a narrative framework. They argue that children “must be allowed to speak as subjects who have expertise about their own lives, rather than be spoken about as objects who are acted upon by others” (p19).
2.8 Socio-cultural influences.

As previously discussed, the problem saturated story is usually influenced by socio-cultural assumptions which exist on an external basis to the family but may be internalised (White & Epston, 1990, Freeman & Combs, 1996: Freeman, Epston & Lebovits, Adams-Westcott & Dobbins, 1997). Freeman and Combs (1996) argue that "cultural stories are influencing the way they (individuals) interpret their daily experience and how their daily actions are influencing the stories that circulate in society" (p17). This relationship between socio-cultural assumptions and the problem is likely to be complex and requires careful deconstruction to determine the effect of both on the family. Adams-Westcott and Dobbins (1997) have considered the effect of cultural expectations and assumptions of abuse on their narrative work with children. They suggest that the way the child understands abuse is influenced by the range of ideas they about been exposed to about male and female societal roles. Similarly, Nylund and Ceske (1997) suggest that a dominant cultural assumption that young women should conform to standards of ‘beauty and femininity’ could encourage depression in adolescent girls.

The impact of socio-cultural assumptions has also been considered in the child’s parents. Cultural assumptions of the ‘ideal parents’ may lead to parent blaming or assumptions of ‘bad parenting’ which may cause parent’s to devalue their own experiences and resources (Sax, 1997). The role of the narrative therapist is to consider the effects of these assumptions and to externalise them for exploration (Freeman, Epston & Lobovits, 1997).

2.9 Including the parents and family in narrative therapy.

In NT, it is argued that all of the child’s caretakers have a relationship with the problem. As such, NT assumes that all are potentially ‘equal contributors to therapy conversations” (Anderson & Levin, 1997) (p266). This is not to suggest that all family members will attend all sessions. Instead, frequent consultation with child and his or her family will determine which members will attend and in what capacity.
Specialist essay

(Freeman, Epston & Lobovits, 1997). Freeman, Epston & Lobovits (1997) summarise the various roles that parents might take in NT (See table 2).

Table 2 Parental roles in NT.

| Role 1 | Brainstorming role to brainstorm suggestions and solutions with the child. |
| Role 2 | Co-conspirator role to outwit or spy on a problem, |
| Role 3 | Team role with family on one side and the family (team) on the other. |
| Role 4 | Meaning making role to contribute to the narratives of the child. |
| Role 5 | Participation role (1) to join in a game or ritual with the child. |
| Role 6 | Participation role (2) to supply examples of unique outcomes or exceptions to the problem. |
| Role 7 | Audience role to the child’s restorying and celebrating the change with the child. |

In situations where the child requests that they do not wish their parents to be present or they do not have parental caretakers, other significant people in the child’s life may be invited to attend therapy sessions. Adams-Westcott and Dobbins (1997) discussed the use of a ‘nurturing team’ for children who had had been abused (White, 1995: cited in Adams-Westcott & Dobbins). Children were asked to nominate members of the team to help them to challenge the abuse.

2.10 Different ways of working in NT with the child and family.

Expressive arts.

As previously discussed, narrative conversation may contain a mixture of verbal and non-verbal approaches (White, 1997). Whole families and children can work using a range of expressive arts such as drawing, sandplay, drama, drawing, sand play or sculpting (e.g. Barragar-Dunne, 1992; Barragar-Dunne, 1997; Epston, 1997). The aim of these is to enable the child to open up and draw on their ‘imagination and resourcefulness’ in a form of communication that is meaningful to them (White, 1997). The use of expressive arts may help the child to further personify the problem and to separate it from themselves (Nylund & Corsiglia, 1996). Barragher-Dunne (1997) discussed how a child used a tarantula puppet to externalise ‘mad anger’. Expressive arts may also help the child to strengthen and expand an alternative story. Barragher-Dunne (1997) discussed how a child constructed a ‘happy mask’ to wear when discussing exceptions to the problem-saturated story.
Freeman, Epston & Lobovits (1997) outlined several suggestions about when to use expressive arts combined with NT with children. These included:

1. Children who find it difficult to use their verbal voice in therapy, perhaps due to shyness, learning difficulties or developmental stage.
2. Children who have indicated that they would prefer to work in a different way.
3. Children who have found it difficult to use verbal expression in the past, perhaps due to the effects of abuse.

**Lists.**

The use of lists in narrative therapy can be a meaningful way to engage children. Lists may be useful in cases where the child has found it difficult to explain their concerns and experiences verbally (Buckman & Reese, 1999). They can be used in a variety of ways, which include lists of ideas, descriptions, events, hopes or fears. They may also be used to demonstrate accomplishments and provide meaning to these (Freedman & Combs, 1997). The decision of what to include on the list is a mutual decision between therapist and child. The actual list writing process and later re-reading may help the child to remember experiences. For children who may have been in situations where they have felt disempowered (e.g. abuse, trauma) the list writing process may help them to regain some of their ‘voice’ (Buckman & Reese). If the list is worked on over each session the child and family will be able to see the list ‘growing and developing’ (Freedman & Combs).

**Letters and tapes.**

Narrative letters are widely used in NT (Freedman & Combs, 1996). Their aim is to provide a witness to the emerging alternative story, and to highlight thoughts, and developments, which the family can draw on between therapy sessions. Research has suggested that narrative letters play a useful role in ‘continuing stories and thickening them’ (Freedman & Combs, 1996) (p209). Research by Nylund and Thomas (1994) found that people rated letters to be worth on average 3.2 interviews. Particularly in work with children and families, letters may provide a means to communicate with
children that their experiences and abilities are valued. As such, they may become 'treasured documents' that may be read and re-read to reinforce the emergence of special resources and abilities. The letter may also be useful in situations where family members are not able to attend sessions.

An alternative to the narrative letter format is the use of 'taped stories' (Epston, 1997). These enable the child to directly access the tape whenever they need to and they can be played at particular 'strategic times' (for example at night if the child has night fears). In the same way as letters, the tapes are constructed with narratives that are 'familiar to children' (p65).

Certificates.

White and Epston (1990) have also discussed the role of certificates in documenting the emergence of the alternative story. These are typically used when the child has accomplished or achieved something, The aim is to celebrate the achievement and to provide a concrete witness to the emergence of the alternative narrative (e.g.'s include 'The Escape from Tantrums certificate', and 'Beating Sneaky Wee certificate, White & Epson, 1990).

Sharing advice with others/ consultants.

Part of NT involves the 'circulation of news of change' in order to provide strength to the alternative story or narrative and to validate experiences (Freeman, Epston & Lobovits, 1997). Epston, White and "Ben" (1995) have suggested the idea of consulting a child in order to "document the ways in which they have resisted and surmounted the dominant stories of their lives" (p278). The consultation process is conducted in the form of an interview and may for example ask the child to discuss the way in which he or she has 'won the battle' against fear. The act of engaging the child as a consultant creates a 'new role' for the child. It also provides the message that they are considered an authority on their lives, that their new skills and abilities are respected and valued and that their experiences are considered important enough to be 'circulated to others' (Freeman, Epston & Lobovits, 1997).


3.0 The effectiveness of NT.

As previously discussed, the evidence for the effectiveness of NT has not been well documented. Etchison and Kleist (2000) reviewed four studies, which looked at the effectiveness of NT with children and their families.

Study 1 NT and the reduction of parent-child conflict (Besa, 1994).

This study aimed to evaluate the idea that NT could effectively reduce conflict between parent and child. Parent-child conflict was described in relation to conduct problems, drug and alcohol abuse and school problems. The research employed a single-case research design, which was employed to avoid the use of psychopathological classification issues. Sample size consisted of six families with children aged from eight to seventeen years. The families were selected on the basis of their presentation to the therapy centre. Multiple baseline analysis was used and parents recorded baseline measurements. Outcomes were defined in relation to reduction in incidents of the targeted behaviour. Treatment consisted of NT techniques, such as externalisation and the identification of unique outcomes. The study found that five of the six families had improved and showed between 88% to 98% improvement.

Several criticisms can be made of this study. Besa suggested that with some families 'events outside of therapy had an effect on outcome” (p323). This meant that it was difficult to separate the true effects of NT from external influences. Similarly, the study used a variety of narrative ‘techniques’ and it was unclear how each of them may have contributed to change. A further criticism of the study is that employed a small sample size, which made it difficult to draw any conclusions from the results.

Study 2 Experiences of NT (St. James-O’Connor, Meakes, Pickering & Schuman, 1997).

This study looked at family perceptions of NT and the meaning they attributed to the therapy. It also sought to establish the parts of NT that the families found helpful or
unhelpful. The sample consisted of eight families who were experiencing difficulties with their children (ages ranged from six to thirteen years old). All families were involved in NT treatment in the family outpatient clinic at the time. The families were interviewed and their interviews were transcribed to elicit themes. Six themes were elicited which were thought to be consistent with NT (e.g. externalising conversations) and NT was experienced as ‘empowering’. The authors noted that all family members reported a reduction in the problem and that this was greater in families who had been involved in treatment for a longer period.

Again this study is subject to some criticism. It employed a small sample size with no control group, which meant that it was difficult to draw any definite conclusions about the relative efficacy of NT. Similarly, the participants were engaged in treatment at the time and so may have been wary about giving negative feedback in case they felt it would effect their future treatment.

Study 3 Attributions of family arguments (Weston, Boxer, & Heatherington, 1997).

This study was a descriptive study, which aimed to examine children’s attributions of family arguments. The sample consisted of of ninety two children between five and twelve years old. The children were recruited mainly via advertisements and were from white middle class families with two parents. Data was collected by asking families to listen to audiotaped family arguments of marital conflict and parent-child conflict. Structured interviews were also conducted to find out the children’s perceptions of family arguments. The results found that children’s perceptions of family conflict supported ‘systemic type attributions’ (p42). The authors concluded that these types of attributions were consistent with social constructivist clinical approaches (e.g. NT) (Etchison & Kleist, 2000).

Several criticisms can be made of this study. The families who participated in the study were non-clinical and formed a largely homogenous group in terms of class and family grouping. This meant that it was difficult to draw any conclusions about the results for the general population. The authors noted that some of the open ended
questions were difficult to answer in the younger children, which meant that there might have been differences in the validity and reliability of some of the accounts. The use of more varied information gathering would have been helpful to elicit accounts (e.g. props).

**Study 4 Transforming narratives (Coulehan, Friedlander & Heatherington, 1998).**

This study was based on the narrative approach by Sluzki that an individual’s construction of the problem moves from an individual level to a more systemic level (1992; cited in Coulehan et.al., 1998). The study aimed to study the transformation process in eight families. The sample consisted of eight families who requested help for their child and who were deemed appropriate for a transformation. The results were collected by initial interviews and post-session questionnaires combined with an observational coding system. The results found that three of the eight families moved throughout the expected transformation process towards an ‘interpersonal and systemic view’.

The main criticism of this study was the inconsistent use of a reflective team. At the start of the study the decision was to incorporate a reflecting team at times when the staff schedules permitted. The authors found that in most of the ‘successful families’ a reflecting team was also present, which meant that it was difficult to “rule out the possibility that the reflecting team itself was equally or more influential than the behavioural sequences observed” (p31). The inconsistent use of the reflecting team also meant that any replication of the study would have been difficult. A second major criticism of the study was the over-representation of single parent families in the unsuccessful group, which meant that any comparisons between the two groups was difficult.

**4.0 Conclusion.**

This essay has considered the use of NT in work with children and their families. It began by looking at the theoretical rational of NT before considering it’s potential
usefulness in work with this client group. The essay finished with a discussion of research, which has aimed to evaluate its efficacy.

The use of NT with children and their families offers a potentially innovative, creative and collaborative approach to working with children. The benefits of NT appear to be that it places an important emphasis on the child’s ‘voice’ which appears to have a positive effect on therapeutic intervention (Freeman, Epston & Lobovits, 1997). The overall aim of treatment in a narrative framework is not to determine what needs to be corrected or challenged. Instead, intervention takes place in “the world of experience” by helping young people and their families to create “more preferred stories” based on daily experiences (Adams-Westcott & Dobbins, 1997). The child and family are encouraged to draw on their own resources to break free from the problem-saturated story to create a new story based on strength and resistance. The long term expected benefit of this is that client’s will develop more personal agency and become their own ‘experts’ in the future if problems should arise again. In terms of the current constraints on resources in the NHS this would potentially appear to be useful.

Kelley (1998) discussed the introduction of NT into the managed care system in the United States. Kelley suggested that NT is a therapy that does have broad stages of treatment and as such can be successfully integrated into mainstream clinical work. The suggestion in White and Epston’s (1990) re-authoring approach is that “some activities are more appropriate at earlier or later stages of treatment” (p116). Monk, Winslade, Crocket and Epston (1997) suggest that NT is goal directed. The primary goal is to develop an alliance with the person that “encourages and promotes abilities to enhance relationships with one’s self and with others” (p61). The idea that NT is goal directed suggests that it could be translated into treatment goals and care plans in the NHS (Kelley, 1998). Finally, a further benefit of NT is its brevity. The majority of NT is carried out over a few sessions. As time progresses, the number of sessions is usually spread out in order to give the family the opportunity to try out new ideas. Narrative letters and tapes have also been found to offer useful and effective treatment between therapy sessions (Nylund & Thomas, 1994).
Despite the apparent benefits of NT, there has been limited support for its effectiveness in work with children and their families. The existing efficacy studies have emphasised a range of NT techniques and approaches, sample sizes have been small and there has been an inconsistent use of non-clinical and clinical samples. It would appear that more rigorous controlled studies are needed in the future to evaluate these claims (Etchison & Kleist, 2000). One reason for the current difficulty may be that social constructivist approaches (NT) are 'inconsistent with traditional quantitative empirical research methods' which form the basis of controlled outcome studies (Gale, 1993:). As such, therapists who work in NT are more likely to emphasise qualitative research which considers meaning instead of 'objective' measures (Gale, 1993). If NT is more suited to qualitative research then it may well be that a subtle shift is needed in terms of how we perceive the role of qualitative research and also the basis on which we evaluate the effectiveness of clinical practices.
References.


CLINICAL DOSSIER

OVERVIEW

This Clinical Dossier contains summaries of the range of clinical experience obtained during the three years of training. It also contains summaries of the five clinical case reports. The case reports are submitted in full in Volume II.

Note, all identifiers in this section have been changed to preserve anonymity.
ADULT MENTAL HEALTH PLACEMENT SUMMARY

PLACEMENT DETAILS:

Supervisor(s): David Brock
              Alison Conning

NHS Trust: Surrey Oaklands

Base(s): Wingfield Rehabilitation Service, Redhill, Surrey

Dates: October 1999 – April 2000

SUMMARY OF CLINICAL EXPERIENCE:

This placement provided me with a diverse range of experience in the context of an adult mental health rehabilitation setting and CMHT. This enabled me to work with clients with severe enduring mental health problems in an inpatient/outpatient setting as well as clients with a broad range of mental health problems. Clinical work was primarily within a cognitive-behavioural perspective and comprised assessment for treatment interviews and short-term interventions, psychometric and neuropsychological assessment. Experience was gained in a range of presenting problems including depression, anxiety, OCD, schizophrenia, PTSD, phobic reactions, and cognitive impairment. Experience was gained in the use of the WAIS-III, BAI and BDI.

I observed and co-facilitated a ten week psycho education group for adults with severe and enduring mental health problems.

TEACHING AND PRESENTATIONS:

I presented an outline of the service related research project described below to the psychology department. When the research had been completed I fed back the results and clinical recommendations of the research to members of the rehabilitation team.

MEETINGS, SEMINARS, VISITS AND RESEARCH:

I attended monthly psychology department and adult mental health psychology department meetings. I also attended two case reviews in the rehabilitation service inpatient units. I attended two weekly team meetings for the rehabilitation service.

I visited two of the inpatient settings in the rehabilitation service.

I attended a team workshop for a new Assertive Outreach Service in the context of the rehabilitation service.

The service related research project “An evaluation of a psychoeducation group for adults with Schizophrenia” was devised and data was collected during the latter part of this placement.
ADULT MENTAL HEALTH CASE REPORT SUMMARY

Title: Assessment and treatment of depression in a female client.

Presenting problem:

Mrs Smith was referred to the Community Mental Health Team with depression following the birth of her baby. Mrs Smith had experienced symptoms of depression for fifteen months. She had been referred by her GP.

Assessment procedure:

1. This consisted of two assessment for treatment interviews with Mrs Smith.
2. Two psychometric measures were administered during the assessment: Beck Anxiety Inventory (BAI), Beck Depression Inventory (BDI).

Formulation:

The cognitive theory of depression (Beck, 1976) provided the theoretical framework for the formulation. Mrs Smith’s early experiences (e.g. critical father) influenced the development of dysfunctional beliefs to help her make sense of herself and the world. The unplanned pregnancy and later birth of the baby (the trigger) combined with a house move activated negative beliefs about herself and her view of the world. Mrs Smith’s depression was maintained by negative cognitions and symptoms of depression such as reduced activity levels.

Intervention:

After the formulation had been discussed with Mrs Smith a number of therapy goals were identified (e.g. to increase activity levels). The initial aim of the cognitive-behavioural intervention was to provide relief of depression symptoms with a focus on motivational and behavioural problems. The initial phase of the intervention therefore focused on activity scheduling, discussion of cognitive techniques such as distraction, socialisation to the CBT model of depression and psychoeducation. Following this the intervention focused on the identification and evaluation of negative automatic thoughts in order to modify thinking patterns.

Outcome:

At the end of nine sessions Mrs Smith was discharged from therapy sessions. She had achieved all of the goals identified at the outset and reported that she had regained control over her life. She reported that the symptoms of depression had lifted and this was reflected in her psychometric scores which were within the normal range.
LEARNING DISABILITY PLACEMENT SUMMARY

PLACEMENT DETAILS:

Supervisor(s): Neil Sinclair

NHS Trust: Invicta Trust

Base(s): Crisis Intervention Service, West Malling, West Kent

Dates: April 2000–October 2000

SUMMARY OF CLINICAL EXPERIENCE:

This placement provided me with experience in a crisis intervention service for adults with severe challenging behaviour and in a community learning disability team. Clinical experience was gained working with children and adults with mild, moderate and severe learning disabilities in settings that included special schools, residential accommodation and day services as well as with adults referred to a specialist inpatient service for challenging behaviour. Experience was gained in a behavioural and cognitive behavioural perspective.

Clinical work comprised assessment for treatment interviews, behavioural assessment (Functional Analysis), short-term interventions, psychometric and neuropsychological assessment. Clinical work was undertaken with clients and services on a range of problems including challenging behaviour, anger management, relationship problems, suicidal ideation, self-harm, bereavement and loss. Two neuropsychological assessments were carried out to assess cognitive functioning. Experience was gained in the use of the WAIS-III, BPVS, the Vineland, and Family Relations Test. I also observed and participated in an assessment of parenting skills in a family with parents with mild learning disabilities.

TEACHING, PRESENTATIONS AND ORGANISATIONAL WORK.

I designed and co-facilitated two workshops for a group of fifteen staff in a residential setting. The first full day workshop was for working with clients with challenging behaviour. The second half day workshop was for working with anger management difficulties. Both workshops consisted of a mixture of lectures, brainstorming sessions, discussion and small group work.

I provided ongoing supervision and support for staff in one of the two inpatient services, e.g., completing ABC charts, monitoring their implementation and providing additional support when required.

I worked with two other members of the service to redesign the existing risk assessment form. The revised risk assessment form was distributed to members of staff and piloted.
MEETINGS, SEMINARS, AND VISITS

I attended weekly team meetings at the Crisis Intervention Service. The meetings included clinical reviews of the clients in the service and I provided regular feedback with regards to the clients I was working with. I also attended five multi-disciplinary team meetings at the community team.

I visited two NHS day services. I also visited a special day school and a residential setting for adults with learning disabilities.
LEARNING DISABILITY CASE REPORT SUMMARY

Title: A Functional Assessment of a female client with challenging behaviour.

Presenting problem:

Ms. Smith was admitted to an inpatient unit for adults with challenging behaviour. All clients who were admitted to the unit were referred to psychology for an assessment of their behaviour and guidelines for appropriate psychological intervention and management.

Assessment procedure:

A Functional Assessment was carried out to determine why the behaviour was occurring and why it was reoccurring. Information was gathered from the following:

1. I met with Ms. Smith’s key worker and named nurse at the unit to obtain information about her personal history, a description of the problems and her current daytime activities. Time was also spent looking through historical records and reports obtained prior to Ms. Smith’s admission.
2. The Functional Assessment Interview (FAI) was administered which identified variables (e.g. activities, events and situations) through observation.
3. Motivation Assessment Scale (MAS) was administered to Ms. Smith’s key worker and named nurse for each of the target behaviours.
4. ABC charts were completed over a four week period.
5. The Vineland Test of Adaptive Functioning was administered to Ms. Smith's key worker.
6. Informal observations were made of Ms. Smith in the unit and Momentary Time Sampling Observations were made to record her engagement in activities and interaction with others.

Formulation:

Ms. Smith had a history of long term institutional care, combined with frequent moves between services, different carers and varied professionals groups. When Ms. Smith was young she encountered a number of difficult experiences (e.g. emotional neglect, physical abuse) which made it unlikely that her physical and psychological needs were being adequately met. Over time, it seemed likely that the patterns of behaviour developed where Ms. Smith’s needs were not being met and she was both isolated and rejected. Once in institutional care it appeared that Ms. Smith continued to be socially and emotionally isolated. Her needs were more likely to be met following incidents of challenging behaviour and the pattern of behaviour was maintained.

Intervention:

The outcome of the Functional Assessment was an intervention plan which incorporated the information obtained from the methods used in the assessment. The
intervention followed the organisational model proposed by La Vigna and Willis (1995). The framework of the intervention plan consisted of proactive strategies (e.g. staff training and activity scheduling) and reactive strategies (e.g. to refocus Ms. Smith during incidents of challenging behaviour).

**Outcome:**

The intervention plan was presented to the team in a draft format at the end of the placement. The intervention plan was implemented and monitored by the Clinical Psychologist in the unit.
CHILD AND FAMILY PLACEMENT SUMMARY

PLACEMENT DETAILS:

Supervisor(s): Penny Bebbington
Shona Lowes

NHS Trust: Surrey Oaklands

Base(s): Child Psychology Service, Epsom, Surrey

Dates: October 2000 –March 2001

SUMMARY OF CLINICAL EXPERIENCE:

This placement was based in a Child Psychology service for children below the age of five and their families. Other experience was gained from taking referrals from a child and adolescent community mental health team. Clinical work comprised assessment for treatment interviews and short-term interventions. Neuropsychological assessment enabled me to expand my knowledge and skills in the assessment of cognitive impairment in younger children and the assessment of problems such as Autism. Experience was gained working with children and their families using cognitive-behavioural, behavioural, developmental and systemic approaches. I worked with children and their families with a range of presenting problems including: obesity, divorce, anxiety, behaviour difficulties, sleep problems, enuresis, ADHD, relationship difficulties and school refusal. During the placement I learnt to adapt my work in way that was sensitive to the needs and understanding of the child. Experience was gained in the use of the WISC-III, WPPSI, Spence Children’s Anxiety Scale, BDI, and the Leyton Obsessional Compulsive Inventory.

TEACHING AND PRESENTATIONS:

I co-designed a six hour parenting course with two Health Visitors for the management of difficult behaviour in toddlers. The group was not run during this placement due to funding restrictions. I also made a short presentation to the psychology department on the use of a psychodynamic approach to sleep problems. I co-presented with another Clinical Psychologist to a group of children at a sixth form college about the role of a Clinical Psychologist.

MEETINGS, SEMINARS AND VISITS:

I attended monthly meetings for the child psychology department. I attended several multi-disciplinary meetings for a child development team. I visited an adolescent acute inpatient service, a pre-school nursery, two primary schools and a Health Visitors’ toddler and baby clinic.
CHILD AND FAMILY CASE REPORT SUMMARY

Title: A cognitive behavioural child and family approach to school based anxiety and school refusal.

Presenting problem:

Paul was referred to the Child and Adolescent Community Health Team by his GP. The referral stated that he was being verbally bullied at school and was subsequently experiencing anxiety about going to school.

Assessment procedure:

1. The initial assessment consisted of one assessment for treatment interview with Paul and his family.

2. Two psychometric measures were administered as part of the assessment. These included the Spence Children’s Anxiety Scale (SCAS) and the Birleson Depression Scale.

3. Consultation with the Special Educational Needs Co-coordinator (SENCO) was made to inform the school of my input and to obtain further information about Paul’s attendance at the school.

Formulation:

The cognitive theory of emotional disorders provided a basis for the formulation of Paul’s school based anxiety (Beck, Emery & Greenberg, 1985). An early experience (exposure to his older brother’s bullying) was instrumental in the development of threat related schemas about the world. The critical incident for the activation of these schemas was Paul’s movement to the larger environment of his secondary school and the repeated verbally bullying and teasing encountered at school. This led to the production of negative automatic thoughts, anxiety symptoms, behavioural avoidance of school and increasingly threat biased cognitions. These were perpetuated in a circular link between threat related cognitions and anxiety symptoms.

Intervention:

Intervention was based on a structured CBT treatment for childhood anxiety disorders (Kendall, Kane, Howard, & Siqueland, 1990). It was divided into three phases:

1. Learning about anxiety and learning new skills. This included education about anxiety and its management, development of problem solving skills, coping strategies and monitoring thoughts, feelings and behaviour.

2. Applying the skills. This stage involved a continuation of the above elements with an increased focus on the development of problem solving skills in order to identify and challenge unrealistic thinking.
3. Review of progress and relapse prevention. This stage involved a discussion of the techniques and skills learnt in the context of the previous sessions.

Parental involvement was present throughout the sessions in order to promote a more active and collaborative problem solving approach within the family.

Outcome:

Paul’s scores on the two psychometric measures had fallen below the cut off scores for childhood anxiety and depression. Paul and his family reported improvements in Paul’s anxiety levels and an increase in the ability to cope with different situations. Feedback from the school revealed that Paul’s levels of absence had dropped from 21% (before treatment) to 13% (after treatment).
OLDER ADULT PLACEMENT SUMMARY

PLACEMENT DETAILS:

Supervisor(s): Clare Crellin

NHS Trust: Mid Sussex NHS Trust.

Base(s): Linwood Community Mental Health Team, Haywards Heath, Sussex.

Dates: April 2001 – September 2001

SUMMARY OF CLINICAL EXPERIENCE:

This placement provided me with a broad range of experience in a community service for older people with mental health problems. My base was in a community team, although client referrals came from a variety of sources, namely a day service based at the Princess Royal Hospital and an EMI inpatient setting. This enabled me to work with several clients on an individual and organisational level. I also enjoyed the opportunity to consider lifespan issues. Experience was gained working with a range of problems including loss and bereavement, anxiety related to falling, depression, memory difficulties, dementia, and physical health problems, alcohol abuse, and agoraphobia. Experience was gained working predominantly in psychodynamic perspective. A range of assessment procedures was used including HADS, MEAMS, Verbal Fluency test, Trail making, WAIS-III, WMS-III, and word recognition tests.

TEACHING AND PRESENTATIONS:

A 1 day teaching workshop was jointly planned and co-facilitated with another trainee Clinical Psychologist and a Clinical Psychologist. The workshop was about the management of difficult and challenging behaviours in the elderly for a group of twelve homecare workers and residential nursing staff. The workshop consisted of group exercises and discussion, brainstorming and the discussion of these issues was highlighted with case examples raised by the group participants.

Three 1 ¼ teaching sessions were jointly planned and co-facilitated with another trainee Clinical Psychologist for fifteen staff from an inpatient psychiatric ward at the Princess Royal Hospital. The workshop was about the management of loss and grief on the ward. The participants consisted of the ward manager, nursing staff and occupational therapists. The main emphasis was on the grief process in the elderly. The sessions consisted of teaching and various group discussions.

I made a short presentation at a monthly EMI multidisciplinary team meeting with another trainee Clinical Psychologist. The presentation outlined the role of the trainee and the stages undertaken to reach clinical training. One aim of the presentation was to promote the role of the Trainee Clinical Psychologist within the older adult multidisciplinary team.
I observed an educational session run by my placement supervisor. The session was attended by older adult female carers and looked at stress and coping strategies in the caring role.

MEETINGS, SEMINARS AND VISITS:

I attended four multi-disciplinary EMI monthly clinical reviews. I attended three monthly psychology department meetings for psychologists from a range of settings and disciplines within the trust. I attended two meetings with the Ward Manager of the EMI inpatient ward to discuss the ward and the presenting needs of the patients. These meetings facilitated the development of the loss and grief workshop for staff on the ward. I visited an older adult’s psychiatric day unit, a residential home and an inpatient EMI ward.

I attended a one day training event on Clinical Governance for medial staff in the Trust. The workshop included teaching and group exercises.
OLDER ADULT CASE REPORT SUMMARY

Title: The Neuropsychological Assessment of an 86 year old man with suspected cognitive decline.

Presenting problem:

Mr Jones was referred to the psychology department for older adults following concerns that he was in the early stages of a dementing illness indicated by short term memory problems and word finding difficulties. He was referred by a CPN for older adults.

Assessment procedure:

It was decided that a neuropsychological assessment would be appropriate to determine the presence or absence of cognitive decline. The assessment consisted of the following:

1. An assessment interview with Mr Jones and his daughter in order to obtain detailed information about his personal and family history, his current status, a description of the problems encountered and the impact of the problems on his life.
2. NART-2.
3. WAIS-III.
4. WMS-III.
5. Graded Naming Test.
6. Trail Making Test.
7. Verbal Fluency.
8. The Hospital Anxiety and Depression Scale (HADS).

Formulation:

The neuropsychological profile for Mr Jones did not suggest that he was in the early stages of a dementing illness at the time of assessment. His overall cognitive functioning was in the superior range and his scores on the memory test all suggested average (and above average) functioning when compared with a reference group. His scores on the tests of executive functioning and language tests did not indicate any cognitive impairment. He was also well orientated in time, person and place. There was some variation in the verbal index scores and performance index scores on the WAIS-III. At the time of assessment these differences could be accounted for by poor concentration and distractibility combined with Mr Jones arthritis which may have affected his response speed. Although Mr Jones’s scores on the HADS did not suggest clinically significant scores for anxiety and depression Mr Jones himself admitted that he had found it difficult to cope with the loss of his wife and the persistent loneliness experienced without her.
**Intervention:**

The results of the assessment were shared with Mr Jones which provided important reassurance to both Mr Jones and his daughter. A short period of psychological counselling was discussed with Mr Jones regarding the issues relating to the loss of his life. The opportunity for retesting in a year's time was also discussed with Mr Jones.

**Outcome:**

A report was prepared and then discussed with the CPN referrer which outlined the results of the assessment and the above recommendations. Mr Jones's case was handed onto another Clinical Psychologist for future contact for referrals and assessment.
NARRATIVE THERAPY SPECIALIST PLACEMENT SUMMARY

PLACEMENT DETAILS:

Supervisor(s): Margaret Henning

NHS Trust: Sussex Weald and Downs NHS Trust

Base(s): Horsham Psychology Department, Horsham Hospital, Sussex.

Dates: October 2001 – April 2002

SUMMARY OF CLINICAL EXPERIENCE:

This placement provided me with a good range of experience working with adults using a Post-Milan systemic narrative approach. My base was in a psychology department and clients were either primary care referrals or from the Horsham based CMHT. I worked with clients with a broad range of mental health problems and had good experience in the development of therapeutic knowledge and skills in assessment, formulation and intervention using this approach. I gained experience of direct work with clients in a range of presenting problems including adjustment to physical health problems, depression, sexual trauma, low self esteem, alcohol abuse, anxiety, PTSD and relationships difficulties. I also worked as a member of the observing team for a family consultation service with problems including anxiety, ADHD, behaviour difficulties and marital breakdown.

I prepared and co-facilitated a group for eight females with an eating disorder (anorexia, bulimia, obesity). The group was run with a Clinical Psychologist and a Counselling Psychologist and drew on principles of narrative therapy techniques (e.g. externalisation, production of unique outcomes etc.). The group consisted of a mixture of discussion work, small group work, brainstorming and formal teaching.

TEACHING AND PRESENTATIONS:

I attended and provided ongoing input in a multidisciplinary narrative therapy supervision group which was run on a fortnightly basis. The group operated on the basis whereby one member of the group would present details of a difficult case and the other members of the team would provide input about possible ways of working with the client. I also presented details of my narrative case report (assessment, formulation, intervention and outcome) to the narrative therapy supervision group at the end of my placement.

MEETINGS, SEMINARS, VISITS AND RESEARCH:

I attended fortnightly meetings in the psychology department to discuss referrals, review cases and other business issues. Meetings were attended by psychologists from a range of adult mental health settings in the Horsham and Crawley area. I attended one multidisciplinary meeting at the Horsham CMHT. I visited the Horsham...
and Crawley CMHT's and also spent a day with the Horsham Assertive Outreach Team.
SPECIALIST NARRATIVE THERAPY CASE REPORT SUMMARY

Title: Narrative Therapy with a 26 year old man presenting with adjustment difficulties to a degenerative eye disease.

Presenting problem:

Mr Slater was referred to the psychology service for adults by his GP following a diagnosis of rod-cone dystrophy (a degenerative eye disease resulting in central retinal damage). The GP stated that Mr Slater was finding the diagnosis difficult to come to terms with and this was leading to psychological distress.

Assessment procedure:

The assessment consisted of one session with Mr Slater in which details of the history and development of the problem was obtained, his family history, educational background, current circumstances and previous contact with mental health services was established.

The Clinical Outcomes ion Routine Evaluation (CORE) was administered and Mr Slater had been asked to return a departmental assessment questionnaire.

Formulation:

Formulation was provided by a narrative framework in which psychological problems are seen as being shaped by and maintained by dominant problem saturated narratives. The assessment suggested that Mr Slater’s dominant problem narrative was that his disability was an indication of difference and incompleteness. A second problem narrative appeared to be that he was unable to lose control as this implied weakness. It was likely that Mr Slater was recruited into these attitudes and beliefs from a familial and wider societal context. He was brought up in a family and school environment which discouraged the expression of strong emotion and encouraged a strong ‘male culture’. The school environment also discouraged the presence of ‘difference’. On a wider societal level, Mr Slater may have been recruited into the dominant cultural beliefs that disability marks an individual as ‘inferior’. Despite the full range of lived experience in Mr Slater’s life, the dominance of the problem-saturated narratives meant that any alternative stories of strength and resistance had been marginalised and largely ignored. This had led to the maintenance of the problem narratives in Mr Slater’s life.

Intervention:

Intervention was based on a Post-Milan Systemic Narrative Therapy approach. Externalising conversations were used to separate Mr Slater from the problem and to encourage him in the development of more collaborative relationship with the eyesight problem so that it no longer ‘dictated’ his life. Externalising conversations were used to map the influence of the problem on Mr Slater’s life and then to map his
influence over the problem. Unique outcomes were elicited where Mr Slater provided examples of his influence over the problems. The reauthoring of an alternative story was made with Mr Slater based on a different story to the problem narratives.

**Outcome:**

Mr Slater was discharged at the end of the sixth session when he was self-generating examples of his alternative narrative. His therapy outcome score on the CORE was a significant reduction from his pre-therapy score and placed him well below the range for a clinical population. Mr Slater reported that he had regained his identity and a sense of control over his life. He felt more able to accept the disability and felt more realistic about his abilities and capabilities. He no longer experienced anger towards the loss of his sight and felt more able to ask for help if he needed it.
Paediatric Psychology Specialist Placement Summary

PLACEMENT DETAILS:

Supervisor(s): Sarah Waugh

NHS Trust: South West London and St. Georges NHS Trust

Base(s): Paediatric Psychology Department, St Georges Hospital.

Dates: April 2002– September 2002

Please note, the information below is a summary of the placement so far.

SUMMARY OF CLINICAL EXPERIENCE:

This placement has provided a good introduction to work with a paediatric client group in the organisational context of a large hospital. This enabled me to develop my understanding of systemic issues raised by working with patients, families, medical staff and other professionals. I also developed skills in providing brief psychological interventions in ward settings with children, families and staff. Direct and indirect work with children was mainly from a cognitive-behavioural and behavioural perspective and formulation was informed by systemic issues. The caseload of clients came from the hospital and community setting. The range of presenting problems included: encopresis, feeding problems, obesity, bullying in relation to cleft lip palate, psychosomatic problems, sleep problems, adjustment to burns incurred by accident, behavioural problems and adjustment to bone marrow transplant. A follow up neuropsychological assessment of a boy with HIV was carried out to determine whether any changes had occurred in his cognitive profile.

MEETINGS, SEMINARS, VISITS AND RESEARCH:

I attended weekly psychology departmental meetings with the paediatric psychology department. The meetings included business issues, peer supervision and the presentation of papers. I attended three weekly psychosocial meetings for two paediatric wards. I also attended two monthly psychosocial meetings for the children and family with HIV and AIDS team.

I have met and observed the work of a number of staff working in a paediatric setting at St Georges, e.g. a Community Nurse working with children and families with HIV and AIDS, a Community Nurse working with children and their families with leukaemia, Play Specialists conducting diversion techniques for children about to undergo medical procedures.

Information was collected from a variety of sources in order to review the current psychology service provision for children with bone marrow transplants. This included a review of psychological research into the effects of bone marrow transplant on children and families, meetings with a Community Nurse working with children
with leukaemia and a Consultant specialising in bone marrow transplants. I also visited Great Ormond Street and the Royal Marsden to meet the psychologist and medical staff on the child bone marrow transplant team.
OVERVIEW

This Research Dossier contains a service related research project completed in Year 1, the major research project completed in Year 3, and a literature review completed in Year 2.
Service Related Research Proposal

An evaluation of a CBT psycho-education group for adults with Schizophrenia

Year 1
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ACKNOWLEDGEMENTS

My thanks goes to all of the members of the rehabilitation team who were involved in the organisation and running of the group.

The clients who attended the group and made it possible!

Finally, my research tutor, who gave me considerable assistance in putting it all together.
ABSTRACT

Objectives: To evaluate the effectiveness of a cognitive-behavioural (CBT) psycho-education group for adults with Schizophrenia. To determine if the ten week group is effective in increasing knowledge and awareness of Schizophrenia, reducing symptom impact and the distress which arises from the experience of psychotic symptoms, and enhances useful coping strategies. The group will be run as a pilot and so an additional aim is to identify any development needs for the group structure and it's suitability for continued use. Design: Six clients with a primary diagnosis of Schizophrenia were invited to the group. Pre, post and follow up assessments were collected. Setting: Community-rehabilitation centre. Participants: 6 clients with a primary diagnosis of Schizophrenia who fulfilled certain inclusion criteria. Outcome measures: The Cope Scale, Knowledge about Schizophrenia, The KGV, Satisfaction Questionnaire. Results: At the end of the group, a reduction was found in positive symptom scores, negative symptoms, affective symptoms and total symptoms, and a reduction in the use of "maladaptive" coping strategies. There was an increase in knowledge about schizophrenia and in use of "adaptive" coping strategies. At follow up, these scores were maintained. Conclusion: The ten-week group was effective in achieving its aims. It is a potentially useful therapeutic tool for future use within the service for individuals with psychosis.
INTRODUCTION

Over the last ten years, the merits of cognitive behavioural therapy (CBT) have been demonstrated in the treatment of psychosis. These interventions have focused on individual therapy for specific symptoms, whereby CBT techniques such as verbal challenging, belief modification and reality testing are used to identify distorted beliefs surrounding delusions and hallucinations (Chadwick & Lowe, 1994), or enhancing the individuals cognitive and behavioural coping skills, to reduce the distress resulting from psychotic symptoms or to directly impact on the symptom itself (Tarrier, Beckett, Harwood, Baker, Yusupoff & Ugartebru, 1990). Additional interventions have focused on problem solving, (Hansen, Lawrence & Cristoff, 1985); goal setting (Kuipers, Garety & Fowler, 1996) and relabelling and psychoeducation (Kingdon & Turkington, 1991). Most place the individual within a normalising framework whereby the diagnosis is “decatastrophised” to the individual (Turkington & Kingdon, 1996).

The majority of work in this area has focused on therapeutic interventions for the individual or family interventions (Gledhill, Lobban & Sellwood, 1998). Research on clinical effectiveness has tended to reflect this with reports of single case studies, or individual progress in clinical trials (e.g. Tarrier et al, 1990, Tarrier, Yusupoff, Kinney, McCarthy, Gledhill, Haddock & Morris, 1998). Gledhill et al, (1998) argue that the use of a group format to deliver CBT for Schizophrenia may have several benefits:

1. Sharing individual beliefs amongst the group about psychotic symptoms may help enhance self-esteem, reduce stigma and anxiety, particularly if individuals feel that their symptoms (e.g. hallucinations) are unique to them.

2. The use of coping strategies may be generalised and improved if they can be modelled in a group setting by other members. The group setting is likely to encourage social interaction which in turn may facilitate feedback from others to test peoples beliefs about themselves.

3. Some of the negative symptoms of Schizophrenia e.g. motivational difficulties may be reduced if the individual is involved in a group setting.
4. Group intervention enables delivery of therapy to a wider group of individuals, which is an important consideration in the current climate of the NHS.

The study by Gledhill et al reported the beneficial effects of a CBT group format for people with Schizophrenia and found that post intervention, individuals had more self-esteem, had greater knowledge of their illness, felt more able to cope with their symptoms and were less depressed.

A family therapist and clinical psychologist at a rehabilitation unit designed a pilot group for service users with Schizophrenia. The ten week group used techniques adapted from cognitive-behavioural ideas with the main focus on psychoeducation, but also, goal setting, developing and enhancing more useful coping strategies and responses and relabelling of beliefs about psychotic symptoms and experiences. The aim here is to not just “give information which may or may not be accepted” but to facilitate the sharing of experiences and relabel some of the distorted assumptions surrounding psychotic experiences and the stereotypes of mental illness (Kuipers, Garety and Fowler, 1996). The focus throughout the ten-week group was on empowering the clients and placed the setting within a normalising framework.

The group was developed on a pilot basis following a successful group for families and carers living with Schizophrenia. This had proved highly effective when evaluated and following suggestions by the group members, it was felt that the two groups might run conjointly. The current group was adapted for service users from the carers group.

The main aims are to determine if the group is effective in:

1. Increasing knowledge and awareness of mental illness.
2. Reducing symptom impact and the distress, which arises from the experience of psychotic symptoms.
3. Enhancing useful coping strategies.
Additional aim:

4. Identify any development needs for the group structure (e.g. content, duration) and determine its suitability for continued use in the rehabilitation centre as a group intervention.

METHOD

Participants

Referrals to the group were invited from other members of the community rehabilitation team over a two to three month period prior to the groups' start. Potential participants were selected by the clinical psychologist, family support worker and psychiatrist with the following inclusion and exclusion criteria.

Inclusion:

- Participants needed to be in the rehabilitation service.
- Have a primary diagnosis of schizophrenia.
- Persistent difficulties with symptoms (positive/and or negative symptoms).
- Stable on medication.
- Can participate in a group setting.

Exclusion:

- Very unstable on medication.
- Difficulty participating in a group setting.
- Florid symptoms of psychosis.

Six participants were selected for the group and all of the individuals accepted (this included two females and four males). All individuals had family members who had attended a recent psycho-education group for carers and were continuing to
experience difficulties regarding their diagnosis (although this was not necessarily an inclusion criteria). (See Table 1, for more descriptive information regarding the six participants).

**Measures and Procedures**

The following measures were collected at base line, post-group and at a three month follow up period:

1. **KGV (M) Symptom Scale (Lancashire, 1994) (appendix 2)** – a global measure of psychotic symptoms (anxiety, depression, delusions, hallucinations, enhanced mood etc.). It contains a mixture of structured questioning and observations by the rater, which are scored with the individual. (This is a modified version of the Psychiatric Assessment Scales (PAS) (Krawiecka, Goldberg & Vaughan, 1977).

2. **Knowledge Scale (Smith & Birchwood, 1987) (appendix 3) – a multiple-choice questionnaire which assesses the clients’ knowledge and understanding of schizophrenia (symptoms, medication, prognosis etc).**

3. **The Cope Scale (Carver, Weintraub and Scheier,1989) (appendix 4).** This is a multi dimensional coping inventory, which looks at the different ways that individuals respond to stress. It incorporates fifteen types of coping, which are broadly grouped into helpful (adaptive) and less helpful (maladaptive) coping responses which may ‘impede’ adaptive coping. Carver et al argue that a method of coping may become “dysfunctional” if it is used for a relatively long period of time and if other methods may be more appropriate.

A satisfaction questionnaire (Gledhill, Lobban & Sellwood, 1998) (appendix 1) was given to individuals at the end of the final session (session 10).
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Table 1. Descriptive information for the six participants.
Content of sessions

The group involved ten sessions, which were held weekly. Each session lasted for one hour. The group was run by a family support worker, a clinical psychologist and a clinical psychologist in training (See Table 2 for outline of the weekly sessions).

Table 2. Outline of the ten sessions in the group

| Session 1 | Introduction to group, ground rules, goals, and concerns. |
| Session 2 | Experiences of mental health, effect on relationships, interaction with services. |
| Session 3 | Stress and vulnerability, triggers of emotional distress and relapse. |
| Session 4 | Diagnosis by professionals, symptoms, experience of treatment and causes of mental health problems. |
| Session 5 | Medication and psychological interventions, complimentary therapies. |
| Session 6 | Experience of positive and negative symptoms, coping strategies and coping strategy enhancement. Motivation difficulties and reducing the chance of distressing experiences returning. |
| Session 7 | Voices and belief formation. Personal loss and it’s effect on recovery. |
| Session 8 | Avoiding crisis, early warning signs for relapse and relapse prevention. |
| Session 9 | Benefits, legal situation and CPA. |
| Session 10 | Ending. Hopes and expectations for the future. Return to goals. |

Results

Attendance for the psycho-education group was good for the ten sessions. Two participants (1 and 2) missed three of the ten sessions, one participant (6) missed two of the sessions and the other three participants did not miss any sessions.

The small sample size of six meant that a statistical analysis was not possible. However descriptive data for each of the measures are reported below.

Please note that at the follow up phase it was only possible to obtain data from three of the six participants (2, 4 & 5). This was due to a deterioration in one of the client’s mental states and a subsequent withdrawal of engagement from the service. The other two clients chose not to participate in the follow up stage.
This showed a small overall decrease in positive symptom scores, negative symptoms, affective symptoms and total symptoms score at the post-group phase (See Table 3 below). Data for the three clients’ in the follow up stage revealed a further overall decrease in total symptom score, negative symptoms and affective symptoms.

Table 3. Mean scores for positive and negative symptoms, affective symptoms and total symptom scores.

<table>
<thead>
<tr>
<th></th>
<th>Positive symptom score</th>
<th>Negative symptom score</th>
<th>Affective symptom score</th>
<th>Total symptom score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre group mean</td>
<td>1.3</td>
<td>2.7</td>
<td>3.2</td>
<td>7.7</td>
</tr>
<tr>
<td>Post group mean</td>
<td>1</td>
<td>2</td>
<td>2.7</td>
<td>6.2</td>
</tr>
<tr>
<td>Follow up group mean</td>
<td>1.3</td>
<td>0.6</td>
<td>2.6</td>
<td>4.6</td>
</tr>
</tbody>
</table>

Information on individual total symptom scores can be seen in Appendix 5.

For two participants, (1 and 2) their total symptom score increased at post group, whereas for the other four participants, their total symptom score decreased slightly. At follow up, one participants’ (2) total symptom score decreased further, one stayed the same (4) and one increased slightly (5).

2. Knowledge scale

This revealed an overall increase in scores collected at the end of the group sessions and a further increase at follow up. (See Table 4 below)
Table 4. Mean scores for Knowledge Scale

<table>
<thead>
<tr>
<th>Pre group mean</th>
<th>Post group mean</th>
<th>Follow up mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.7</td>
<td>15.3</td>
<td>17</td>
</tr>
</tbody>
</table>

Information on individual scores can be seen in Appendix 5.

For one participant (1) the score at the post group stage was the same as the score at the pre group stage. For another of the participants’ (6) the score at the post group stage was considerably lower (by ten points) than the score at the pre group stage. This member of the group reported feeling unwell at the time of the post group assessment, which may have impacted on his performance. For the other four participants, their scores all increased from between 2 – 11 points.

At follow up, two clients’ (4 & 2) retained their scores from post group and the third client showed a slight decrease but this still remained considerably higher than the baseline score.

3. The Cope Scale

Overall, this showed a slight increase in total scores at the end of the group for the eight coping strategies, which have been categorised as more useful or “adaptive”. Whereas, scores for the other five areas of coping which have been categorised as “less useful” are marginally lower at the post-group stage compared to the pre-group stage. (See Table 5 below).

At the follow up stage, there is a further increase in total scores for the eight coping strategies, which have been categorised, as “adaptive”. Total scores for the less useful coping strategies remain stable. Individual scores for the six participants can be seen in Appendix 5.

For three participants (3,4,6) there was an increase in their total mean scores at the end of the group for the coping strategies which have been categorised as “adaptive”. For
one participant (2) their score remained the same at post-group stage as their score at the pre-group stage. For the two remaining participants (1, 5) their total scores for “adaptive” coping strategies have decreased from pre to post group.

For five out of the six participants (1,2,3,4,6), there was an overall decrease in mean scores for “maladaptive” coping strategies, at post group stage. For the remaining participant, their score increased from pre to post group.

At follow up, for all three participants (2,4, & 5) there was an increase in their total mean scores for the “adaptive” coping strategies. For two of the three participants (4 & 5) their scores on coping strategies categorise as “maladaptive” were stable or decreased slightly. For the other participant (2) their use of “maladaptive” coping strategies increased slightly.

Table 5. Mean scores for Cope Scale

<table>
<thead>
<tr>
<th>Adaptive coping strategies</th>
<th>Pre mean</th>
<th>Post group mean</th>
<th>Follow up group mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive reinterpretation and growth</td>
<td>9.5</td>
<td>10.8</td>
<td>13.3</td>
</tr>
<tr>
<td>Active coping</td>
<td>9.3</td>
<td>10.0</td>
<td>13.6</td>
</tr>
<tr>
<td>Planning</td>
<td>8.1</td>
<td>10.3</td>
<td>12</td>
</tr>
<tr>
<td>Seeking instrumental social support</td>
<td>9.3</td>
<td>9.8</td>
<td>11</td>
</tr>
<tr>
<td>Seeking emotional support</td>
<td>7.2</td>
<td>9.3</td>
<td>11.3</td>
</tr>
<tr>
<td>Suppression of competing activities</td>
<td>8</td>
<td>9.8</td>
<td>10.3</td>
</tr>
<tr>
<td>Religion</td>
<td>5.3</td>
<td>5.8</td>
<td>8</td>
</tr>
<tr>
<td>Restraint coping</td>
<td>9.5</td>
<td>10.5</td>
<td>14.3</td>
</tr>
<tr>
<td>Total</td>
<td>8.3</td>
<td>9.5</td>
<td>11.72</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Maladaptive coping strategies</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on and venting of emotions</td>
<td>10.0</td>
<td>9.2</td>
<td>10.3</td>
</tr>
<tr>
<td>Denial</td>
<td>6.8</td>
<td>6.8</td>
<td>7.9</td>
</tr>
<tr>
<td>Mental disengagement</td>
<td>7.3</td>
<td>5.7</td>
<td>4.7</td>
</tr>
<tr>
<td>Behavioural disengagement</td>
<td>6.8</td>
<td>6.2</td>
<td>6.3</td>
</tr>
<tr>
<td>Use of alcohol and drugs</td>
<td>8.0</td>
<td>8.2</td>
<td>11.7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>7.8</strong></td>
<td><strong>7.2</strong></td>
<td><strong>7.1</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Other category</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Acceptance</td>
<td>8.0</td>
<td>7.8</td>
<td>11.7</td>
</tr>
<tr>
<td>Use of humour</td>
<td>7.0</td>
<td>8.3</td>
<td>12.7</td>
</tr>
</tbody>
</table>
4. **Satisfaction Questionnaire**

Four of the six participants found the group enjoyable, felt that they benefited in some way from attending the group and from meeting people who had similar problems to their own. Five of the six participants felt that they would like to be involved in another group like this one in the future and three out of the six felt that they were more able to cope with their problems since attending the group.

The acceptability of the current group format was also supported. Only one of the six participants felt that there were things about the way the group was run that they did not like, all six of the participants felt comfortable about discussing their problems in the presence of others and all six felt that they would not have preferred to have been seen individually by a psychologist. Finally, only one of the six participants felt that they would have preferred to come to this group at a different point in time (see additional comments). For summary of this information see Table 6.

**Table 6. Yes /No responses for Satisfaction Questionnaire**

<table>
<thead>
<tr>
<th></th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>I found the group enjoyable.</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>I feel that I benefited in some way.</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>There were some things about the way</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>the group was run that I did not like.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel that I benefited in some way</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>from meeting people who had</td>
<td></td>
<td></td>
</tr>
<tr>
<td>similar problems to my own.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I found it difficult to discuss my</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>problems in the presence of others.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would have preferred to have been</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>seen by a psychologist on my own.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I feel more able to cope with my</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>problems since attending the group.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would like to be involved in another</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>group like this in the future.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I would have preferred to come to this</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>group at a different point in time.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Additional comments:**

- I would have preferred to come to the group when I first went into hospital.
• I enjoyed the friendly atmosphere in which the information was handed out.
• I learned about the medication we take.
• Mostly, very useful and interesting.

DISCUSSION

The results of the study indicate that the group was effective in achieving its’ aims. Namely, increasing knowledge and awareness of mental illness, reducing the impact of symptoms and the distress which arises from it and enhancing useful coping strategies. These were maintained at follow up although it should be noted that there was individual variation in each of the six participants and that in the follow up, only three of the six participants provided data. These results support the findings from previous research on the use of CBT for Schizophrenia, either in a controlled trial setting (Kuipers et al, 1996, Tarrier et al, 1998) or in a group format, (Gledhill et al, 1998).

The group was also perceived by the participants to be acceptable in terms of its’ format and content and all of the participants felt that they preferred a group setting instead of individual therapy, which would support the groups continued use within the service. All participants seemed to benefit from meeting other individuals with similar problems and over the course of the ten weeks, the individuals began to meet informally away from the group setting. This seemed to enhance mutual trust and the ability to share experiences within the sessions and also reinforced the normalising framework of mental illness. A concern about the length of the group was that the ten sessions over ten weeks might be too long and may lead to non-attendance as the weeks progressed. However, these concerns were unfounded, as the attendance rate was good throughout the ten weeks of sessions.

Several criticisms can be made of this study. The Cope Scale (Carver et al, 1989) has previously only been used with a non-psychotic population and it may have been more appropriate to have used a questionnaire, which looks specifically at perceived ability to cope with and control psychotic symptoms and experiences. This could be
collected as a weekly rating within the group, as well as pre and post group (e.g. Gledhill et al., 1998). A measure of empowerment and insight may also have been useful to identify any changes in perceptions of having a mental illness. Finally, the use of a control group was discussed prior to the start of the group, however, it was felt that the participants who would be placed in this group should be given the opportunity to attend the actual group at a later date. Since it was a pilot, this could not necessarily be guaranteed. In the future, a more rigorous trial may be useful with randomised controls.

The evaluation of the pilot group for adults with Schizophrenia has demonstrated that it has achieved its aims, is a potentially useful approach and should continue to be run for clients on a therapeutic basis. Several considerations have been made for the group’s future use within the service. One client suggested that she would have found the group useful at an earlier date, when she first went into hospital. One possibility would be to offer the group to individuals who have been more recently diagnosed. A second consideration is that the group could be developed into a package with comprehensive guidelines, to be used by other professionals in the trust. Additional considerations are to integrate some sessions for carers with sessions for clients’, to enhance shared understanding of the illness and its’ impact on both groups of people. Also, to enable individuals who have finished the ten week group to attend ‘top up’ sessions in the next group offered.

The aim is to run the group two to three times a year, which has the advantage of being more cost-effective than individual therapy. One disadvantage of the group approach is that it is not possible to have “individual formulation and intervention”, (Gledhill et al 1998), which may arguably lead to a more detailed understanding of individual symptoms and symptom impact. A point of note here is that all of the six participants stated that they preferred a group format to individual therapy and seemed to benefit from sharing experiences. Consideration of an individual’s suitability for group therapy should take into account the individual needs and requirements and should be offered as an alternative and not the only option.
Since the time of the study, the group is now being run for the second time. The results of this research were presented to members of the rehabilitation service.
REFERENCES


Appendices

Appendix 1    Satisfaction Questionnaire    p156
Appendix 2    Knowledge about Schizophrenia Scale    p159
Appendix 3    KGV Questionnaire    p166
Appendix 4    Cope Questionnaire    p181
Appendix 5    Participant data for KGV, Cope and Knowledge scores    p186
Appendix 6    Letter from team regarding feedback of results    p189
Appendix 1

Satisfaction questionnaire.
SATISFACTION QUESTIONNAIRE

Thank you for attending the education group here at

It would be most helpful if we could have some feedback on how you found it. Please complete the following questions by circling the appropriate answer. Please feel free to add any additional comments.

1. I found the group enjoyable. Yes No

2. I feel that I benefited in some way by attending the group. Yes No

2b. If you have answered yes, what did you find helpful? Yes No

3. There were some things about the way the group was run that I did not like. Yes No

3b. If you have answered yes, what did you not like about the group?

4. I feel that I benefited from meeting people who had similar problems to my own. Yes No

5. I found it difficult to discuss my problems in the presence of others. Yes No

6. I would prefer to have been seen by a psychologist on my own. Yes No

7. I feel more able to cope with my problems since attending the group. Yes No

8. I would like to be involved in another group like this in the future. Yes No
9. I would have preferred to have come to this group at a different point in time.  
   Yes No

9b. If you have answered yes, when do you think that it would have been useful to have come to this group or received this information?

10. If we were to run this group in the future, what could we change about it?  
    Yes No

11. Please make any additional comments.  
    Yes No

Thank you for completing this questionnaire.
Appendix 2

Knowledge about Schizophrenia Questionnaire
Put a tick in the appropriate box:

1. Who can become schizophrenic?
   (1) Anyone
   (2) Men Only
   (3) People with personality disorders
   (4) Criminals
   (5) Don’t Know

2. The usual age when the illness first attacks is:
   (1) Anytime
   (2) Middle age
   (3) In early twenties
   (4) Childhood
   (5) Don’t Know

3. The chance of developing schizophrenia is:
   (1) 1 in 1000
   (2) 1 in 500
   (3) 1 in 100
   (4) 1 in 200
   (5) Don’t Know

4. If one parent has schizophrenia the chances of their child also having schizophrenia is:
   (1) The same as anyone else
   (2) Higher than anyone else
   (3) Lower than anyone else
   (4) A 99% possibility that the child will also have schizophrenia
   (5) Don’t Know

5. An attack of schizophrenia may be triggered by:
   (1) A knock on the head
   (2) Difficulties at birth
   (3) Physical illness
   (4) Stress
   (5) Don’t Know
6. Which of the following is most common in schizophrenia?

(1) [ ] To have just one attack and recover completely
(2) [ ] To have several attacks but with periods when you feel better in-between
(3) [ ] To be permanently ill with no periods of recovery whatever
(4) [ ] To have one attack but not completely recover to what you were before
(5) [ ] Don't know

7. Which of the following do you believe are common symptoms of schizophrenia? (there is more than one answer)

(1) [ ] Hearing voices
(2) [ ] Lack of energy
(3) [ ] Incontinence
(4) [ ] Delusions
(5) [ ] Headaches
(6) [ ] Irritability
(7) [ ] Loss of appetite
(8) [ ] Lack of affection
(9) [ ] Sleep problems
(10) [ ] Overactivity
(11) [ ] Withdrawal
(12) [ ] Don't know

8. Which of the following are negative symptoms of schizophrenia? (there is more than one answer)

(1) [ ] Hearing voices
(2) [ ] Withdrawal
(3) [ ] Lack of affection
(4) [ ] Lack of energy
(5) [ ] Thought Disorder
(6) [ ] Delusions
(7) [ ] Irritability
(8) [ ] Don't know
9. A positive symptom of schizophrenia?

(1) [ ] A symptom that is definitely due to schizophrenia and not due to anything else
(2) [ ] A symptom that is used to diagnose schizophrenia
(3) [ ] When something is added to a person's normal behaviour
(4) [ ] When there is a loss from the person's normal behaviour
(5) [ ] Don't Know

10. When schizophrenic symptoms reappear and get much worse this is called:

(1) [ ] Relapse
(2) [ ] Omission
(3) [ ] Remission
(4) [ ] Prolapse
(5) [ ] Don't Know

11. When a person with schizophrenia is admitted to hospital under 'section' this means:

(1) [ ] Voluntary admission
(2) [ ] Compulsory admission
(3) [ ] Admission with the patient's consent
(4) [ ] Admission by the police
(5) [ ] Don't Know

12. The average length of stay in hospital for a first attack of schizophrenia is:

(1) [ ] 3 - 6 weeks
(2) [ ] 6 months
(3) [ ] 12 weeks
(4) [ ] One year
(5) [ ] Don't Know

13. Medication can help reduce (remove symptoms) in what % of patients?

(1) [ ] 25% (quarter)
(2) [ ] 75% (three quarters)
(3) [ ] 50% (half)
(4) [ ] 100% (all)
(5) [ ] Don't Know
4. The main medications given to remove schizophrenic symptoms are:

(1) Antihistamines
(2) Narcotics
(3) Neuroleptics
(4) Tranquillisers
(5) Don't Know

5. If a person with schizophrenia is taking his medication the risk of getting a second attack of schizophrenia within one year is reduced from 75% to:

(1) 70%
(2) 50%
(3) 10%
(4) 30%
(5) Don't Know

6. Rehabilitation is the word for:

(1) Giving medication
(2) Helping the person to settle back to a normal life out of hospital
(3) Helping the person to find accommodation
(4) Hospital treatment
(5) Don't Know

7. Medication is more effective with:

(1) Positive symptoms
(2) Negative symptoms only
(3) All symptoms equally
(4) Mainly the negative symptoms
(5) Don't Know
8. Which of the following are often associated with the onset of schizophrenia? (there is more than one answer)

- Too much stress
- Poor diet
- Inability to get angry and express your feelings directly
- Runs in the family
- Biological problems, body chemicals
- Personality 'type' - just the kind of person
- A split in the personality
- Family problems while he/she was a child
- An upsetting experience, loss of an important person e.g. by death, divorce etc.
- Don't know

9. If you notice side effects of the medication you are taking, you should:

- Wait to see if the side effects go away
- Ask the doctors advice
- Come off the medication altogether
- Take a lower dose of the medication than that prescribed by the doctor
- Don't Know

10. What is the best thing to do if you hear voices?

- Listen to them carefully
- Do as the voices say
- Keep active and take your mind off the voices
- Talk back to the voices
- Talk to someone or read out loud
- Don't know

11. What is the best way to help yourself stay well and out of hospital? (there is more than one answer)

- Try to mix with people more
- Try to keep active and do things with your time
- Take things easy, don't do too much
- I will always be ill so there is nothing I can do about it
- Get plenty of rest and sleep
- Take my medication regularly
- Don't know
22. How can you recognise a 'delusion'? (there is more than one answer)

(a) [ ] The beliefs are usually of a certain kind, e.g. that people want to hurt you
(b) [ ] Everybody else disagrees with the belief
(c) [ ] There is no such thing as a delusion
(d) [ ] Other people have the same belief
(e) [ ] Don't Know

23. If you had a belief which some people called a delusion what would you do about it?

(a) [ ] Talk about it openly and try to discuss it
(b) [ ] Keep my ideas to myself
(c) [ ] Keep on my guard all the time as I might be in danger
(d) [ ] Try to distract my mind away from it and keep as active as possible
(e) [ ] Try to prove to others that it is correct and really happening
(f) [ ] Don't know

24. Neuroleptic medication (e.g. Modcate) is used to:

(a) [ ] Reduce the symptoms
(b) [ ] To make the person feel less anxious
(c) [ ] To stop side effects
(d) [ ] To make the person sleep
(e) [ ] Make the person quieter
(f) [ ] Don't know
Appendix 3

KGV Questionnaire
1. ANXIETY - rating scale

0 = The subject reports no anxiety in the past month.

1 = The subject reports mild anxiety. The subject's anxiety lies within the normal range of variation in mood experienced by the majority of people in the course of their daily lives. A mild and transient response to minor life stresses. The subject can easily and quickly stop their anxious thoughts and feelings by turning their attention to other things, or, these thoughts and feelings quickly come and go of their own accord. No signs of motor tension or autonomic hyperactivity are present.

2 = The subject reports moderate anxiety. The subject is able to exercise some control over their anxiety, and can reduce or put a stop to the anxiety by turning their attention to other things, but this requires a distinct and sustained effort. If signs of motor tension or autonomic hyperactivity are present these are very mild or of very brief duration.

3 = The subject reports marked anxiety. The subject has no control over the anxiety when it occurs and cannot turn their attention to other things, even when a distinct and sustained effort is made. At least one marked and persistent sign of motor tension or autonomic hyperactivity should accompany the anxiety. The anxiety has been present in this form on the minority of days in the last month.

4 = The subject reports severe anxiety. The subject has no control over their anxiety when it occurs and cannot turn their attention to other things, even when a distinct and sustained effort is made. At least one marked and persistent sign of motor tension or autonomic hyperactivity should accompany the anxiety. The anxiety has been present in this form on the majority of days in the last month.

Notes
(1) Signs of motor tension include: physical restlessness, trembling, involuntarily tensed muscles, tension pains affecting neck, back or legs, and tension headaches. Signs of autonomic hyperactivity include: gastro-intestinal dry mouth, difficulty swallowing, epigastric discomfort, frequent loose motions; respiratory feeling of constriction in the chest, difficulty inhaling, hyperventilation; cardiovascular discomfort over the heart, palpitations, missed heartbeats, throbbing in the neck; genitourinary frequency and urgency of micturition, failure of erection, lack of libido, increased menstrual discomfort; nervous system tinnitus, blurring of vision, dizziness, prickling sensations, sweating, blushing.

(2) Some subjects utilise avoidance strategies as a means of coping with their anxiety. They may report experiencing little or no anxiety in the previous month because they have avoided those situations which would have provoked anxiety. For example, a person who experiences severe anxiety in public situations may have avoided this by stopping at home all the time, relying on a relative or other carer to carry out essential tasks like shopping or going to work. In these circumstances it is recommended that the score for anxiety should be based on the level of reported anxiety experienced by the subject, but the presence of avoidance strategies, the frequency with which they are employed, and the disruption they cause to the person's social functioning should also be noted.
2. DEPRESSION - rating scale

0 = The subject reports no depression in the past month.

1 = The subject reports mild depression. The subject's depression lies within the normal range of variation in mood experienced by most people in the course of their daily lives. A mild and transient response to minor life stresses. The subject can easily and quickly stop their depressive thoughts and feelings by turning their attention to other things, or, these thoughts and feelings quickly come and go of their own accord. No biological symptoms of depression are present.

2 = The subject reports moderate depression. The subject is still able to exercise some control over their depression, and can reduce or put a stop to the depression by turning their attention to other things, but this requires a distinct and sustained effort. If biological symptoms are present these are very mild or of low frequency.

3 = The subject reports marked depression. The subject has no control over their depression when it occurs and cannot turn their attention to other things, even when a distinct and sustained effort is made. At least one marked and persistent biological symptom of depression should be present. The depression has been present in this form for the minority of days in the last month.

4 = The subject reports severe depression. The subject has no control over their depression when it occurs and cannot turn their attention to other things, even when a distinct and sustained effort is made. At least one of the biological symptoms of depression and at least one indicator of severe depression should be present. The depression has been present in this form for the majority of days in the last month.

Notes

(1) Biological symptoms of depression include: psychomotor retardation, sleep disturbance, diurnal variation in mood, loss of appetite, unintentional loss of weight, constipation, loss of libido, amenorrhoea.

(2) Indicators of severe depression include: a conviction of worthlessness or hopelessness; mood congruent delusions concerning guilt, ill health, impoverishment, nihilism, punishment and persecution; mood congruent hallucinations with a critical, threatening or catastrophic content; uncontrollable weeping; a complete loss of the ability to feel emotion; specific plans for committing suicide, or active preparations for suicide, or attempts at suicide with serious intent to die.
3. SUICIDAL THOUGHTS AND BEHAVIOURS - rating scale

0 = No thoughts that life is pointless or not worth living. No hopelessness about the future. No thoughts that self or others would be better off if subject were dead. No thoughts about possibility of taking own life. No active desire to die, or preparations for suicide, or attempts at suicide.

1 = Occasional brief thoughts that life has no point or is not worth living, and/or that the future is hopeless, and/or that self or others would be better off if subject were dead. No thoughts about possibility of taking own life. No active desire to die, or preparations for suicide, or attempts at suicide.

2 = Frequent or prolonged thoughts that life has no point or is not worth living, and/or that the future is hopeless, and/or that self or others would be better off if subject were dead. Thoughts about possibility of taking own life, but no thoughts about specific methods of doing this. No preparations for suicide or attempts at suicide.

3 = Frequent or prolonged thoughts that life has no point or is not worth living, and/or that the future is hopeless, and/or that self or others would be better off if subject were dead. Thoughts about committing suicide that include consideration of specific methods. No preparations for suicide or attempts at suicide.

4 = Firm belief that life has no point or is not worth living, and/or that the future is hopeless, and/or that self or others would be better off if subject were dead. Has formed desire to kill self. Has a plan for committing suicide by a specific method and has made preparations for implementing this plan, or has made an attempt at suicide in the last month using a method which the subject thought could be lethal.

Notes

(1) Record a positive rating if the subject satisfied the relevant criteria at any time in the last month.
(2) If the subject is given a positive score, a more detailed assessment of suicidal risk is recommended, using valid and reliable instruments e.g Beck Suicide Inventory, Beck Hopelessness Scale, Beck Suicide Intent Scale.
4. ELEVATED MOOD - rating scale

0 = The subject reports no instances of elevated mood in the past month.

1 = The subject reports mildly elevated mood. The subject's experiences a feeling of happiness, or excitement, or enhanced wellbeing, which lies within the normal range of variation in mood experienced by the majority of people in the course of their daily lives. The feeling quickly subsides, either spontaneously, or when the subject's attention is turned to other things. The subject experiences no increase in the rate of mental processes or physical activity.

2 = The subject reports moderately elevated mood. The subject experiences a feeling of exceptional happiness, or excitement, or enhanced wellbeing. The feeling persists for several hours or longer, and is not affected by attending to other things. The subject may also experience a slight increase in the rate of mental processes or physical activity.

3 = The subject reports markedly elevated mood. The subject experiences a feeling of intense happiness, or excitement, or wellbeing. The feeling persists for several hours or longer, and is not affected by attending to other things. The subject may also experience a marked increase in the rate of mental processes or physical activity, or a reduced need for sleep, or act upon grandiose ideas. Elevated mood was present in this form on a minority of days in the last month.

4 = The subject reports severely elevated mood. The subject experiences a feeling of intense happiness, or excitement, or wellbeing. The feeling persists for several hours or longer, and is not affected by attending to other things. The subject may also experience a marked increase in the rate of mental processes or physical activity, or a reduced need for sleep, or act upon grandiose ideas. Elevated mood was present in this form on a majority of days in the last month.

Notes

(1) Include drug induced mood states and note the cause.
5. HALLUCINATIONS - rating scale

0 = The subject reports no unusual sensory experiences in the last month.

1 = The subject reports any of the following: illusions; eidetic imagery; intensified or
dulled perceptions; distorted perceptions; brief and elementary hypnagogic and hypnopompic
hallucinations.

2 = The subject reports any of the following: pseudo hallucinations; elementary
hallucinations when fully awake.

3 = The subject reports true hallucinations occurring on a minority of days in the last
month.

4 = The subject reports true hallucinations occurring on a majority of days in the last
month.

Notes

(1) Illusions are misperceptions of real stimuli.
(2) Eidetic imagery is intense mental imagery which can be called up and terminated by
voluntary effort.
(3) Hypnagogic hallucinations occur at the point of falling asleep and hypnopompic
hallucinations occur at the point of waking up. In non-psychotic subjects they are brief and
elementary.
(4) Elementary hallucinations comprise experiences such as brief noises, flashes of light,
sensations of movement at the edge of the visual field.
(5) True auditory hallucinations are noises or voices which seem to come from a location
which is external to the subject's head. They sound as if they are coming from within the
room, or from outside in the street, or sometimes from a part of the subject's own body, e.g.
their stomach. Pseudo auditory hallucinations are noises or voices seem to be located inside
the subject's head.
(6) True visual hallucinations have all or most of the qualities of a real object. They appear
solid, three dimensional, coloured, and may move about in space. Pseudo visual
hallucinations do not appear convincingly real because they lack most of the above qualities.
They may appear translucent, flat and colourless.
(7) The distinction between true and pseudo hallucinations cannot reliably be applied to
hallucinations experienced in other sensory modalities, e.g. smell, touch, deep sensation and
taste. If the subject reports a clear instance of an hallucination affecting one of these senses,
this should be rated as a true hallucination.
6. DELUSIONS - rating scale

0 = The subject reports no unusual ideas in the last month.
1 = The subject reports any of the following: overvalued ideas; ideas of reference.
2 = The subject reports partial delusions present during the last month.
3 = The subject reports full delusions present on a minority of days in the last month.
4 = The subject reports full delusions present on a majority of days in the last month.

Notes

(1) An overvalued idea is an idiosyncratic belief held on inadequate grounds, which is not delusional or obsessional in nature, and which is not a conventional belief within the subject's culture or religion.

(2) Ideas of reference arise in people who are overly self-conscious. The subject feels that other people are taking notice of him in ordinary public situations, recognises that this feeling originates within himself and is out of proportion to any possible cause, but cannot help having the feeling.

(3) A delusion is a belief that is firmly held on inadequate grounds, is resistant to rational argument or evidence to the contrary, and is not a conventional belief within the subject's culture or religion. It is held with full conviction but is not arrived at by a process of sound logical reasoning and is not adequately supported by evidence. Delusions are usually false beliefs, but may occasionally be true or become true. It is not the falsity of the belief which determines whether it is delusional, but the nature of the mental processes which led to the belief.

(4) A partial delusion meets all the criteria for a delusional belief except that it is held with less than full conviction. The following questions are suggested to assist the rater in distinguishing between full and partial delusions:
   "How certain are you that (specify the belief) is true?"
   "Do you think that you could be mistaken about (specify the belief)?"
   "Do you have any doubts about (specify the belief)?"

(5) Care should be taken when asking questions concerning thought insertion, thought broadcast, thought echo or commentary, thought block, and thought withdrawal. The basic experiences enquired about under these headings are not in themselves sufficient to justify a positive rating for delusions. To allow a positive rating for delusions, the rater must also establish that the subject has acquired delusional beliefs concerning these experiences. For example, the basic experience enquired about under the heading Thought Broadcast is that of hearing one's own thoughts spoken aloud in one's head. This should be taken as a simple description of the subject's experience and should not be classed as a delusional belief. If, in addition, the subject believes that their thoughts are so loud that other people can share their thoughts at a distance, this could be classed as a delusional belief concerning their experience of loud thoughts.
7. FLATTENED AFFECT - rating scale

0 = The subject exhibits no evidence of flattened affect during the interview.

1 = The subject's emotional responses appear mildly flattened. Emotive topics evoke an emotional response from the subject but this is slightly less than might normally be expected.

2 = The subject's emotional responses appear moderately flattened. Emotive topics evoke an emotional response from the subject but this is distinctly less than might normally be expected.

3 = The subject's emotional responses appear markedly flattened. Very little emotion is shown, even when discussing emotionally highly charged topics. The subject cannot convey the impact of distressing symptoms and events, and shows little sign of concern when discussing current problems and future plans.

4 = The subject's emotional responses appear severely flattened. No emotional expression whatever regardless of the topic discussed. The subject's face is expressionless, their voice unvaryingly monotonous or confined to a repetitive pattern of inflection which is unrelated to the content of their speech. There is no expressive use of gesture or posture.
8. INCONGRUOUS AFFECT - rating scale

0 = The subject exhibits no evidence of incongruous affect during the interview.

1 = The subject’s emotional responses appear mildly incongruous. Slightly inappropriate or odd emotional responses occur during the interview.

2 = The subject’s emotional responses appear moderately incongruous. Distinctly inappropriate emotional responses occur occasionally during the interview. The majority of emotional responses are not incongruous.

3 = The subject’s emotional responses appear markedly incongruous. Distinctly inappropriate emotional responses occur frequently during the interview. The majority of emotional responses are incongruous.

4 = The subject’s emotional responses appear severely incongruous. Distinctly inappropriate emotional responses occur constantly during the interview. All of the subject’s emotional responses are incongruous.
9. OVERACTIVITY - rating scale

0 = The subject exhibits no evidence of overactivity during the interview.

1 = The subject appears mildly overactive. They are occasionally fidgety or restless but are able to remain still for substantial periods of time. The subject is never so restless that they get up from their chair and pace about the room.

2 = The subject appears moderately overactive. They are fidgety or restless for the majority of the interview and are able to remain still for only short periods of time. They may rise from their chair and pace about the room on one or two brief occasions, but it is always possible for the subject to return to their seat and complete the interview.

3 = The subject appears markedly overactive. They are constantly fidgety or restless and unable to remain still for more than a few seconds. They may rise from their chair frequently and pace about the room. It may not be possible to complete the interview in a single session because the subject spends a substantial part of the time pacing.

4 = The subject appears severely overactive. The subject is grossly excited, remains seated for only brief periods, and spends most of the time pacing rapidly about the room or even running around. The subject cannot be interviewed.

Notes

(1) The abnormal movements which are typical of medication induced akathisia should be rated under Abnormal Movements and Postures and not under this section of the measure.

(2) The abnormal movements which are typical of medication induced tardive dyskinesia should also be rated under Abnormal Movements and Postures and not under this section of the measure.
10. PSYCHOMOTOR RETARDATION - rating scale

0 = The subject exhibits no evidence of psychomotor retardation during the interview.

1 = The subject exhibits mild psychomotor retardation. There is slight slowness in movement accompanied by short delays in responding to questions and slight slowness of speech when answering questions.

2 = The subject exhibits moderate psychomotor retardation. There is distinct slowness in movements accompanied by definite delays before responding to questions and distinct slowness of speech when answering questions.

3 = The subject exhibits marked psychomotor retardation. There is very pronounced slowness of movements accompanied by long delays before responding to questions and pronounced slowness of speech when answering questions.

4 = The subject exhibits severe psychomotor retardation. There is extreme slowness of movements or the subject is immobile, long delays before responding even to very simple questions, and speech is restricted to brief answers or the subject is mute.

Notes

(1) The subject must show evidence of slowed thought processes to justify a positive rating for Psychomotor Retardation: for example, by a reduced rate of speech, or pauses between phrases, or pauses before answering questions.
11. ABNORMAL SPEECH - rating scale

0 = The subject exhibits no evidence of abnormal speech during the interview.

1 = Mild abnormality of speech observed. The train of speech is occasionally disjointed but it is always possible to discern a logical connection between the ideas expressed by the subject. Or, occasional instances of vagueness or irrelevance but the subject always returns to the point without prompting. No neologisms, perseveration or verbigeration occur.

2 = Moderate abnormality of speech observed. There are occasional breaks in the train of speech where it is impossible to discern a logical connection between the ideas expressed by the subject, but the majority of the subject’s speech is normal. Or, occasional instances of vagueness or irrelevance during which the subject needs prompting to return to the point of the question, but most replies are relevant. Or, occasional neologisms, perseveration or verbigeration against a background of predominantly normal speech.

3 = Marked abnormality of speech observed. Frequent breaks in the train of speech where it is impossible to discern a logical connection between the ideas expressed by the subject, only a minority of the subject’s speech is normal. Or, frequent instances of vagueness or irrelevance during which the subject needs prompting to return to the point, only a minority of replies are relevant. Or, frequent neologisms, perseveration or verbigeration repeatedly disrupt the flow of speech, but some meaningful communication is still possible.

4 = Severe abnormality of speech observed. Continual breaks in the train of speech where it is impossible to discern a logical connection between the ideas expressed by the subject, so no meaningful communication is possible. Or, all the subject’s speech is markedly vague or irrelevant, with no relation between the interviewer’s questions and the subject’s answers. Or, speech consists entirely of neologisms, perseveration or verbigeration.

Notes

(1) Speech that is difficult to understand solely because it is spoken quietly or is mumbled should not be rated under this item. If the subject’s speech is difficult to discern for either of these reasons the interviewer must attend closely to what is said and attempt to establish whether the logical and grammatical structure is intact or shows signs of breaking down.
12. POVERTY OF SPEECH - rating scale

0 = No lack of speech. Subject gives full and informative replies to questions and voluntarily provides additional relevant information.

1 = Occasional difficulties or silences but subject gives full and informative replies to most questions without repeated prompting or encouragement from the interviewer.

2 = Subject only speaks when spoken to and tends to give brief replies. Does not volunteer additional information without repeated prompting or encouragement from the interviewer.

3 = Most replies are monosyllabic despite prompting or encouragement from the interviewer. Frequently fails to answer at all.

4 = Speaks only two or three words. Or, murmurs constantly but says nothing intelligible to the interviewer.

Notes

(1) Poverty of speech should be distinguished from poverty of content of speech. Speech which is vague and imparts little or no information to the listener exhibits poverty of content. With poverty of content the subject may be very talkative and yet be so vague as to convey no useful information at all. Poverty of content should be rated under the item Abnormal Speech.
13. ABNORMAL MOVEMENTS - rating scale

0 = No evidence of abnormal movements or postures.

1 = Slightly unusual movements or postures, which are inconspicuous and are not likely to attract attention of others in social situations.

2 = Moderately unusual movements or postures, which are conspicuous and likely to attract attention of others in social situations, but occur infrequently and are not sustained over long periods.

3 = Markedly unusual movements or postures, which are conspicuous and likely to attract attention from others in social situations, and occur frequently or are sustained over long periods.

4 = Extremely unusual movements or postures, which are conspicuous and likely to attract attention from others in social situations, and occur almost continuously throughout the interview.

Notes:

(1) When evaluating the degree of conspicuousness of an abnormal movement or posture, the rater should make a judgement on how noticeable it would be to other people if it were to occur in an ordinary, day to day social context. For example, if the subject behaved in that way in a shop, or on a bus, or in a public space, what is the likelihood that other people would notice the behaviour? If it seems likely that others would notice it, would they attend to it briefly or persistently? Behaviour which might draw little attention in a ward or day hospital setting might be highly conspicuous in ordinary social situations.
14. ACCURACY OF ASSESSMENT - rating scale

0 = All elicited symptoms rated. All ratings based on complete and consistent information. Any contradictions, ambiguities and uncertainties fully resolved by further questioning of the subject.

1 = All elicited symptoms rated. All ratings based on adequate information. Minor unresolved contradictions, ambiguities or uncertainties remain after further questioning of the subject.

2 = A minority of elicited symptoms left unrated due to major unresolved contradictions, ambiguities or uncertainties.

3 = A majority of elicited symptoms left unrated due to major unresolved contradictions, ambiguities or uncertainties.

4 = All elicited symptoms left unrated due to major unresolved contradictions, ambiguities or uncertainties. Only observed behaviours rated.

Notes

(1) If any rating is thought to be of doubtful accuracy, use this section of the data sheet to record in detail which particular ratings are suspect and why they are judged to be suspect.
(2) Remember that the score for this section should not be included when calculating the subject's total symptom score.
Appendix 4

Cope Questionnaire
WAYS OF COPING

We are interested in how people respond when they confront difficult or stressful events in their lives. There are lots of ways to deal with stress. This questionnaire asks you to indicate what you generally do and feel, when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Please try to respond to each item separately in your mind from each other item. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every item. There are no “right” or “wrong” answers, so choose the most accurate answer for YOU – not what you think “most people” would say or do. Indicate what YOU usually do when YOU experience a stressful event.

Please think about how you have been feeling over the last month when you answer the questions.

1 = I usually don’t do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

1. I try to grow as a person as a result of the experience. 1 2 3 4
2. I turn to work or other substitute activities to take my mind off things. 1 2 3 4
3. I get upset and let my emotions out. 1 2 3 4
4. I try to get advice from someone about what to do. 1 2 3 4
5. I concentrate my efforts on doing something about it. 1 2 3 4
6. I say to myself “this isn’t real”. 1 2 3 4
7. I put my trust in God. 1 2 3 4
8. I laugh about the situation. 1 2 3 4
9. I admit to myself that I can’t deal with it and stop trying. 1 2 3 4
10. I restrain myself from doing anything too quickly. 1 2 3 4

11. I discuss my feelings with someone. 1 2 3 4
<p>| | | | |</p>
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<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>12.</td>
<td>I use alcohol or drugs to make myself feel better.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>13.</td>
<td>I get used to the idea that it happened.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>14.</td>
<td>I talk to someone to find out more about the situation.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>15.</td>
<td>I keep myself from getting distracted by other thoughts or activities.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>16.</td>
<td>I daydream about things other than this.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>17.</td>
<td>I get upset and am really aware of it.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>18.</td>
<td>I seek God’s help.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>19.</td>
<td>I make a plan of action.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>20.</td>
<td>I make jokes about it.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>21.</td>
<td>I accept that this has happened and that it can’t be changed.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>22.</td>
<td>I hold off things about it until the situation permits.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>23.</td>
<td>I try to get emotional support from friends or relatives.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>24.</td>
<td>I just give up trying to reach my goal.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>25.</td>
<td>I take additional action to try to get rid of the problem.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>26.</td>
<td>I try to lose myself for a while by drinking alcohol or taking drugs.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>27.</td>
<td>I refuse to believe that it has happened.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>28.</td>
<td>I let my feelings out.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>29.</td>
<td>I try to see it in a different light, to make it seem more positive.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>30.</td>
<td>I talk to someone who could do something concrete about the problem.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>31.</td>
<td>I sleep more than usual.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>32.</td>
<td>I try to come up with a strategy about what to do.</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>33.</td>
<td>I focus on dealing with this problem and if necessary let other things slide a little.</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

34. I focus on dealing with this problem and if necessary let other things slide a little. 1 2 3 4
34. I get sympathy and understanding from someone. 1 2 3 4
35. I drink alcohol or drugs in order to think about it less. 1 2 3 4
36. I kid around about it. 1 2 3 4
37. I give up the attempt to get what I want. 1 2 3 4
38. I look for something good in what is happening. 1 2 3 4
39. I think about how I might best handle the problem. 1 2 3 4
40. I pretend that it hasn't really happened. 1 2 3 4

1 = I usually don't do this at all
2 = I usually do this a little bit
3 = I usually do this a medium amount
4 = I usually do this a lot

41. I make sure not to make matters worse by acting too soon. 1 2 3 4
42. I try hard to prevent others things from interfering with my efforts at dealing with this. 1 2 3 4
43. I go to cinemas or watch TV, to think about it less. 1 2 3 4
44. I accept the reality or the fact that it happened. 1 2 3 4
45. I ask people who have had similar experiences what they did. 1 2 3 4
46. I feel a lot of emotional distress and I find myself expressing those feelings a lot. 1 2 3 4
47. I take direct action to get around the problem. 1 2 3 4
48. I try to find comfort in my religion. 1 2 3 4
49. I force myself to wait for the right time to do something. 1 2 3 4
50. I make fun of the situation. 1 2 3 4
51. I reduce the amount of effort I'm putting into solving the problem. 1 2 3 4
52. I talk to someone about how I feel. 1 2 3 4
53. I use alcohol or drugs to help me get through it. 1 2 3 4
<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>54. I learn to live with it.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>1 = I usually don’t do this at all</td>
<td></td>
</tr>
<tr>
<td>2 = I usually do this a little bit</td>
<td></td>
</tr>
<tr>
<td>3 = I usually do this a medium amount</td>
<td></td>
</tr>
<tr>
<td>4 = I usually do this a lot</td>
<td></td>
</tr>
<tr>
<td>55. I put aside other activities on order to concentrate on this.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>56. I think hard about what steps to take.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>57. I act as though this hasn’t even happened.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>58. I do what has to be done, one step at a time.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>59. I learn something from the experience.</td>
<td>1 2 3 4</td>
</tr>
<tr>
<td>60. I pray more than usual.</td>
<td>1 2 3 4</td>
</tr>
</tbody>
</table>
Appendix 5

Participant data for KGV, Cope and Knowledge scores
Cope "adaptive" scores
at base line, post treatment and follow up for all participants.

Cope "maladaptive" scores
at base line, post treatment and follow up for all participants.

lissing data = 0
KGV Total Symptom Scores
at base line, post treatment and follow up for all participants.

Scores for Knowledge of Schizophrenia
at base line, post treatment and follow up for all participants.
Appendix 6

Letter from team regarding feedback of results
Trainee Clinical Psychologist
c/o University of Surrey
Guildford
Surrey

Dear

Just a note to say thank you for the presentation you made with regards to the psycho-education group for people with schizophrenia that you co-facilitated during your placement at

Regards

Clinical Psychologist
MAJOR RESEARCH PROJECT

Experiencing a diagnosis of ADHD in adulthood.
A qualitative study using Interpretative Phenomenological Analysis.

Year 3
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ACKNOWLEDGMENTS

I would like to thank my supervisors Dr Mick Finlay and Dr Suzy Young for their support and assistance with this research and Dr Brian Toone for his help and feedback on my interview schedule and application for ethical approval.

I would also like to thank the staff at the ADHD clinic for all their help in the collection of the data. Finally I would like to thank the ten adults who were involved in this study. The courage they showed dealing with the far reaching effects of undiagnosed ADHD inspired me from the beginning.
ABSTRACT

The study explored the impact of a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) and treatment with stimulant medication on a group of adults. A semi-structured interview was used to elicit accounts of the adults' experiences prior to and after the diagnosis had been made. Interpretative Phenomenological Analysis (IPA) (Smith, 1996) was used to analyse the data. The participants consisted of five males and five females, aged between 22 and 42 years. All were diagnosed with ADHD in adulthood. Analysis resulted in three themes; impact on the self, adjustment process to the diagnosis and self and society. The diagnosis was found to have a profound impact on the participants' views of themselves. Participants discussed a sense of having to re-negotiate their own identity and sense of self after the diagnosis had been made. The adjustment process to the diagnosis of ADHD reduced the uncertainty experienced by not having a diagnosis. Participants encountered a range of emotional responses to the diagnosis and the adjustment process was described as non-linear and recursive. The diagnosis of ADHD was associated with real and anticipated stigma. The themes were discussed in relation to existing literature. Methodological issues and the clinical implications of the study are discussed.
1.0 Introduction.

1.1 Introduction – an overview to Attention Deficit Hyperactivity Disorder (ADHD) in adults.

Attention Deficit Hyperactivity Disorder (ADHD) is a childhood disorder characterised by the symptoms of impulsivity, short term attention and distractibility (Barkley, 1998). A full description of the diagnostic criteria for ADHD can be found in Appendix 8. The persistence of the disorder into adulthood was not widely recognised until the mid 1980’s when the first prospective longitudinal studies of childhood ADHD were carried out (e.g. Weiss, Hechtman, Milroy & Perlman, 1985; Mannuzza, Klein, Konig & Giampino, 1989). It is now agreed that about one third of children diagnosed with ADHD continue to indicate some core symptoms of the disorder in adulthood (Barkley, 1998).

There is a paucity of research into adult ADHD compared with the substantial body of research in childhood ADHD. The majority of studies have consisted of longitudinal follow up studies of children identified with ADHD (e.g. Manuzza et al., 1989; Weiss & Hechtman, 1993). These studies have found that adults identified with ADHD in childhood tend to have poorer academic and occupational achievement (Murphy & Barkley, 1996). In addition they have been found to be at greater risk of anti-social behaviour problems, substance abuse, and criminal behaviour (Weiss, Hechtman & Weiss, 1999). There is also evidence that the persistent rejection and negative feedback from others combined with repeated experiences of failure during the developing years may affect the adults’ self-esteem and interpersonal functioning (Hechtman, Weiss & Perlman, 1980). Co-morbid depression and anxiety have also been described as common problems in adults with ADHD (Young, 2000).

1.2 ADHD diagnosed in adulthood.

1.2.1 Difficulties in diagnosing ADHD in adulthood.

Murphy (1995b) suggests that there are several reasons why the diagnosis of ADHD in adulthood is more difficult. First, there is often an overlap between ADHD
symptoms and other co-morbid conditions in adults, some of which may have resulted from years of "ADHD related frustration and failure" (Barkley, 1998) (p347). This may create a complex psychiatric picture of symptoms which can mask the symptoms of ADHD as well as complicating the diagnostic procedure. Second, the diagnosis of ADHD in adulthood is achieved by applying the diagnostic criteria for children with ADHD using DSM-IV (APA, 1994). This is difficult as the symptoms may be manifested quite differently at different ages.

1.2.2 Previous studies.

Over the last ten years a small body of literature has begun to emerge on the population of adults whose ADHD is not diagnosed until adulthood (Barkley, 1998). The studies have focused on adults who self-referred to clinics specialising in adult ADHD diagnosis and treatment. The results support the specificity and reliability of the diagnosis in adulthood as reported symptoms are consistent with the range of symptoms described in children and adolescents with ADHD (Barkley, Murphy & Kwasnik, 1996).

Ratey, Greenberg, Bemporad and Lindem (1992) identified a cohort of 60 adults whose ADHD had not been recognised until adulthood. They found that the adults shared characteristics of low self-esteem, self-loathing and underachievement. The majority of adults had been treated for mood and anxiety disorders. Ratey et al., (1992) suggested that the reason that the diagnosis had been missed was that the adults had found ways to compensate for their difficulties. In addition, many had a mixture of atypical symptoms or their picture was complicated by the presence of co-morbid disorders. Most of the adults had made repeated contacts to other services prior to their referral to the ADHD clinic to determine the cause of their difficulties. However, the outcome had been unsuccessful. This lack of recognition may lead individuals to feel angry and lack trust in services as they may feel that they have been labelled 'untreatable' (Young & Harty, 2001).

A study by Murphy and Barkley (1996) found that one of the main differences between self-referred adults and ADHD children followed over development was that
self-referred adults were likely to have higher intellectual levels. They also tended to have a milder form of ADHD than those diagnosed in childhood which meant that the ADHD was more difficult to recognise. An earlier study by Shekim, Asarnow, Hess, Zaucha & Wheeler (1990) compared a sample of adults who had been diagnosed with ADHD in childhood with those who were not diagnosed until adulthood. They found that those identified with ADHD in adulthood had more dysthymic diagnoses than those diagnosed and treated in childhood. They suggested that an adult who is not diagnosed for ADHD in childhood may develop a "chronic sense of failure and low self-esteem that may have led to secondary dysphoria and depression" (p423).

Rucklidge (1997) suggested that adults diagnosed with ADHD in adulthood are likely to encounter repeated experiences of failure during childhood and adolescence. Since a diagnosis of childhood ADHD has not been made the chronic difficulties of inattention and hyperactivity cannot be explained by a particular disorder. Instead they may be viewed by others as indications of stupidity, lack of motivation or laziness. Attribution theory (Weiner, 1986) states that in the absence of an external explanation to make sense of negative experiences the individual is more likely to attribute the cause of the negative event to 'something about himself or herself' (p21). In view of this the child is likely to internalise the interpretation of the problem and blame themselves. This internal attribution may then lead to future expectation of failure and exacerbate the risk of hopelessness, depression and low self-esteem.

Rucklidge and Kaplan (2000) studied a sample of 51 women identified with ADHD in adulthood. They found that women with symptoms of ADHD tended to have a learned-helplessness attributional style characterised by an internal-uncontrollable attributional style (Abramson, Seligman & Teasdale, 1978). They suggested that this had developed as a means to cope with repeated negative experiences. The study found significantly higher rates of depression, anxiety and stress levels in the ADHD sample than in a control sample of females. The study also found that the women had a more external locus of control and lower self-esteem. The authors concluded that the combination of internal explanations for negative events combined with low perceived control "may leave one at great risk for emotional problems and distress" (p719).
The findings from the above studies suggest that adults who are not diagnosed with ADHD until adulthood are at an increased risk of developing negative self-perceptions, low self-esteem, a chronic sense of failure and anxiety or mood disorders.

1.2.3 **Uncertainty created by the lack of a diagnosis.**

Barkley, (1998) suggested that as the undiagnosed adult grows up there is often a sense that there is something wrong, however there is no available explanation to explain what it is. Although the individual may be aware of the existence of a problem (either through a recognition of difference between themselves or others and/or negative responses from others around them) it is difficult for them to make sense of it. According to Attribution Theory (Weiner, 1986) the response to uncertainty is to seek an explanation to establish a cause (Brewin, 1988). Brown (2000) suggested that there is often a discrepancy between the individuals’ apparent abilities and their actual achievements. This may be reinforced by the expectations of others and attributed to lack of effort. These wide discrepancies in the undiagnosed adults abilities and skills may also create further uncertainty (Solden, 1995).

The uncertainty created by the lack of a diagnosis appears to be a potential source of difficulty for adults with undiagnosed ADHD (Solden, 1995). The negative implications of uncertainty have been widely demonstrated in the field of health psychology, and it has been correlated with helplessness and distress (e.g. Idler, 1993). Conrad (1987) defined several types of uncertainty related to a medical diagnosis. The first consists of the uncertainty of sensing that something is wrong, either a perception of feeling different or an awareness of different symptoms in the body. The uncertainty created by this awareness of difference may eventually trigger the person to seek a consultation with appropriate medical caregivers. The second consists of medical uncertainty where medical professionals may be unaware of the reasons for the problems. Medical uncertainty may occur for a protracted period of time which may increase the person’s level of emotional distress. The third may stem from the actual diagnosis. Although relief may be experienced at this stage it also creates a new set of uncertainties (e.g. what will treatment be like, will it affect relationships etc.?).
1.3 The impact of diagnosis and treatment.

1.3.1 The impact of diagnosis on children diagnosed with ADHD.

The majority of research in the area of childhood ADHD has been quantitative. However, several studies have used a qualitative approach to focus on the subjective impact of the diagnosis on the child and family. It is important to consider these briefly as they may have implications for the diagnosis of ADHD in adulthood. A qualitative study by Byram (1998) looked at the impact of the ADHD diagnosis on the child and family. The study of ten children and their parents found that the diagnosis of ADHD had significant implications for the way that the parents viewed their relationship with the child. After the diagnosis had been made the parents described feelings of relief as their child’s behaviour could finally be explained by the ADHD diagnosis. Following this, the parents experienced a reduction in blame of the child and subsequently reported improvements in their relationship with the child. The diagnosis of ADHD became the central organising feature around which the child and adults made sense of and explained the child’s behaviour.

A qualitative study by Cooper and Shea (1999) of sixteen adolescents diagnosed with ADHD found that the diagnosis was seen as a mixed blessing by the participants. On one hand the diagnosis was a welcome relief as it provided a reduction in uncertainty and an explanation for childhood behavioural difficulties. On the other hand, ADHD was viewed as a debilitating condition which had stigmatising qualities. A later qualitative study by Krueger and Kendall, (2001) confirmed some of the potential risks of a diagnostic label of ADHD. They interviewed a sample of sixteen male and female adolescents who had been diagnosed with ADHD for a minimum of two years. They found that the adolescents were unable to separate their self-perception from the diagnosis of ADHD. Instead they had incorporated “the stigmatising beliefs and negative attributes of ADHD into how they perceived their self to be” (p65).

1.3.2 The impact of diagnosis on adults diagnosed with ADHD.

At the time of this research there were no equivalent studies which looked at the impact of a diagnosis of ADHD in adulthood. Current literature surrounding this area
is largely provided by anecdotal evidence from clinicians working in the field of adult ADHD. However the majority of authors in the field of adult ADHD agree that the diagnosis marks a significant stage for the adult and has a number of adaptive functions. The way that the diagnosis is communicated is critical to the adult’s understanding of the disorder and their motivation to follow through with treatment (Murphy, 1995b). Murphy (1995b) suggests that the ADHD diagnosis can lead to a reduction in negative self-perceptions as the problems can now be understood and explained in relation to a specific medical disorder. However this suggestion is based on clinical evidence. Rucklidge (1997) found support for the suggestion by Murphy (1995b) in a study of fifty female adults with ADHD. She found that once ADHD had been identified the participants reported enhanced control and a reduction in personal blame for the problems resulting from the symptoms. Rucklidge suggested that this may eventually enable the adult to begin to re-build self-esteem, however she acknowledged that this would be a long, protracted process for many.

The diagnosis also removes the uncertainty that the adult may have experienced since childhood that something was wrong. According to Radley (1994) the process of diagnosis removes the individual from an ‘ambiguous position’ (p143) where the individual is aware that there is a problem but it is not formally defined as such. Once the diagnosis has been made it legitimises the problem and the person can receive appropriate support and “can place their future within some kind of stable perspective” (Radley, 1994) (p143).

One of the negative consequences of a diagnosis of ADHD may be the effects of labelling or stigma. However to the authors’ knowledge this has not yet been addressed in an adult population. Rucklidge (1997) suggested that those individuals who do not receive a diagnostic label until adulthood may be protected from earlier effects of social ostracising. This seems unlikely though in view of the proliferation of other labels given to children with undiagnosed conditions emphasising characterological blame in the absence of other explanations (Sang, 1988).
1.4 The impact of medication.

1.4.1 The socio-cognitive effects of medication.

The bulk of research which has looked at pharmacological treatment of adult ADHD has consisted of controlled treatment trials or outcome studies (e.g. Wilens, Biederman, Spencer & Prince, 1995). Research has not addressed the psychological impact of stimulant medication in adults although several studies have addressed this issue in the treatment of childhood ADHD. These will briefly be discussed below as again they may have implications for late diagnosis and treatment.

Whalen & Henker (1976) suggested that medication use in childhood ADHD produced a set of ‘socio-cognitive effects’, or “messages conveyed to a child and significant others” beyond the immediate effects of behavioural change (p236). The authors drew on Attribution Theory (Weiner, 1986) to explain their theory in more detail. Attribution theory predicts that if the cause of the behaviour is attributed to be beyond the person’s control this will lead to more adaptive responses than if the behaviour is viewed as deliberate. The latter is more likely to be associated with disapproval and criticism (Weiner, 1986). Whalen and Henker suggested that the prescription of medication for children with ADHD underlines the view that the behavioural problems of ADHD have a physical cause and therefore are beyond the child’s control.

Whalen and Henker (1976) suggested that stimulant medication may have a more long-term adverse effect on a child’s self-perceptions. It may mean that children tend to attribute their successes to external factors such as the tablet rather than their own efforts (Milich, Licht, Murphy & Pelham, 1989). The implication of this is that if medication is viewed as a ‘change agent’ it may reduce the person’s sense of self-efficacy and belief in their ability to exert change (Whalen & Henker, 1991). Some support has been found for these ideas. Byram (2001) carried out a qualitative study of ten children with ADHD. The study found that the children tended to view stimulant medication as the ‘control mechanism’ for their behaviour. An earlier study of 55 children with ADHD (Johnston, Fine, Weiss, Weiss, Weiss & Freeman, 2000)
found that mothers and children tended to view “medication as a relatively more salient cause of their child’s positive behaviour”, (p380) whereas in a non-medicated condition the mothers and children were more likely to make attributions of individual effort.

The use of stimulant medication has also been associated with social stigma in children. A study by Henker & Whalen, (1980) found that children tried to conceal their medication from other children in their class as they feared that they would be ostracised by them. A later qualitative study by Cooper & Shea (1999) of a sample of adolescents with ADHD highlighted further negative implications of stimulant medication. The participants believed that medication had “dampened” certain aspects of their personality and they identified a split between their quieter ‘medicated self’ and their ‘normal self’ without medication.

Despite this, most research which has looked at the use of medication in the treatment of ADHD in children has highlighted the more positive effects (Milich, 1994). Stimulant medication has been associated with improvements in school performance, social behaviour, and more adaptive relationships between the child and caregiver (e.g. Pelham & Milich, 1991). It has also been found to have a positive impact on the child’s self-perceptions and mood (Pelham, Murphy, Vannatta, Milich, Licht, Gnagy, Greenslade, Greiner & Vodde-Hamilton, 1992). The implication of this for individuals not diagnosed with ADHD until adulthood is that they have been inadvertently excluded from the earlier potential benefits of medication.

1.5 Stages of adjustment following a diagnosis.

1.5.1 Stages of adjustment following a diagnosis of chronic illness.

Several authors have compared adjustment to an ADHD diagnosis with adjustment to a diagnosis of chronic illness (e.g. Robin, 1998: Barkley, 1998). Barkley (1998) suggests that although chronic illness has a number of differences from ADHD (e.g. it can be terminal, progressive etc.) there are a number of similarities. In particular, at
the point of the diagnosis the individual may become aware that there is no cure for the condition and treatment is likely to be needed for the duration of the person's life.

Taylor (1983) provided a theory of cognitive adaptation to threatening events such as the diagnosis of chronic illness. The theory suggests that the individual responds to the threatening event with "cognitive adaptive efforts that may enable them to return to or exceed their previous level of psychological functioning" (p1170). She proposed three themes involved in successful adaptation to the threatening event. These include: the search for a meaning in the experience, gaining a sense of personal control over the illness and treatment, and enhancing or restoring self-esteem.

The idea of the diagnosis marking the onset of an illness career has been described by Hughes (1958: cited in Karp, 1994). The 'career' seeks to describe the process through which the individual first seeks medical care and the way that the individual's behaviour and experience changes over time in response to this (Conrad, 1987). The definition of 'career' also implies that at each point a redefinition of self is made as each marks a "critical turning point to identity"(Karp, 1994) (p8). Karp looked at the illness careers of twenty participants who had been diagnosed with depression. He found evidence for five generic stages that the participants moved through in order to make sense of the diagnosis of clinical depression (See Table 1). The stages corresponded to changes in identity as individuals first began to view themselves as 'ill' and began to negotiate an 'illness identity' (p7).

The adjustment to chronic illness has implications for the person's sense of self and their identity (Wright & Kirby, 1999). Several theories have been proposed in this area. Bury (1982) described chronic illness as a 'biographical disruption' to the self in which the person's self-concept is called into question. In a similar vein to Taylor (1983), Bury emphasised the important role of the search for an explanation of the illness in order to establish some meaning. Finally, Charmaz (1983) discussed how chronic illness may create a 'loss of self' for the individual following the diagnosis. Four factors contribute to this loss of self, which include: being discredited, burdening others, a sense of social isolation and leading a restricted life.
Table 1. The stages in the career path of depression (Karp, 1994).

<table>
<thead>
<tr>
<th>Career path.</th>
<th>Description.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Inchoate feeling</td>
<td>A period of time where the individual is unable to name the problem or associate their feelings with depression.</td>
</tr>
<tr>
<td>Something is really wrong with me</td>
<td>The individual develops a clearer sense that something is really wrong.</td>
</tr>
<tr>
<td>Crisis</td>
<td>The individual moves from the sense that something is wrong to the realisation that they have depression. This crisis stage is usually associated with the diagnosis of depression and entrance into the medical world of treatment.</td>
</tr>
<tr>
<td>Coming to grips with an illness identity</td>
<td>The individual begins to come to terms with the diagnosis of depression and begins to develop theories about the cause of depression.</td>
</tr>
<tr>
<td>Getting past it</td>
<td>The individual begins to think beyond the incident of depression.</td>
</tr>
</tbody>
</table>

1.5.2 **Stages of adjustment following a diagnosis of ADHD in adulthood.**

The adjustment process following a diagnosis of ADHD in adulthood has not yet been empirically defined (Robin, 1998). Clinical evidence (e.g. Solden, 1995) suggests that adjustment reactions to the ADHD diagnosis follow a grief cycle similar to the stage model proposed by Kübler Ross (1969). The grief cycle proposed by Kübler Ross consists of the following stages; shock, denial, sadness, anger, guilt and finally acceptance.

The main difference between an ADHD diagnosis in childhood and adulthood may be in the initial response to the diagnosis (Barkley, 1998). Parental responses to the diagnosis of ADHD in their child have initially centred on shock and denial reactions as the parents accommodate to their loss of a ‘normal child’ (Carr, 1999). However, contrary to this idea, a study by Byram (1998) reported earlier suggested that initial response to the diagnosis may be characterised by relief as the family is finally able to make sense of the child’s behaviour.

If the diagnosis is not made until the teenage years the adolescent may initially experience denial and resentment in response to the diagnosis (Robin, 1998). Robin (1998) suggests that this is because teenagers are often unsure of their identity and
place a high priority on their being similar to their peers. A diagnosis of ADHD may be hard to accept as it suggests that something is ‘wrong’ and as a result the teenager may initially resist the diagnosis.

It is likely that the adult who is diagnosed with ADHD may respond to the diagnosis with relief before moving through other stages in the grief cycle as the uncertainty of non-diagnosis is removed (Murphy, 1995a). A later study carried out in an adult ADHD clinic in the UK (Van der Linden, Young, Ryan & Toone, 2000) found support for this suggestion. In a sample of 96 adults referred to the clinic, 30 adults were diagnosed with ADHD. All of the adults (regardless of the outcome of the diagnosis) were asked to report their level of satisfaction with the assessment. Of those adults who received a diagnosis of ADHD, 77% had a positive response to the diagnosis. Conversely, a high level of dissatisfaction was experienced by the adults who did not receive a diagnosis which suggested that adults may actively seek a positive diagnosis.

Murphy (1995b) proposed a six stage model to explain the adjustment process following a diagnosis of ADHD in adulthood (See Table 2). The six stages are based on clinical evidence obtained by Murphy in his work at an adult ADHD clinic in the United States. Adjustment to the diagnosis of ADHD is achieved by a linear progression through the stages.

1.6 Research aims of the current study.

The introduction has indicated the paucity of research undertaken in adults diagnosed with ADHD so far. Much of the research has looked at prospective outcomes of adults’ diagnosed with ADHD in childhood. Despite the small body of literature that has begun to emerge on the population of adults whose ADHD is not diagnosed until adulthood few studies have adequately addressed the subjective experience of the impact of late diagnosis on the individual. Most of the literature that has addressed this issue has been provided by clinical evidence and not from a research base. In view of the increasing numbers of adults who are presenting to services with chronic problems of attention, impulsivity and hyperactivity it would seem important to
Table 2. The six stages of adjustment to a diagnosis of ADHD in adulthood (Murphy, 1995).

<table>
<thead>
<tr>
<th>Stage</th>
<th>Description of stage.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relief and optimism</td>
<td>The initial response to the diagnosis is one of relief as the adult finally receives an explanation for a long standing history of problems.</td>
</tr>
<tr>
<td>Denial</td>
<td>The relief and optimism may soon give way as the reality of the diagnosis begins to sink in and the adult begins to view ADHD as a chronic disorder. The adult may deny that they have ADHD or avoid thinking about the potential impact that it has in their lives.</td>
</tr>
<tr>
<td>Anger and resentment</td>
<td>The adult may experience anger for a number of reasons (e.g. anger directed towards services for failing to diagnose ADHD for so long)</td>
</tr>
<tr>
<td>Grief</td>
<td>In some adults the anger may lead to sadness for several reasons. First, the adult may experience sadness that a number of years have been ‘wasted’ prior to the diagnosis whilst others may grieve for the loss of their ‘normal self’ prior to the diagnosis (Wren, 2000). Grief may also presuppose depression as the implications of ADHD as a chronic condition begins to sink in.</td>
</tr>
<tr>
<td>Mobilisation</td>
<td>The adult begins to move out of the main grief process and regains some optimism to begin to work towards managing the ADHD and their life outside of it.</td>
</tr>
<tr>
<td>Accommodation</td>
<td>This is the final stage and marks the point where the adult begins to accept the ADHD and the limitations that it may impose on the person’s life</td>
</tr>
</tbody>
</table>
address this issue in order to highlight particular psychological needs in this heterogeneous population which could inform future initial consultation work, treatment and intervention.

Qualitative methods are useful for uncovering a more in-depth understanding of phenomena that may well not be understood. At the time that this research was conducted no qualitative research had been published which specifically focused on the diagnosis of ADHD from the adult’s perspective. As previously discussed, existing research in the area of adult ADHD has mainly involved follow up studies of children identified with ADHD in childhood. Several research studies have addressed the area of undiagnosed adult ADHD, however these have been quantitative in nature. The apparent lack of qualitative research in the area meant that this study was exploratory in nature. It required a research approach that would allow a deeper understanding of the meanings attributed to the event of an adult diagnosis of ADHD from the perspectives of those that had been diagnosed. It was not concerned with the production of more generalised statements or the confirmation or disconfirmation of lines of inquiry derived from the preconceptions of the researcher.

Since the way that adults make sense of their ADHD diagnosis is likely to be complex and heterogeneous, it is important that the research method is able to take into account the possibility of multiple meanings or realities in order to gain a more holistic understanding of the phenomena (Bryman, 1988). Qualitative methodology would appear to be appropriate to this end.

The study has the following aims:

1. To explore adults’ accounts of the impact of ADHD diagnosis and treatment upon their understanding of themselves, their behaviour and their relationship with others. To explore these by comparing retrospective accounts of experiences and perception pre-diagnosis with post-diagnosis perspectives.

2. To explore the adjustment process the adults have made following the diagnosis.
2.0 Method.

2.1 Outline of qualitative methodology.

Qualitative research is usually concerned with understanding the meaning of the phenomena under study (Willig, 2000). The aim of qualitative research is therefore to attempt to understand the way that people experience events and make sense of their surroundings (Elliot, Fischer & Rennie, 1999). Qualitative research is much less concerned with establishing cause-effect relationships than the "quality and texture of experience" (Willig, 2000) (p9). Qualitative research does acknowledge that it is impossible to sideline the researcher's own perspective completely, however it does not make any claim to do this. Instead it accepts that "self-reflective attempts to bracket existing theory" and the researchers own values "allows them to understand and represent their informant's experiences and actions more adequately than would be otherwise possible" (Elliot et al., 1999) (p216).

2.2 Interpretative Phenomenological Analysis (IPA).

The study utilised Interpretative Phenomenological Analysis, which aims to gain an insight into the participant's world view by gaining an 'insiders perspective' (Conrad, 1987; cited in Smith, 1996) of the topic under investigation. Participants are asked to "tell their own story in their own words about the phenomena" (Smith, Flowers and Osborn, 1997) (p70). However, IPA recognises the dynamic process of research and acknowledges that it is impossible to ever truly enter the participant's personal world completely. Access to the participants' world depends on "the researchers own conceptions which are required in order to make sense of that other personal world through a process of interpretative activity" (Smith, 1996) (p264). Analysis of the participants' original account by the researcher (e.g. from transcripts or diaries) emphasises the process of interpretative work which is inevitably shaped by the researcher's own beliefs and perspectives. As such the analysis that results is "the joint product of the reflection by both participant and researcher" (Smith et al., 1997) (p70).
Smith, Jarman and Osborn (1999) suggest the importance of distinguishing IPA from discourse analysis, a constructivist methodology. IPA differs from discourse analysis in the way that it perceives cognitions. Discourse analysis is wary of the possibility that verbal reports can be mapped onto underlying cognitive processes. IPA however, acknowledges that participants' cognitions are not readily transparent through original accounts but engages in analysis in order to “be able to say something about that thinking” (Smith et al., 1999) (p219).

IPA has primarily been developed in the field of health psychology however its emphasis on providing a “rich and comprehensive description of a phenomenon” suggests that its use is wide ranging (Willig, 2000) (p148). This study is exploratory in nature and aims to gain insight into the participant’s experience of a diagnosis of ADHD in adulthood. The use of IPA in this study was thought appropriate as it enables the quality of the participant’s individual experience to be captured through the eyes of the adult with ADHD. Similarly, Smith et al., (1999) suggests that IPA may be usefully employed to “enrich the literature of an area previously studied quantitatively” (p264). As discussed, the research methodology employed in the area of adult ADHD has been quantitative in nature and it was hoped that the use of IPA in this study would enrich the existing knowledge base.

2.3 Research design.

2.3.1 Participants.

According to the principles of IPA, participants are not selected to represent a particular population. The aim of IPA is to provide an in depth examination of individual cases (Smith, 1995). A later study by Osborn and Smith verified this claim and suggested that participants should “provide specific instantiations of the psychological experience” of the topic under consideration (p68). They should not be expected to speak on behalf of their peers and therefore should not be seen as ‘exemplars’ of a specific population.
Participants were recruited from a specialist adult ADHD clinic. All participants were adults over the age of eighteen who had received a diagnosis of ADHD in adulthood and who were currently under treatment at the ADHD clinic. Stimulant medication was the only formal intervention provided by the clinic for the participants and all participants were on an optimum dose. The diagnosis of ADHD was made according to DSM IV criteria (A.P.A, 1994). All adults underwent the same assessment procedure for the diagnosis of ADHD in adulthood. They were asked to attend the assessment with an informant (preferably a parent). All patients underwent a detailed psychiatric interview to elicit ADHD and non-ADHD symptoms and a psychological assessment which involved a patient interview and battery of psychometric tests. The informant was also interviewed to provide retrospective accounts of the patient’s behaviour during childhood. Information was also collated from other objective retrospective accounts (e.g. school reports) before the diagnosis was determined.

2.3.2 Recruitment method.

The researcher attended the clinic to discuss the research with the ADHD service and was provided with potential names of participants from staff members. Following this, the adults were approached by post via an information sheet and covering letter (See Appendix 2 & 3). The information sheet informed the adults that the research was voluntary and that the researcher would telephone them in a period of time to ask if they wanted to participate and to invite them for an interview. Additionally, where possible adults were verbally informed about the study during follow up appointments and were provided with the information sheet. In this case the adults were asked to consider their participation in the research and if they agreed, a covering letter and information sheet was then sent to their home address.

In total, twelve participants were invited to participate in the research. Of these, one participant declined due to work commitments and the second failed to attend the interview.
2.3.3 Sample description.

Ten adults were interviewed which included five females and five males aged between 22 years and 41 years (mean age 32.9). The mean length of time since diagnosis was 26.7 months (3 months to 6 years). Two of these adults had received a formal diagnosis of ADHD prior to the formal diagnosis at the ADHD clinic. Both of these had received their first diagnosis outside of the UK. All participants were white and described their ethnic origin as white English, white European, white Scottish or white other. All participants spoke English as their first language. Two participants were married and five were co-habiting with partners. Three participants had children (range 1-3 children) and all three of these participants had at least one child diagnosed with ADHD. Five of the participants were employed in full time work, one participant worked at home on a part-time basis, three participants were unemployed and one participant was studying at college. Seven participants were taking Methylphenidate, three were taking Dexedrine. Table 1 provides details of the demographic characteristics of the ten participants.

Table 3. Demographic characteristics of the participants.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Ethnic Origin</th>
<th>Occupation</th>
<th>Marital status</th>
<th>Time since diagnosis</th>
<th>Medication for ADHD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Joe</td>
<td>38</td>
<td>White English</td>
<td>Courier</td>
<td>Single</td>
<td>2 years</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Tom</td>
<td>41</td>
<td>White Scottish</td>
<td>IT Manager</td>
<td>Co-habiting</td>
<td>3 months</td>
<td>Dexedrine</td>
</tr>
<tr>
<td>Jack</td>
<td>39</td>
<td>White English</td>
<td>Runs own business</td>
<td>Married</td>
<td>6 months</td>
<td>Dexedrine</td>
</tr>
<tr>
<td>Paul</td>
<td>22</td>
<td>White European</td>
<td>Student</td>
<td>Single</td>
<td>4 years</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>David</td>
<td>30</td>
<td>White English</td>
<td>Unemployed</td>
<td>Single</td>
<td>6 years</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Jessica</td>
<td>23</td>
<td>White Other</td>
<td>Unemployed</td>
<td>Co-habiting</td>
<td>5 years</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Liz</td>
<td>38</td>
<td>White Scottish</td>
<td>Unemployed</td>
<td>Single</td>
<td>7 months</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Emma</td>
<td>33</td>
<td>White Scottish</td>
<td>Manager</td>
<td>Divorced. Co-habiting</td>
<td>6 months</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Katie</td>
<td>39</td>
<td>White English</td>
<td>Works at home</td>
<td>Married</td>
<td>20 months</td>
<td>Methylphenidate</td>
</tr>
<tr>
<td>Sarah</td>
<td>27</td>
<td>White English</td>
<td>Account Manager</td>
<td>Co-habiting</td>
<td>36 months</td>
<td>Dexedrine</td>
</tr>
</tbody>
</table>
2.3.4 Ethical approval.

Ethical approval was obtained from an NHS trust ethical committee and from the University Advisory Committee on Ethics at the University of Surrey prior to the start of the research. A copy of the research proposal and the letter of approval from the ethical committee may be found in the Appendix 1.

2.4 Research interview.

2.4.1 Construction of the interview schedule.

The method of data collection used was a semi-structured interview. This was considered appropriate because it enables the participant to express their own ‘story’ of the topic under consideration without being too constrained or led by the interviewer. At the same time it enables the interviewer to be guided by the participant towards a deeper understanding of the area. In this way the semi-structured interview should provide richer data than a structured interview (Smith, 1995).

The construction of the interview reflected the procedure described by Smith (1995). This involved an examination of the existing literature in the area of ADHD in adulthood in order to identify areas of relevant interest and the identification of broad themes. The researcher also consulted two experienced practitioners in the field in order to build on and elaborate the themes. Following this the broad themes were translated into open questions which were placed in a logical order. The interview was split into two sections to reflect this. The first half retrospectively considered the time prior to the diagnosis of ADHD and asked questions about the difficulties experienced by participants, self-perceptions and coping strategies. The second half focused on the diagnosis and the post diagnosis experience and adjustment to the diagnosis. It also considered self-perceptions following diagnosis, coping strategies and views on the use of stimulant medication (See Appendix 6 for the interview schedule). The questions were both jargon free and aimed to be neutral (Smith, 1995). The role of the interview schedule was not a prescriptive one but was intended to be a
guide for the interview. Over the course of the interview the questions were adapted to facilitate the discussion at the time and took into consideration any new issues which arose (Smith, 1995).

2.4.2 Interview procedure.

After the participants had been sent the information sheet, the researcher contacted them at home to discuss whether they wanted to participate in the research. The participants were given the opportunity to ask any further questions about the research and were also reminded of confidentiality issues and the right to withdraw. Once the participants agreed to their involvement they were asked to arrange a date with the researcher for the interview. Four participants were interviewed at the ADHD clinic and six participants were interviewed in their home.

At the start of the interview participants were required to sign a consent form (See Appendix 4). They were then asked to complete a short background information questionnaire with the researcher (See Appendix 5). The interview with each adult lasted between 75 and 95 minutes. Each interview was audio-taped for transcription purposes (an example of a transcript can be found in Appendix 7).

2.5 Data analysis.

Data analysis followed the procedure outlined by Smith, Jarman & Osborn (1999). It consisted of an idiographic case approach which meant that analysis began with intensive engagement with individual cases before integration in the later stages of research (Willig, 2000). Smith et al., (1999) suggest that the idiographic approach works well with a small sample size of up to ten participants. This is to ensure that a clear picture can be maintained of "individual cases and the location of themes within them" (p225).

The transcripts were read a number of times in order to gain a deeper understanding of the participants’ accounts. During the initial reading any preliminary areas of interest, connections or initial thoughts were captured in the left hand margin. After the initial
reading the right hand margin was used to capture more abstract key words or themes to convey the quality of the interview data. In all cases the identified themes were taken from the text and transcript extracts were collected which supported the theme. Once the list of preliminary themes had been decided, some appeared to be clustered and these were then grouped together on the grounds of conceptual similarity. Superordinate themes or master themes were identified and these marked the higher order category of the cluster of smaller sub-themes. At all times the researcher moved between the themes and the text to ensure that the themes accurately reflected the text from which they had been taken (Willig, 2000).

When the above process had been conducted with one transcript, the master-theme list from the first interview was used to inform analysis of the remaining nine transcripts. Each transcript was read and more identifiers were found which further articulated the master theme list. At the same time any new themes were identified. At the end of this process a final list of master themes was constructed for the participant group. The themes aimed to provide an in depth meaningful account of the adult ADHD experience and the transcript extracts were chosen on the basis of their ability to articulate this.

2.6 Quality issues in qualitative research.

Qualitative research has encountered a number of disputes regarding its credibility over the years in relation to issues of reliability and validity, objectivity, interviewer bias and generalisation (Osborn & Smith, 1998). One of the difficulties has been that the criteria used to evaluate the rigour of quantitative research has often been generalised to qualitative research (Elliot, Fischer & Rennie, 1999). However, this transferability may not always be appropriate as qualitative inquiry has very different epistemological roots to quantitative research which is grounded in positivism and the establishment of objective knowledge (Elliot et al., 1999).

To this end, a list of guidelines have been published which explicate good standards of practice for conducting and evaluating qualitative research (Elliot et al, 1999). These
are discussed below and demonstrate the way that the researcher has attempted to address them:

1. **Owning one’s perspective.** The researcher undertook this project with an interest in raising awareness of adult ADHD in the UK and developing existing research in the area. The researcher hoped that the project would highlight the individual perspectives of the adults diagnosed by ADHD in order to demonstrate some of the difficulties encountered by a late diagnosis. The researcher undertook the research as a trainee clinical psychologist. As such, the researcher was interested in the psychological impact of late diagnosis (e.g. emotional reactions, adjustment process, stigma).

2. **Situating the sample.** Basic descriptive data about the participants is provided in section 2.3.3 to allow the reader to consider the sample of the participants in more detail.

3. **Grounding in examples.** Transcript extracts are provided to demonstrate the data analytic procedure.

4. **Providing credibility checks.** A group of five trainee clinical psychologists and a research psychologist looked at one transcript independently and discussed the emerging themes with the researcher. A clinical psychologist looked at four of the transcripts independently and discussed the emerging themes again with the researcher. Later on the same clinical psychologist and a research psychologist looked at the master theme list in order to ensure that the themes were representative of the data.

5. **Coherence.** The themes are presented in a meaningful, structured way and are organised into super-ordinate themes and sub-ordinate themes.
6. **Accomplishing general versus specific research tasks.** The research was based on the experiences of five males and five females who had been diagnosed with ADHD in adulthood. The researcher acknowledged that the results may not necessarily generalise or be representative of other populations.

7. **Resonating with readers.** The researcher attempted to present the research in a way which would be meaningful to readers and enable them to gain more insight into the subject matter of adult ADHD.
3.0 Results.

3.1 Overview of themes.

Three inter-related super-ordinate themes emerged from the analysis. These were: impact on the self (pre-diagnosis self and post-diagnosis self), adjustment to the diagnosis and the self and others. Within each of the three themes, further subordinate themes emerged which described the participant's experiences.

3.2 Theme 1: Impact on the Self (pre-diagnosis self and post-diagnosis self).

Prior to the diagnosis all participants identified the profound impact of not having a diagnosis on the way that they viewed themselves. The participants explored the impact of the diagnosis on themselves and identified the changes that had occurred in the way that they viewed themselves.

Pre-diagnosis self.

3.2.1 Self as inadequate.

The 'self as inadequate' theme was reflected in a variety of different ways by the participant group. The notion of inadequacy or 'not being good enough' in some way was ubiquitous and began in early childhood right through to the point in adulthood where the participant was first diagnosed.

3.2.1.1 Falling short of expectations.

Participants described the feeling that they were not able to meet the expectations of other people. These expectations often seemed to stem from the idea that on the outside there was nothing 'different' about the participant:
"I always found it frustrating dealing with the expectations of other people because people take a look at you and, you know I've got a good accent and so on and they think, oh, you can expect good things from this person" (David).

Falling short of expectations was often experienced at an early age when teachers were unable to reconcile the apparent intelligence of the participant with their observable academic performance:

"...I did use to get ridiculed a lot in the classroom by some teachers because they're saying "there's John and he's nothing like as intelligent as you, at least he keeps trying whereas you've got the brains but you're just not trying" sort of thing" (Tom).

3.2.1.2 Self as failure.

Participants described how repeated experiences of failure in their life had in turn become internalised and led them to view themselves as failures:

"The other thing was that it always seemed that however hard I tried I could never get anywhere – it was like constant failure and that was so frustrating" (Katie).

A view of self as a failure was often derived from a perceived failure to meet the expectations of others and self awareness of being unable to achieve their own potential. For Jessica, the dichotomy between 'knowing and doing' only seemed to enhance perceptions of failure:

"There were people around me who were achieving and I knew they weren't as smart as me but they used to get all this praise and all this, certificates and things like that. Then I used to think that I was failing. I knew I could do it, I just didn't know how to do it".
3.2.1.3 Comparisons with others.

As in the extracts above, most participants described how their self perception was partly informed by comparing themselves with other people. Many participants articulated a difference between themselves and others, generally one involving self-deprecation. The comparison between themselves and others was often idealised:

"And also, don't know, I don't know, just really that other people had some knack that I didn't, that they were sort of perfect and I wasn't" (Liz)

3.2.1.4 Self-esteem.

Participants discussed the impact of low self-esteem prior to diagnosis and treatment. For some, the impact of this was both serious and potentially fatal. Low self-esteem was a long standing problem stemming from early childhood experiences. David described how low self-esteem had led to suicidal ideation:

"Uh, I just had no value. I was probably pretty suicidal most of the time. I never thought I was worth anything although I've never made any attempts to kill myself"

Paul's low self-esteem was physically manifested in deliberate self-harm:

"I didn't care about my presentation, it was like cutting at my face, scratching my fact and my legs, my whole body...."

The development of low self esteem was often associated with non-diagnosis of ADHD in childhood. Emma described how low self esteem had contributed to the development of an eating disorder. This was amplified by comparisons between self and idealised others:

"...the secondary effects of non-diagnosis lead to low self-esteem and low confidence levels... the thing about bulimia was about never being satisfied"
with how I looked or who I am or the way I came across or everything was about me being wrong and everybody else being right”.

3.2.1.5 Lack of control.

Prior to the diagnosis of ADHD and medication use, participants described the experience of a lack of control over their behaviour and immediate environment. The inability to inhibit their responses led to a sense of frustration and helplessness which reinforced their negative self-perceptions:

“My feeling was very much frustration because I couldn’t control what I was trying to do because I was trying to stay on it and focus and so on but I couldn’t work work out any means of control to be honest” (Tom).

Several participants described an inability to control strong emotions. In particular frustration was often expressed by verbal and physical aggression:

“I’d get really angry and I couldn’t control it and I used to fight with my mum sometimes. I used to smash things up and stuff like that” (Jessica).

3.2.1.6 Self as problem.

A number of participants had internalised the view that ‘the problem’ resided in themselves and that they were ‘the problem’. Joe and Emma attributed their problems to aspects of themselves:

“I just thought it was my personality..... I just thought it was something about you, I just thought it was me.....” (Joe).

“I thought it was something to do with my brain, my head....I felt that I was always being, for as long as I can remember always had these things going on
so I just thought it was part of me, part of my head, part of my make up” (Emma).

The only explanation for this was to blame themselves for the problems:

“... I was never achieving the things that people expected of me... and what can you blame it on? It ends up you blame it on yourself” (David).

### Variable self.

Participants described a strong sense of inconsistency in their abilities and actions. This was characterised by the concept of ‘Variable self’.

#### Lack of consistency.

Lack of consistency was described by the majority of participants. The experience of fluctuating abilities, behaviour and relationships with others was usually associated with frustration and bewilderment and had a negative impact on the self.

“... I just thought, this sense of everything is coming at me and nothing is moving and everything is either up here or down here, I just couldn’t stand it” (Emma).

David described how his inconsistent academic performance at school resulted in profound confusion:

......”I would hand in a report that I thought that I hadn’t spent any time and effort on and I would get high marks. And then I'd hand on one that I’d agonised on for hours and hours and weeks and I’d get you know ‘must do better’... I just found that so demoralising, that it didn’t seem to matter whether I spend loads of time on it or not (David).
Liz described a need to make sense of the uncertainty created by the inconsistency between her ability to perform well in lectures but poorly in exams:

"I just know I was absolutely brilliant in the classes and seminars, people used to come for help and things and then I got to the exam and I failed so I had to re-sit and I only scraped through.... it was just really disorientating, thinking 'what's going on here?'".

3.2.2.2 Islands of excellence.

In spite of their struggles with a feeling of inconsistency and self-deprecation, it was striking how most participants were able to highlight particular areas of competence that had been preserved since childhood. These perceived skills or 'islands of excellence' may have represented protective factors for the participants. Many of the 'islands of excellence' represented creative skills or physical abilities:

".... I liked my creative flair and... I guess lateral thinking you know like brains very innovative, doing new stuff so you could almost capitalise on that quality... I was proud of that because I did stand out you know for example if I was doing art I was very good in the class and I liked it because I didn't have to put much effort in" (Sarah).

Several participants discussed the importance of highlighting and preserving their islands of excellence to enhance their self-esteem and self-worth:

"I think whenever I find myself to be good at something, I kind of make a mark on the wall you know, mentally speaking you know. I've tended to pick up on anything I can be good at. I try and use them as much as I can in my life. Partly for self-esteem...". (Tom).
Post-diagnosis self.

3.2.3 Re-negotiation of self following diagnosis and medication.

Following the diagnosis and the start of medication the participants discussed a sense of having to re-negotiate their own identity and sense of self to incorporate the ADHD diagnosis. This re-negotiation of self is also discussed in Theme 2 as it is connected with adjustment to the diagnosis and medication.

3.2.3.1 Who's me, who's the ADHD?

Once the diagnosis of ADHD had been made a number of participants described the process of separating themselves from the ADHD:

"I don't know, I don't like conforming I never have, whether that's ADD or it's probably me being me really" (Sarah).

"I mean I've got all sorts of stuff that isn't ADD, that can't be explained by ADD..." (Liz).

By distinguishing between self and ADHD the participants were able to engage in a process of re-defining 'self'. This appeared to have two benefits. The first was to enable them to make sense of the changes that the diagnosis of ADHD had created and the second was to enable them to reconcile the differences between their self-perception prior to the diagnosis and post-diagnosis. Sarah described a need to re-negotiate her self-perception in order to incorporate the ADHD part:

"It's weird, it feels a bit like you have to add in the ADD bit of you into you when you've been diagnosed, it was always there but you were never conscious that that's what it was".
The process of re-definition and distinction of self versus ADHD caused confusion for some participants. For Jack this had led him to question the potential usefulness of the diagnosis:

“One of the things I was thinking about was the idea that I was maybe not the person I thought I was..., all these years I thought I was this person and then suddenly I’m this person with ADD. But then is that the same thing? That sort of made me think maybe that was a down side to actually knowing about the ADD”.

A common theme was a concern that the knowledge created by the diagnosis would change them in some way as a person. One participant described her anxiety over a sense of being part of an evolving process post-diagnosis:

...“there’s ways to go forwards but you don’t want to take them because you’ve got a right to be who you are and you feel safe to be that person because you know that person. ... I thought it might change me and the way I was, I was scared” (Jessica).

3.2.3.2 Medication as changing self:

Participants described the effect that medication had on their sense of self and usually discussed it in terms of it being an agent of change. Several participants were concerned that the medication was changing their personality.

“I did go through a period of worrying about...whether my personality was changing with Ritalin” (David).

A distinction between their self-perception prior to the start of medication and post-medication was often made. This created a need to re-negotiate their whole perspective of themselves.
"You know, thinking how much of this is medication and how much of this is my mind?" (Liz).

"When I took my Ritalin.... It's like finding out you're adopted or something like that, it just completely changes your whole perspective. It made me feel like a different person because I'd never looked at myself before" (Jessica).

This sometimes led to a need to establish whether the 'changing self' they experienced was solely defined by pharmacological treatment. Some participants described a need to stop taking the medication in order to define who they really were:

..."and I actually wonder if part of what I was doing was just saying right what am I, who am I and how does that feel? Lets just scrape away all this old chemical stuff and just see what was there" (Liz: p19:15-18).

For some participants an emphasis was placed on the more positive aspects of medication as an agent of change. Joe discussed how medication had facilitated the expression of positive personality traits:

"See you know you're a nice person, you know there's this nice person trying to get out but who the bloody hell is he? and when you take the Ritalin and that nice person's there now, that side of me personality which I hope is now the dominant part of my personality is there".

3.2.3.3 Sadness at loss of old self.

Several participants described the sense of loss they experienced following the onset of medication. They in particular mourned the loss of the more vibrant, exciting aspects of their unmedicated ADHD selves:

"I have become a bit more inward if you like. Um in some respects I think I'm a bit more boring than I used to be" (Sarah).
Jessica found it difficult to adapt to the changes inspired by the medication and discussed a need to return to the person she was without medication:

"You know, when I used to take my medication, I used to think 'is this how it feels to be normal'? and then I'd think 'if this is how it feels to be normal, I want to go back to being my ADD self again'!"

Despite the profound sense of loss that some of the participants experienced they generally agreed that "the advantages of medication outweigh the disadvantages" (Jessica). Sarah acknowledged that she "wouldn’t want to be without the medication".

3.2.3.4 Medication as controlling self.

Most participants acknowledged the adverse effects of stimulant medication and described a sense that the stimulant medication controlled them as opposed to a sense that they had control over it. Liz and Jack were concerned that the medication "took over" for the period of time it was active:

"And coming back and being quite hyper and quite sort of don't know just feeling that in a way the Ritalin was driving me rather than something there to help me..." (Liz).

For Jack the controlling effect of the medication was not long lasting but reflected the short-term effect of stimulant medication. Jack discussed the idea that his 'non-medicated self' reflected his true self:

"It's like it takes over for a few hours and then I go back to normal me".

The need to avoid reliance on the stimulant medication was often discussed:

"... but um, I mean I can survive without Ritalin you know. I will do for long periods. I mean I've been off it for quite a few months now" (David).
However for some participants the advantages gained from the medication far outweighed the need to ‘escape’ from it. Paul described how his need for Ritalin to manage his ADHD outweighed his need to manage a side-effect of the drug:

“...for me you can’t live without it, it’s not the addictiveness but it’s having no option I think. It’s not the dependence but the reliancy on it”.

Others reconciled the issue of self control and medication use by using it selectively for identified periods of social or intellectual demand. Emma was selective in her use of stimulant medication and said that “if I want to do something then I like to take it”.

Jack described medication as a tool to enhance his attention span in order to aid communication with his wife:

“I use it sometimes as a tool. If I want to spend time with my wife, it there’s anything that I need to remember or talk to her about. I want to be in the situation where if we are alone together she has my full on attention” (Jack).

3.2.4 Changing understanding of the self.

3.2.4.1 Increased awareness of self:

Following the diagnosis many participants talked about an increased understanding of themselves and their own capabilities. Joe described the differences he noticed in his level of self-awareness prior to and following the diagnosis:

..."I’ve never been bothered about the way I am, it’s just all of a sudden I am now aware of how I am and what I’m doing, whereas before I wouldn’t be...” (Joe).

For Tom this had led to an increased acceptance of himself and the development of more realistic expectations by accepting his own limitations:
"Now I kind of learn to forgive myself to a fair degree anyway because I have learned that it's almost like a secondary effect... you've got ADD to live with, but if you're very critical with yourself it's even worse. So at least if you can get rid of the self-criticism then at least you've got less to deal with."

A number of participants attributed this developing insight to the stimulant medication and an increased ability to focus.

"I think the medication has helped me, everything that I've talked about before, I think that it's helped me, just to become more focused... It helps me to look at myself sometimes and help me to know I can achieve things" (Jessica).

"it completely transforms your outlook on life, your view of other people and the view of yourself changes because you can accept things, you can see things, you can understand things. It's clear, there's not that mist around..." (Katie).

However a corollary aspect for some individuals was that this led to them ruminating over the negative experiences of the past. Paul talked about the way that stimulant medication had opened up a 'Pandora's box' of memories that he had not had to consider before.

"it's like with Ritalin it's just opened this whole you know, it's like being locked in a box, it's like the box had opened as it's made me start to think about the person I am and all the things in my past to deal with".

David wondered if the increased insight had led him to reduce the expectations he once had of himself. There was a sense that in some respects he had given up trying as he was no longer able to pursue the dreams that he had before the diagnosis:

"I suppose I have slightly more realistic aspirations in some respects and I understand my failures but I'm still pretty hard on myself. You know I still
don't like the way I'm going through life um but there is not a lot I can do about it. And I suppose I've become more fatalistic in that respect”.

3.2.4.2 Self-esteem changes.

Many of the participants reported some improvement in the way that they viewed themselves following the diagnosis. However, improvement in self-esteem was not an immediate or automatic consequence of diagnosis. Participants discussed a process of repairing the 'damage' caused by a life-time history of repeated criticism, put-downs and failure. There was a sense that the low self-esteem developed early on in life had long-term and far-reaching effects which would be difficult to change:

"Because of the low confidence and self-esteem I was always seeking approval and I think that has an impact on relationships and I think of some level I still do it now. I'm like, 'I want you to tell me now that I look nice, tell me now'" (Emma).

Joe attributed part of his improvement in self-esteem to increased acceptance by others. This may have reflected improvements in the interaction between himself and others since the start of treatment for ADHD:

"I start to realise then that I am now accepted, whereas before I just didn't feel that I was. Yeah, so the self-esteem is slowly being built up, people like me for what I am, people phone up and stuff like that”.

The reported changes in self esteem were not always viewed as ‘improvements’. Jessica felt that the ‘down side’ of diagnosis was an increased understanding of her problems. This had had a negative impact on her self-esteem.

"Sometimes, on some levels my self-esteem got worse, sometimes if you don't know about something, you can't worry about it. Now I know about it, I worry about it more" (Jessica).
Jessica’s increased understanding of the cause of her problems led her to believe that she should make certain changes in her life. However, this in turn appeared to lead to a self-defeating cycle of failure and low self esteem:

"... in some way I believe in myself less because I know I should be able to make a difference but I don’t. I think because I’ve been struggling for some long, sometimes I find it hard to get up again”.

3.2.4.3 Changes in perception of control.

After the diagnosis and medication participants observed changes in their perception of control over their behaviour and immediate environment. For many participants this meant an increase in control:

“If something irritates me I’m more able to control and communicate rather than outburst” (Sarah).

Emma’s perceived increase in control signalled more positive implications for the way that she viewed herself:

“I feel much more in control than I did. The ability to explain to people ‘hang on a minute, I haven’t got that, can you just explain that?’ And I’ll quite happily say ‘I have an impairment, this is the impairment’. And I feel much better with that and having some sort of ownership of that...” (Emma).

Many participants attributed the increase in control to the use of their stimulant medication:

“I feel like I’m in more control when I’m on medication then when I’m off it. I also feel I’m in control of my destiny in terms of what I do over the next few days” (Jack).
The increase in control was not experienced by all participants. Liz was concerned that despite her diagnosis and medication she “still couldn’t get it together”:

... “But... that might come back to how much control do I have of this? I still don’t have that control and I still you know I’m still adjusting to all the new stuff as well” (Liz).

3.2.4.4 Re-location of blame.

Following the diagnosis some participants reported a reduction in self-blame and a re-location of blame towards the ADHD. This signalled a move from an internal to an external attribution of blame:

“It certainly removed a lot of the blame from myself, that it was all my fault scenario. I’m just weird. It just stopped all that inward negative stuff and gave more outward right, this is the situation and this is the best way to deal with it” (Emma).

Although the diagnosis had led to a reduction in self-blame, for Tom this did not mean that he was unwilling to take responsibility for it:

...”it’s something that I’m not responsible for, it just came along. Whereas before I felt responsible for it, so now it’s like I’m not to blame. And I’m willing to be responsible, I’m willing to take it on as a responsibility but I’m not willing to find myself at fault for it or be blamed”.

3.3 Theme 2: Adjustment process to the diagnosis.

This section discusses the stages of adjustment participants went through following the diagnosis and the emotional reactions experienced in response to it. Theme 2 is closely linked with the post-diagnosis self outlined in Theme 1 because both consider the participants’ adjustment to diagnosis and medication. Theme 1 is concerned with changes in the participants’ self-perception following the diagnosis and medication.
whereas Theme 2 focuses more on a cycle of adjustment. The process is presented in Figure 1 and includes the process of re-negotiation of self discussed in Theme 1.

Prior to their diagnosis most participants discussed a need to find an explanation for their problems. This culminated in their diagnosis and experiences of medical treatment for ADHD. Following their diagnosis, they began a process of re-defining their problems in light of the meaning provided by the diagnosis. They encountered a range of emotional responses in this adjustment process.

3.3.3 Deciding something is wrong.

The search for an explanation often began at an early age and usually started with the realisation that something was “not right” (David). Once this decision had been made the participants entered a quest to provide an explanation of the problems.

3.3.3.1 Knowing something’s wrong.

Many participants discussed a sense of knowing something was wrong but not knowing what it was. For Tom, this created a state of confusion and frustration as there was no available explanation at the time:

“For most of my life I’d always assumed there was a reason but there was no reason. I couldn’t hook onto something. In one way I kept thinking, I’ll eventually have an explanation but as I got into my later thirties and there was still no explanation you kind of just assume that you’re going to have to try and get on with it”.

Some participants did not notice that there was problem at first:

“I mean people used to call me lazy and stuff like that but I never used to think there was a problem – I used to think I was all right. I know that sounds funny but my mum she put a lot of confidence in me and we did a lot of stuff that helped me to build my own confidence” (Jessica).
Figure 1. THE PROCESS OF OBTAINING A DIAGNOSIS OF ADHD IN ADULTHOOD

Despite the linear presentation of this diagram, the stages should be considered as mutually influencing and recursive in nature.
The realisation that there was something wrong was often triggered later on in childhood. Joe realised something was wrong when a girlfriend drew his attention to it:

"...I did start to believe that there was a problem because also I was being made aware of something whereas I'd been totally blissful whereas now I was being made aware of it"

3.3.3.2 Search for a meaning.

Once the realisation that something was wrong had been established, participants and their families began to search for an explanation of the problems. Participants talked about their exposure to assessments and consultations with various services and professionals in order to try to find an answer to their questions. The search for an explanation was frequently associated with despair and hopelessness as the search was often met with an unsatisfactory outcome. "It almost got to the point where we gave up" (Joe). Tom discussed the various routes that he went down in order to determine what was wrong:

"As I got older I thought it was something like in psychoanalysis when you trace back to your childhood to find something that happened. So it was always digging around trying to think of something that might have affected me in that way and lead to the cause later on... when I was in my teens we tried hypnosis we tried faith healing, none of which really made a difference..."

3.3.4 Trigger to seek the diagnosis.

Participants were often motivated to seek a definitive explanation for their problems following a significant life event or trigger. Liz needed to find out the reasons for her problems because she was concerned that she was having a breakdown:

"You know at the time I was just so desperate to get everything sorted out and to find out what was wrong with me. I was really thinking that I was having
the problems. The second benefit was that it enabled participants to understand their problems in relation to the diagnosis:

"You know you’re not completely useless, we now actually understand what’s wrong. I mean it’s like trying to you know criticise someone for not being able to run a fast hundred metres with a broken leg. once you get diagnosed you understand why you can’t run a hundred metres..." (David).

A number of participants were clear that they did not want to use their diagnosis of ADHD as an excuse for ‘bad’ behaviour. Joe was conscious that he needed to take on some of the responsibility:

"ADD is not an excuse for your behaviour because there are times when you do control it, I know it’s because I’m on Ritalin but if I can do it now, I wouldn’t turn around and say ‘oh you’ll have to excuse me I’ve got ADD’ because it’s just a cop out” (Joe).

Several participants described the formal diagnosis as a gateway to pharmaceutical treatment. Sarah had already made the diagnosis for herself on an informal basis but she could not access the medication until she had sought the more formal diagnostic procedure:

"The diagnosis, all it does is confirm what you already know but it just gives you that window of opportunity to be able to do that change. In a sense you don’t need the diagnosis... but because of the medication being what it is, unless you’ve got it officially you can’t do anything about it” (Sarah).

3.3.7 Relief and elation.

Following the formal diagnosis, euphoria and relief were the two most common emotional reactions experienced by the participants. There was a sense that the diagnosis had been a final hurdle in their search for a meaning or explanation of the
some sort of breakdown or maybe Alzheimer's or something. Everything was going horribly wrong and people were starting to think she's not as good as she thinks she is”.

Sarah had moved into a new job at work and was unable to deal with the change of demands:

"..."then I changed job to become a customer service manager and a lot of my time I had to sit still basically and analyse a lot of information. I had a real problem actually trying to concentrate um and I would be fidgeting a lot”.

3.3.5 Making an informal diagnosis.

Prior to the formal process of diagnosis an informal diagnosis was made by nearly all of the participants. This was usually made following the discovery of an article about ADHD, often via an internet search or in a magazine. Paul described the emotional experience of the informal diagnosis. He identified an article which provided a perfect match between his own characteristics and those identified in the article:

“I think it was titled ‘I’m not stupid, I’m not lazy but what the Hell is wrong with me’? It was about this guy and the way it was written it was like, you know it was like amazing and as though I was mentioned in there...”.

For parents of ADHD children the diagnosis was usually made by recognising the similarity between their own problems and those of their children:

"...through looking into the condition from there um within months Peter my husband and I sort of looked at each other one night and both said the same thing” (Katie).

3.3.6 Formal diagnosis as meaning maker.

The formal diagnosis was considered to be an important stage for the participants. The first benefit of the formal diagnosis was that it confirmed ADHD as the source of
problems and the euphoria and relief seemed to stem from the fact that their problems had finally been confirmed.

"A sigh of relief after all these years when Doctor x diagnosed it was like wow, hoorah, somebody who actually gave me recognition"... (Paul).

..."but to be honest, the overall thing was enormous enormous relief, utter like kind of like a weight taken off my shoulders I certainly didn’t know was there if you know what I mean" (Tom).

For Joe who had already made an informal diagnosis, the euphoria and relief had begun prior to the formal diagnosis:

..."then when you read it in black and white, you’re thinking ‘I do that, Oh my God, I do that, oh’ and that’s a relief, it’s a relief to actually know there’s a reason for it. Because it’s like you’re reading all this stuff and you’re thinking no one had actually pointed it out to you... and you just think ah, and there’s a euphoric relief... ”.

The initial relief and elation experienced by the participants may have compromised their ability to take in the information provided by the professionals at the diagnosis stage. Jack had felt so overwhelmed with the positive diagnosis of ADHD that he had been unable to concentrate on anything else:

"I don’t think I took in any of the things the doctor said to me though, it was all blurred as I was so relieved".

3.3.8 First experience of medication.

With the formal diagnosis over, the participants highlighted their first experience of stimulant medication. For many, the first dose of medication provided them with some positive indication of what the future might look like. David was able to sit all
of the way through a lecture without getting up and Jack was able to concentrate on a long conversation with his wife:

"I went home and sat down and had the most coherent conversation she'd had with me" (Jack).

Jessica described her first experience of Ritalin as a 'life changing moment':

..."... I'd taken the Ritalin and I went to sit upstairs in my room and it was like being in the movies, all the mess just started to hit me.... I was in hysterics and then I realised what my mum had been saying all that time about how untidy it was. That was the most amazing, possibly one of the most amazing things in my life when I took that tablet. I never ever realised what it was like until then".

3.3.7 Change in expectations.

For many of the participants, the period after the diagnosis and start of stimulant medication led to a more optimistic view of the future and what it could be like. This was a cause for concern particularly when it was characterised by unrealistic raised expectations.

..."one of the things I had was this real expectation that everything suddenly would be wonderful, that I'd suddenly be able to get the hang of everything. I thought I've got a good brain and good education and everything should suddenly kick in..." (Liz).

Jack discussed his decision to make a number of changes in his life following the start of his stimulant medication and raised expectations for the future:

"I had work and started throwing things up in the air, I got rid of the business and sold everything, ditched it all, drove up to London. I brought a newspaper and looked for high powered, a high earning job to get us out of debt".
3.3.8  **Frustration and depression.**

Some participants described a general sense of feeling low or frustrated following the initial relief of the diagnosis. For many participants they ‘returned to earth’ quite suddenly following the period of euphoria and raised expectations. Emma experienced low mood following the initial relief because she was left with the feeling that she did not know where to begin to deal with the implications of the diagnosis:

> “I had a bit of being low afterwards, I can’t explain. I think it was after the relief, after I’d found out, it was like ‘Ok, right, now what do I do’? I don’t know, nothing too tangible, can’t get a grip on it”.

Jessica began to feel depressed following the diagnosis because she did not want to believe that there was a ‘problem’:

> “Because I didn’t want to believe that I had it, I didn’t want to use it as an excuse.... Coming from that, I think I felt bad about my ADD for a while. I didn’t work on it, I didn’t take my medication, I didn’t do anything and I think I was depressed and in a really bad way”.

Raised expectations were often linked with but not necessarily the cause of frustration and depressed mood. For some participants it was the realisation that the diagnosis and stimulant medication was not an immediate cure or that they were unable to meet with the unrealistic expectations they had created for themselves. Liz discussed the frustration and depression she experienced following the realisation that things were not just suddenly going to improve post diagnosis:

> “I thought this is fantastic and then the realisation that there’s so much more to it than you know. I had so many habits that I had to unlearn”.

Tom described the frustration he experienced following the realisation that things were not moving as smoothly as he had envisaged at the diagnosis stage:
“Actually there’s still a bit of frustration because I want to get on with things as quick as possible and err... I think knowing the explanation but not having the next stage worked out is a bit frustrating actually”.

3.3.9 Bereavement and anger over regrets.

All of the participants talked about the regrets they experienced following the diagnosis. The main source of regret was that the diagnosis of ADHD was not made until adulthood. Many participants acknowledged that awareness of ADHD as a disorder was probably minimal in their childhood and in some cases unknown but they still experienced a huge amount of regret that something was not done earlier. Some participants experienced a sense of loss or bereavement about the life they could have lived if they had been diagnosed at an earlier age. Joe talked about the number of regrets he experienced prior to the diagnosis:

...” Because now that you’d sat back and thought about your whole life... So then you start thinking about all the relationships you’ve been in, all the rows you’ve been in, all the jobs you’ve been in and out of because you couldn’t keep your mouth shut or you couldn’t concentrate on work. Oh, my whole life now up until I was diagnosed was just one massive regret”.

Liz expressed a sense of loss at the ‘wasted years’ that she had endured without knowing her diagnosis:

...” and then going back in my mind and thinking this, this, this, this and this and then going through that full cycle of that needn’t of happened if I’d known about this and this huge sense of having wasted a lot of years”.

Paul talked about what life would have been like if he had been diagnosed earlier:

“In the past it would have made my life just a hell of a lot easier. I wouldn’t have like half the scars on my body.... It would have been easier. I would have
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had more friends. I would have been socially acceptable I think is the phrase
I'm going to use there...”.

3.3.10 Doubt and denial.

Several participants experienced feelings of doubt or denial in their adjustment to the
diagnosis. David described the nagging sense of doubt he experienced following the
diagnosis. This meant that he questioned the validity of it as an explanation of all of
his problems:

...”and then I got put on to the Ritalin and it helped but there was always kind
of nagging doubt... So I've always been thinking... is that absolutely the
cause? Because the thing is, a lot of the symptoms are so vague and apply to
everybody in some respect...”.

Jessica talked about her need to deny the diagnosis of ADHD after she had learnt of it.
She felt that if she ventured to believe the diagnosis then she would need to take on
board the responsibility to make some changes in her life and in herself:

“... me finding out that I had ADD, that means that there was a solution to the
problems and I didn't want anything to be solved – I wanted to be me. I didn't
want to be able to take any responsibility. I was running away from the
responsibility that I needed to take and I didn't want to be responsible”.

3.3.11 Partial adjustment and using the diagnosis to make changes.

Most of the participants discussed some sense of entering a stage where they had
begun to make a partial adjustment to the diagnosis. The timing or onset of the partial
adjustment appeared to vary from participant to participant and it sometimes occurred
concurrently with the post-diagnosis reactions identified previously. For many
participants the move towards partial adjustment to the diagnosis was associated with
a need to become more future orientated, to make some decisions about practical
issues and to move towards making some change (either behavioural or lifestyle changes).

The ADHD diagnosis was often used as a marker to instigate these changes:

..."you know knowledge is control isn’t it? Now that I know it gives me the platform to take it forward you know. I’ve already adopted a lot of strategies, now I can really go forward"... (Tom).

Tom discussed the way in which he had used the diagnosis to change aspects of his relationship with his partner:

"Now we’re both trying to work out how best to fit in with it and that kind of stuff so it’s good because actually, what we’re now changing some of our patterns and we’re getting quite good results”.

Partial adjustment to the reality of the diagnosis appeared to be indicated by the need to ‘move on’ in some way and to try to deal with the implications of the diagnosis. Jessica and Joe described a sense that they were able to acknowledge and accept the changes that had occurred since the diagnosis:

“But when I started to accept it, that’s when things started to change and I started to become less violent and less frustrated and... I started to sort myself out more. I mean, I’ve still got a long way to go... but things started to change in my life, when I started to look and see and find different ways of doing things that helped” (Jessica).

“Now you start to think, the drugs are helping and things as far as I’m concerned. I’m a lot happier in myself and know I can deal with situations and deal with them in a rational way” (Joe).

Emma talked about her need to stop thinking about the long term effects of stimulant medication in order to move forward:
"I've stopped going down that road of 'right, I'm going to look into what the research is about the long-term effects of medication'. I've stopped thinking about it because at the end of the day 'are you benefiting from taking the medication'? Yes! So, stop doing your head in about it, just do it”.

3.4 Theme 3: Self versus society.

After the formal diagnosis and prescription of stimulant medication had been made, participants described a heightened awareness of the stigma implied by the label of ADHD. An interesting adjunct to this is that prior to the diagnosis of ADHD participants often experienced negative labelling from others despite the lack of a diagnostic label (see also sections 3.2.1.1, 3.2.1.2 and 3.2.1.3). This will be introduced briefly before the discussion of post diagnosis experiences of stigma.

3.4.1 Labelling prior to the diagnosis.

From an early age participants described the sense that they were different from other children in some way (usually behaviour or relationships with others). Although they were not always able to define these differences in detail they were usually aware that they existed on some level. The awareness of difference often appeared to stem from negative reactions of others towards them – e.g. teachers, childhood peers or family members. Emma identified that she was different from an early age and this difference was supported by her mother:

"I felt that I was very different. My mum used to say a couple of things to me as well, like 'you're quite an unusual child'. But I was very different to a lot of people”.

For those who had been more badly behaved at school an interesting situation emerged where they were labelled as a problem without an identified label or diagnosis available to explain their behaviour. The application of negative labels such
as "lazy", "trouble maker", "clown" was a consistent reminder of their difference and pinpointed them as the agent of the problem:

"...they said that I was like I had problems, like I was a problem child..."

(Jessica).

Some participants identified a need to remove this difference by attempting to ‘fit in’ with their immediate external environment. Katie described the idea of role-playing as an attempt to fit in and be accepted by her peer group. This appeared to help on a more superficial level, however it was a major source of internal stress:

"...any reactions that they had you manipulate yourself round to be that person... it's a very negative thing because you, you try and base yourself to what they want, so in effect their reactions control your life in all ways, shape and form" (Katie).

For others their sense of feeling different from other children exacerbated their need to isolate themselves from others. Many participants described their need to hide or ‘escape’ from other children as they were unable to ‘fit in’ or conform to the expectations of others however hard they tried. Tom talked about his need to “keep a low profile” to avoid encountering difficulties:

"... I'd kind of hide out a lot of the time and I'd get less problems, less attention and I'd weather it out”.

3.4.2 Stigma following the diagnosis

Stigma had either been experienced on a direct or indirect level by participants. Many described an awareness of negative responses from others towards them either as individuals with ADHD or towards ADHD in general. In some cases the occurrence of stigma was anticipated rather than actual. It was not always experienced first hand but was often experienced through negative media representations of ADHD and stimulant medication.
3.4.2.1 Stigma of the label of ADHD.

The disclosure of ADHD was often a difficult one and participants discussed negative reactions from others following the disclosure of their diagnosis. Emma talked about the negative reactions of work colleagues:

..."they just don't know what to do, they stop making eye contact with me which is fabulous for me if I want to drift off anyway and can't always make eye contact with you."

Jack presumed that the reactions of others would be negative if they were to become aware of his diagnosis of ADHD. He attributed a number of characteristics to the ADHD label:

"People would see someone with ADHD as disorganised and dysfunctional and erratic and all the rest of it. I suppose they'd think I had no money in the bank and they wouldn't then want me working in their house."

For many participants part of the difficulty surrounding the label of ADHD was the perception that it was solely a childhood disorder. This perception sometimes generated a sense of isolation and an awareness of being different:

"You know you do feel unique, because and when you do talk to people who have read about ADD they say “I've heard about that but don't kids get it”?, you know, and you have to turn around and say 'well they had to get it from somewhere’” (Joe).

And often generated a negative reaction from others:

"I had a funny altercation in the pharmacy when I was handed the prescription. I said 'what about alcohol'? and he looked at me like I was a three headed monster um and said 'is it for your child?' He obviously thought I was anaesthetising my ADHD child..." (Liz).
3.4.2.2 Stigma of medication.

The stigma of using stimulant medication was experienced by many participants. Again this was either through the observed reactions of others:

... "you go to the chemist and you get the prescription and they say, you know there's quite a lot of stigma with it, they look at you and think 'why's this guy been prescribed this stuff?'" (Tom).

Or through anticipated reactions from others:

... "the concern is because I've got Ritalin in my pocket there's always a risk of it falling out you know at work, dropping it on the floor and people finding out about it because there are very few things that Ritalin can be prescribed to an adult for" (David).

Stigma was frequently propagated by negative media representations of stimulant drug use in ADHD treatment. Katie was concerned that if she was to disclose her use of stimulant medication to others she would be judged on the basis of media representations:

... "the problem is the fact of the classification and the medical perception that ... you know methylphenidate is crack cocaine and all of that. So you have to be very careful who you actually say, who you actually tell what you take because of the perception that the general public gets of it".

3.4.2.3 Problems of disclosure.

For many, the decision of when and who to disclose their ADHD diagnosis to was a difficult one to make. Disclosure difficulties were often discussed in relation to anticipated reactions from others:
“the group that I work in is very political, it's very, if you are deemed to have any kind of weakness as other people perceive it, you're almost a target and people will use things like that against you” (Sarah).

Liz was concerned that people would make judgements about her on the basis of her diagnosis:

“and I probably told too many people in choir about it so it then becomes difficult to not be seen as anything other than the person with that” (Liz).

Tom was concerned that the invisibility of his 'symptoms' meant that he would not be believed if he was to disclose the ADHD:

“I'm quite cautious because I just have this feeling that people won't believe me or will be cynical especially the people who know me quite well but never necessarily see any particular evidence...”.

The tendency for ADHD to be seen as an invisible disability was discussed further by several others and highlighted the potential concerns of disclosing a disorder that may not necessarily be physically apparent:

“Because nobody understands it, because you know if you had a broken leg or you know if you had a withered leg or something, you walk with a cane or you, you know a wheelchair” (David).
4.0 Discussion.

The three main themes that emerged from this study will be summarised and then discussed in relation to existing literature. The introduction of new literature will be made in response to some of the study's findings as recommended by Charmaz (1995) for qualitative research. A discussion of methodological issues raised by this study will then be made with a particular emphasis on the issues concerned with qualitative research. Finally, the implications raised by this study and future directions for research will be addressed.

4.1 Theme 1. Impact on the Self.

Theme 1 consisted of two main parts; pre-diagnosis self and post-diagnosis self. Pre-diagnosis self described the profound impact of not having a diagnosis on the way that the participants described themselves. Post-diagnosis self described the impact of the diagnosis on the participant's views of themselves. The post-diagnosis part of Theme 1 will be discussed in more detail than the pre-diagnosis part in order to reflect the main focus of this study.

Prior to the diagnosis participants made a number of negative evaluations of themselves which was reflected in the 'self as inadequate' subordinate theme. Participants described a long history of repeated and internalised failure, low self-esteem, upward comparisons with others and a lack of internal control over their behaviour and external environment. In addition many participants had attributed the cause of the problem to a character 'flaw' which had led to self-blame. These results provide support for the studies by Ratey et al., (1992), Shekim et al, (1990) and Rucklidge and Kaplan (2000) of participants diagnosed with ADHD in adulthood. They found high levels of low self-esteem, self-loathing, repeated experiences of failure, external control and self-blame in their samples.

The study also provides support for the suggestion by Rucklidge (1997) that in the absence of an external explanation (i.e. a diagnosis) to make sense of negative experiences the individual may be more likely to attribute the cause of the problem to
themselves which may lead to self-blame, low self-esteem and future expectation of failure. Although not directly evaluated the participants showed evidence of an internal-uncontrollable attributional style (Abramson, Seligman & Teasdale, 1978) in their childhood and adult years prior to the diagnosis similar to that found by Rucklidge and Kaplan (2000). Participants described a lack of control and tended to blame themselves for external events.

Participants discussed a lack of consistency in their abilities and actions. This was usually associated with bewilderment and frustration as they were unable to make sense of the reasons why this occurred. This confirms the argument by Solden (1995) that the wide discrepancies and inconsistencies in the undiagnosed adults’ abilities and skills may contribute to an increasing level of uncertainty and confusion about the problems. Despite the feelings of inconsistency participants were able to highlight particular areas of competence that had been preserved since childhood. These ‘islands of excellence’ will be discussed in more detail in the section on clinical recommendations.

After the diagnosis had been made participants described the various changes that had occurred in the way that they viewed themselves. Most of the participants reported some improvement in the way that they viewed themselves although for many there was a sense that repairing the damage caused by a lifetime of repeated criticism and failure would take a long time. This partly supports the suggestion by Murphy (1995) that the ADHD diagnosis can lead to a reduction in negative self-perceptions as the problems can now be understood. However, it also supports the suggestion by Rucklidge (1997) that re-building self-esteem is usually a long protracted process for adults recently diagnosed with ADHD. Charmaz (2000) suggests that the adoption of negative evaluations of self may become a “habitual mode of response” and undoing this “requires many more positive experiences than the original negative ones” (p355).

Rucklidge (1997) found that participants reported enhanced control and a reduction in personal blame for the problems resulting from the symptoms following a diagnosis of ADHD. Murphy (1998) suggested that this may be due to the fact that the problems
can now be explained in relation to a specific medical disorder. In this study a number of participants reported an increase in control and a reduction in self-blame following the diagnosis. Attribution theory (Weiner, 1986) predicts that if the cause of the behaviour is attributed to be beyond the person’s control (i.e. a diagnosed condition such as ADHD) this may lead to more adaptive responses than if it is not.

Whalen and Henker (1976) argued that a diagnosed condition may lead to beliefs of stability rather than variability of cause which may impede the individual’s sense of personal efficacy to make changes. This did not appear to be apparent for a number of the participants in this study. Despite the reported reduction in self-blame nearly all participants were unwilling to use the diagnosis of ADHD as an ‘excuse’ but were aware of a need to take on some of the responsibility for their actions. This supports the research by Karp (1994) which looked at adults diagnosed with depression. The research found that participants described a need to “navigate between rhetorics of biochemical determinism and a sense of personal efficacy” (p23). Karp argued that the participants were unwilling to be absolved of all responsibility for their depression as this would have represented acceptance of a passive, victim role.

An interesting adjunct to this is that many of the participants attributed the increase in control to the stimulant medication and not to personal efficacy. Similarly a number of participants raised the concern that the medication controlled them as opposed to a sense that they had control over it. This supports some of the research carried out on ADHD in child populations which looked at the socio-cognitive effects of stimulant medication. These studies found that children sometimes attributed their successes to external factors such as the tablet rather their own efforts or control (e.g. Milich et al., 1989, Johnston et al., 2000). Several qualitative studies carried out on populations of children and adolescents found that children viewed medication as the ‘change agent’ rather than themselves (e.g. Byram, 2001; Cooper and Shea, 1999).

Whalen and Henker (1991) suggested that this may have an adverse effect on self-perceptions since it may reduce the individual’s belief in their ability to exert change. However a number of participants in this study reconciled the issues of self control and medication use by exercising their own control over the drug. Some participants
discussed a need to avoid reliance and took ‘drug holidays’ whilst others used it selectively for identified periods of social or intellectual demand. Locus of Control theory suggests that individuals need to achieve a balance of control over their health (Dowell & Hudson, 1997). Dowell and Hudson (1997) in a qualitative study of medication taking behaviour in primary care found that some patients were able to regain control by becoming ‘active users’ of medication and were able to modify their treatment regime in accordance with their perceived needs.

Participants described an increased awareness of themselves and an understanding of their own limitations following the diagnosis. A number of participants attributed this developing insight to the stimulant medication and an increased ability to focus. Conversely one of the adverse effects of stimulant medication was that it led to them ruminating over the negative experiences of the past. For some participants this was understandably distressing. Bemporad (2001), in a small study of adults prescribed with stimulant medication for ADHD, found that one of the main benefits of the medication was that the individuals were able to “process experiences in the same way most nonaffected people do” (p305). Stimulant medication enabled the adults to concentrate on one theme or activity at a time and enhanced previously poor impulse control. However similar to this study some of the adults were affected by memories of their past lives because they were no longer able to “rapidly turn their attention elsewhere” due to the medication (p305). In a similar vein, Young (2000) concluded that one of the potential outcomes of treatment is that the adult may “become more reflective, resulting in increased rumination over life’s failures” (p25).

The participants discussed a sense of having to re-negotiate their own identity and sense of self following the diagnosis and start of medication. For a number of participants a distinction between their ‘pre and post diagnosis sense of self’ was observed and a need to reconcile these differences was discussed. A large amount of research in chronic illness has looked at the impact of diagnosis and treatment onset on the self and identity. Research has found that chronic illness is often a threat to the self and identity as it challenges and undermines the individuals’ assumptions of themselves (Charmaz, 1995). When this occurs the individual may need to “separate the person of the present from the person of the past” in order to arise at a new
conception of who they are (Corbin and Strauss, 1987). A number of different descriptions of these changes have been suggested (e.g. biographical disruption; Bury, 1982) however the work by Corbin and Strauss, (1987) appears to have the most relevance to this study.

Corbin and Strauss (1987) argued that when individuals are faced with chronic illness it becomes a part of who they are rather than defining their whole self. The process of biographical accommodation is where the illness is first defined and then integrated into their life. Part of this biographical work is known as identity reconstitution. This is where the individual begins to review the parts of their self that have been lost (perhaps temporarily or forever), the parts that remain and the parts that can be taken forward. They may then need to decide if any new aspects of self can be added. The aim of this is to try to re-gain a sense of who they are and to rebuild their identity. In this study a number of participants were concerned that aspects of their self had been lost following the diagnosis and start of medication (e.g. their enthusiasm and spontaneity). For some this led to a need to review who they really were (e.g. by stopping their medication), whilst others described a need to separate their ADHD from their sense of self in order to make sense of the changes that had occurred.

4.2 Theme 2. Adjustment to the diagnosis.

Theme 2 described the process through which participants went on their search for an explanation of their problems. This culminated in an informal and formal diagnosis and participants described a range of emotional responses to this process.

Once participants had become aware that there was a problem they (and their family) were placed in a position of uncertainty and confusion. The position of uncertainty was often uncomfortable and led to them seeking an explanation for the problems. According to Attribution Theory the response to uncertainty is to seek an explanation in order to establish a cause (Brewin, 1988). Uncertainty has been reported in several studies of chronic illness. Osborn and Smith (1998) found that their participants with chronic pain reported trying to actively make sense of their pain experience by trying to establish a cause. Similarly, Robinson (1988) found that participants with
undiagnosed Multiple Sclerosis entered a long process to legitimise the symptoms they experienced before a diagnosis.

Osborn and Smith (1998) found that participants experienced hopelessness and frustration as they were unable to attribute a cause of the pain or a useful explanation. In this study, participants' search for an explanation of their problems was frequently met with an unsatisfactory outcome from medical professionals. This in turn triggered more despair and hopelessness and in some cases anger as they too were unable to provide an explanation for the problems. This provides support for the suggestion that uncertainty may be associated with psychological distress (e.g. Idler, 1993). It may also have been associated with being in a position of 'diagnostic limbo' (Corbin and Strauss, 1988) in which there is no available diagnosis to confirm the problems. During this time individuals seek multiple services when their "complaints are discounted and dismissed" in order to reassert their own personal credibility (Charmaz, 2000) (p282). Repeated and unsuccessful contact with multiple services and mental health professionals may understandingly be associated with anger and a belief that the person is 'untreatable' (Young & Harty, 2001).

The continued confusion and uncertainty experienced by the participants led them to pursue their own search for an explanation of the problems aside from contact with formal services. The process of information gathering usually via magazine articles and internet searches often culminated in an informal diagnosis being made. This was similar to the above study by Robinson (1988) who found that participants conducted a long period of information gathering in order to remove the "discrepancy between their perception of what they felt was happening to them and the doctor’s perception" (p47).

The adjustment process to the diagnosis of ADHD provided considerable support for Murphy's (1995) stages of adjustment model. Murphy described six stages through which an adult progresses following a diagnosis of ADHD. These consisted of; relief and optimism, denial, anger and resentment, grief, mobilisation and accommodation. However, participants did not appear to move through time and events in a unidirectional way as reflected in the Murphy’s stage model or as implied by the Illness
Career Model described in the introduction section (Hughes, 1958: cited in Karp, 1984). Instead the process was non-linear and recursive as reflected in the concept of ‘trajectory’, and varied substantially between participants (Conrad, 1987). Illness trajectory represents a “passage through time but one with a fluctuating or nonlinear existence” (Yoshida, 1993) (p221). The concept of illness trajectory has been applied in a number of studies of chronic illness (e.g. Conrad, 1987; Strauss & Glaser 1975).

All of the participants experienced a sense of immense relief following the diagnosis which provided evidence for Murphy’s (1995b) stage of relief and optimism. This also supports the study by Van der Linden et al., (2000) which found that adults had a positive response to the diagnosis of ADHD. It does not support Taylor’s (1983) theory of cognitive adaptation to threatening events as the diagnosis of ADHD was not viewed in this way and participants did not seek to “return to their previous level of psychological functioning “ (p1170). Robinson (1988) suggests that initial relief experienced in response to a chronic diagnosis may not be unusual. For individuals who have experienced a range of symptoms over a protracted period of uncertainty the diagnosis provides a point where “credibility is established” (p50).

Following the diagnosis and prescription of stimulant medication the participants all described a more optimistic view of their future. For some participants the initial optimism experienced following the diagnosis led to the development of unrealistic raised expectations and culminated in the realisation that these could not be met. Optimism and raised expectations are briefly addressed in the first of the stages by Murphy (1995b), however they do not represent a separate stage. Solden (1995) suggests that this stage could be described as ‘bargaining’ and occurs where the actual benefits of the ADHD diagnosis and medication do not match the person’s high expectations of it. As a result the adult may be more prone to periods of discouragement.

The participants encountered a range of emotional reactions to the diagnosis similar to those proposed by Murphy (1995b). However, as previously discussed these varied considerably from one participant to the next. There was no indication that the participants followed the order of the unidirectional grief cycle or indeed that they
needed to pass through all of the emotional reactions to move forwards. Similarly, for many participants, different emotional reactions occurred simultaneously or shifted rapidly between one and another. Yoshida (1993) suggested that this type of adjustment reaction can be described in terms of a pendulum since people move back and forth between adjustment responses (p241). The pendulum idea challenges the view that individuals reach a final stage where they fully adjust or accept the diagnosis or illness. This study found some support for this idea. Participants did encounter a sense of partial adjustment to the diagnosis marked by a need to become more future orientated and make some decisions about change (e.g. behavioural or lifestyle). This was similar to the mobilisation and accommodation stages described by Murphy (1995b). However it was not necessarily viewed as a final stage. For many participants partial adjustment occurred concurrently with other post-diagnosis emotional reactions and alongside the belief that the diagnosis and medication was not enough. Length of time since diagnosis did not appear to be related to degree of adjustment.

4.3 Theme 3: Self Versus Society.

Theme 3 emerged through frequent references by participants to either actual or anticipated stigmatised reactions from others. Prior to the diagnosis an awareness of difference from other people was sensed and this was often confirmed by negative labelling. The awareness of difference between the participants and others combined with the persistent application of negative labelling led many participants to withdraw from others. Following the diagnosis participants reported a heightened awareness of real or anticipated stigma either in relation to the label of ADHD or use of stimulant medication. This led to difficult decisions surrounding disclosure to others.

Prior to the diagnosis all of the participants reported persistent negative labelling applied by others, primarily teachers, school peers and in some cases family members. The negative labelling appeared to be consistently applied in the absence of a diagnosis or definitive explanation of the problems. Rucklidge (1997) suggested that adults who do not receive a diagnosis until adulthood may be protected from earlier effects of social ostracising. However contrary to this suggestion the very absence of
the diagnosis appeared to exacerbate the negative effects of the labelling. Participants attributed the cause of the problems to themselves as the negative labelling consisted of largely characterological labelling. Cantor (2000) suggested that in the absence of an available explanation the individual is more likely to develop internalised blame and a feeling of immense shame often caused when individuals evaluate themselves using the perception of others.

The withdrawal and social isolation which often occurred as a result of the labelling may in turn have caused further social rejection or ostracising which provides support for the idea that stigma may be enacted as a result of the labels applied or the coping strategies used to deal with it (Link, 1987). Not all participants responded by social isolation or withdrawal. Some described the need to fit in and be accepted by their peer group. This supports the suggestion by Goffman (1963) that if individuals can present themselves as ‘normal’ they are less likely to be discredited by others. Similarly, Thorne (1993) suggests that individuals may attempt to ‘fit in’ in their need to appear normal.

After the diagnosis of ADHD had been made all participants reported experiencing stigma despite the suggestion by Van der Linden et al., (2000) that “ADHD does not appear to attract the stigma found in some other psychiatric disorders” (p533). Scrambler (1998) suggested that “not all potentially stigmatising labels are immediately unwelcome” (p1054). Indeed for the participants in this study the ‘label’ of ADHD was initially welcomed and positively received after a protracted period of uncertainty. However, for most participants this was a double edged sword as the ‘label’ of ADHD did have some real and anticipated negative consequences.

According to Scrambler (1998) stigma may refer to a trait, attribute or an identifiable mark that means that the individual is seen as different from ‘ordinary peers’. Charmaz (2000) argues that the difference between the individual and others may lead to the development of a ‘master status’ (e.g. disabled person) in which the individual is defined by the stigmatising label applied to them. In some cases the stigmatised label subsumes other characteristics of the person and becomes the defining identity of that person. Krueger and Kendall (2001) found that their sample of adolescents with
ADHD had taken on an identity which incorporated the “stigmatising beliefs and negative attributes of ADHD” (p65). This meant that their definition of self was not separated from the disorder. The participants in this study did not use the ADHD as the main defining characteristic of themselves but instead were able to acknowledge the presence of the disability. They were none the less aware of and influenced by the potentially stigmatising qualities of ADHD.

The participants in this study distinguished between anticipated stigmatised reactions from others and actual experiences of stigma. This finding supports the distinction between enacted and felt stigma proposed by Scrambler and Hopkins (1990). Enacted stigma refers to actual experiences of stigmatised reactions from others while felt stigma refers to a sense of shame for having the difference and a fear that this difference will be discovered. According to Scrambler and Hopkins a fear of enacted stigma may predispose individuals to conceal their diagnosis from others and avoid disclosing this information. This is supported in this study as participants discussed their concerns about whether to disclose their diagnosis of ADHD to others. The decision about whether to disclose or not was often weighed up with the possible risk of being discredited by others upon disclosure. For a number of participants the fear of enacted stigma meant that they concealed their diagnosis from others deemed likely to make a negative judgement about them following the disclosure.

The decision about whether to conceal the diagnosis of ADHD from others may also have been influenced by the perception of ADHD as an invisible disability. For some participants the need to disclose the diagnosis was hampered by fears that it would not be legitimated by others because of its invisibility. Goffman (1963) distinguished between two types of stigma based on the visibility of the condition. Visible disabilities are those that can be seen physically and are defined as discredited. Invisible disabilities are hidden from view and are defined as discréditable. According to Conrad (1987) both pose particular implications for stigma. An invisible disability is concerned with problems of ‘information management’ (when to disclose etc.) in view of an exterior of ‘normality’. In this study several participants identified the decision of whether to disclose or not as potentially stressful and
suggested that the presence of more visible signs of a problem would remove some of the difficulties raised by continual concealment.

Vickers (2000) argued that lack of knowledge or inaccurate knowledge about a disorder or attribute may contribute to stigmatised reactions from others. In the presence of ambiguity individuals may “resort to beliefs and myths to fill in gaps in their knowledge” (p139). As a result the individual may feel misunderstood and may be more likely to conceal their condition. At present the dominant lay perspective in the UK is that ADHD is a childhood disorder and little attention has been paid to its presence in adulthood. The participants in this study acknowledged that some of the negative reactions from others had revolved around the attribution that ADHD was a childhood disorder.

4.4 Methodological limitations of the study.

4.4.1 Relationship between researcher and participants.

According to Smith (1996) the perceived impact of the researcher on the research process and the participants should be considered in qualitative research. However Smith suggests that this should not necessarily be viewed as a methodological weakness.

The researcher was careful to outline her role as a trainee clinical psychologist who was not associated with the medical treatment at the clinic although it is possible that the interviewees viewed the researcher as an agent of the medical system. This may have meant that some participants were more reluctant to disclose certain types of information (e.g. personal experiences at the clinic, relationships with medical staff). However the researcher found that a number of participants were open about misgivings about the diagnosis or treatment, and similarly in their discussion of self identified treatment needs.

The researcher was also mindful that the title trainee clinical psychologist may have made a bearing on some of the participant’s responses. The salience of this issue was
suggested by the fact that several participants asked questions about the role of psychological intervention in working with adults with ADHD. Similarly in some cases the participants may have been more or less reluctant to focus on issues concerned with their previous or existing levels of mental health.

The researcher made a number of efforts to monitor her input into the interviews with the participants although at times her own understanding of adult ADHD (e.g. from discussions, reading literature) may have influenced the types of questions asked or the focus of the area explored. The researcher was aware of the need to return to and stay close to the participant’s contextualised account.

4.5.2 Retrospective accounts.

The adults’ accounts of their experiences prior to the diagnosis and treatment are retrospective in this study. Retrospective accounts are subject to problems of distortion and inaccuracy. Greenwald (1980) suggests that people tend to use their current self-concept as a basis for constructing their past. As such the validity of the data can be questioned (Barkley, 1998). However, these problems were accepted as part of the process of obtaining participants’ accounts for the purpose of the research. According to MacKechnie (1998) acknowledging the inherent biases associated with retrospective accounts “does not entirely discount the status of the individual’s reports as providing valuable hypotheses for future research and clinical management” (p292).

4.5.3 The sample.

The sample was extremely diverse in terms of age, educational level, living arrangements, length of time since diagnosis, and medication used. Males and females were equally represented in the sample. This may be an important consideration for research in the area of ADHD as females are generally considered to be underrepresented in ADHD sample populations (Rucklidge, 1997). MacKechnie (1998) suggests that the diversity of a sample is more likely to reflect clinical reality and may be a strength in the use of qualitative inquiry. However, generalisation
cannot be assumed from the use of diversity in qualitative research. Osborne and Smith (1998) state that the concepts derived from qualitative research may not be generalised to the wider population outside of the sample used but they may transfer to similar structural contexts.

4.5.4 Interview length.

The length of the interview was long for some of the participants. Some interviews lasted for up to 95 minutes. The main reason for the length of the interview was that a number of the questions were asked twice (related to experiences prior to the diagnosis and after the diagnosis had been made). Some participants found it difficult to attend to the questions and to their responses. As a result questions had to be repeated and participants had to be reminded of the subject matter they had been discussing. This process also increased the interview length. In order to prevent the participants becoming fatigued the researcher offered a break or the option to discontinue the interview,

4.6 Clinical recommendations.

Murphy (1995a) suggested that the way that the diagnosis is communicated is critical to adults' understanding of the disorder and may have implications for future treatment adherence. The initial relief and elation experienced by the participants may have compromised their ability to take in the information provided by the professional at the diagnosis stage. Written information in the form of an introduction to ADHD in adulthood may be a useful initial resource for the adults. The opportunity for them to attend a follow up appointment soon after the diagnosis has been made may be useful for adults to discuss their initial reactions to the diagnosis, and to ask any questions that they may not have thought to ask (e.g. in regards to treatment, future appointments etc.). In addition adults could be directed to support groups or other relevant agencies where appropriate.

There appear to be potential risk points for adults as they adjust to the implications of the diagnosis and medication use (e.g. initial high expectations followed by
depression, anger, grief, and denial). Some participants expressed concern about their increased rumination on aspects of the past and their need to negotiate the ADHD into their sense of self. All participants discussed long-standing histories of chronic low-self esteem, repeated experiences of failure and low internal control which have been described as secondary effects or sequelae of the primary symptoms of ADHD (Bemporad, 2000). These may indicate areas where a Clinical Psychologist may provide direct intervention with adults if needed. This highlights the potential value of a multi-modal approach to treatment which combines a mixture of pharmacological treatment and psychological intervention as it addresses both primary and secondary problems of ADHD.

Psychoeducation following the diagnosis of ADHD in adulthood has been widely discussed as an important early intervention for adults diagnosed with ADHD (e.g. Weiss, Hechtman, & Weiss, 1999), (Barkley, 1998). Psychoeducation provides a framework for education about ADHD and treatment options. It also enables the individual to explore in more detail the cumulative effect of not being diagnosed (e.g. protracted periods of uncertainty, the breakdown of relationships) on themselves (Murphy, 1995a). The ‘islands of excellence’ or preserved areas of competency or ability identified by participants in Theme 1 may have a protective function for some adults. These may be acknowledged and encouraged by the psychologist in order to enhance self-esteem and beliefs in self-efficacy in the early stages of intervention (Brown, 2000).

At a later stage after the diagnosis, Cognitive Behaviour Therapy (CBT) may be appropriate for some adults. CBT has recently been empirically validated for adults with ADHD (Wilens, McDermott, Biederman, Abrantes, Hahesy & Spencer, 1999). Young (2001) suggests that CBT may be a useful intervention for adults with anxiety, depression and anger management problems as well as enabling the individual to develop strategies in problem solving skills, interpersonal skills and impulse control.

Most of the participants discussed a long standing history of feeling different and this often led to periods of self-isolation or withdrawal. After the diagnosis had been made participants explored issues of stigma and problems of disclosure. A support
group or therapeutic group with other adults with ADHD may help to counteract some of these feelings of isolation and self-deprecation resulting from stigmatised reactions. It may also provide a forum to discuss and rehearse various problems (e.g. disclosure to a work colleague). CBT may be a useful psychological treatment approach for a group format as it is time limited and provides structured goals (Young, 2001).

4.6 Directions for future research.

It has been shown by this study that qualitative IPA is a useful methodology to obtain an in-depth understanding of the experiences of adults who are diagnosed and treated for ADHD. There are four main suggestions for future research.

This study was based on retrospective accounts of the participants' experiences prior to the diagnosis and after the diagnosis had been made. A longitudinal approach would help to address some of the difficulties raised by retrospective accounts and the variable time period since diagnosis. A sample of adults could be selected at the point of entry to an adult ADHD service (i.e. prior to the diagnosis) and then followed up at regular intervals over a set period of time following the diagnosis.

Robinson (1988) suggests that making sense of the implications raised by a diagnosis is mediated by a "complex series of social interactions," particularly the interaction between the individual, their partner and family members (p55). Future research should address the impact of the diagnosis of ADHD on family members and wider social network and not just the individual.

This study did not reveal any differences between the males and females interviewed. Future research could incorporate a larger sample of adults which may help to determine whether there are any gender effects of late diagnosis.

Limited research has focused on the difference between adults diagnosed with ADHD in childhood and those diagnosed in adulthood. Future research should address this in more detail to determine whether the psychological risks are greater for an
undiagnosed population. The identification of risk and/or protective factors for adults with ADHD may also enhance future psychological understanding.
5.0 Summary.

This study explored the impact of a diagnosis of ADHD and medication in adulthood. In-depth accounts of the adults' experiences were obtained with the use of semi-structured interviews. The study illustrated that the diagnosis had a profound impact on the participants' views of themselves and for most this meant changes in their self-esteem, their view of the problem and an increased understanding of themselves. The diagnosis and medication also led to a process whereby they re-negotiated their identity and sense of self to incorporate the ADHD diagnosis.

The adjustment process to the diagnosis of ADHD did not represent a linear model of adjustment but instead was recursive and non-linear. Adults described a range of emotional reactions to the diagnosis which ranged from frustration and depression to bereavement and guilt. Partial adjustment to the diagnosis was usually associated with a need to become more future orientated, to make some decisions about practical issues and to move towards making some change (either behavioural or lifestyle changes).

The diagnosis of ADHD and use of stimulant medication was associated with real and anticipated stigma. Prior to the diagnosis all participants described the experience of negative labelling from others despite the lack of a diagnostic label. The application of negative labels such as "lazy" was a constant reminder of their difference from others.
6.0 References.


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7.0 Appendices.

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Appendix 1

Letters of ethical approval.
ETHICAL COMMITTEE (RESEARCH)

28 June 2001

Dear Dr.:

Re: Experiencing a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adults (105/01)

The Ethical Committee (Research) considered and approved the above study at its meeting on 15 June 2001.

Initial approval is given for one year. This will be extended automatically only on completion of annual progress reports on the study when requested by the EC(R). Please note that as Principal Investigator you are responsible for ensuring these reports are sent to us.

Please note that projects which have not commenced within two years of original approval must be re-submitted to the EC(R).

Any serious adverse events which occur in connection with this study should be reported to the Committee using the attached form.

Please quote Study No. 105/01 in all future correspondence.

Yours sincerely,

[Signature]

Research Ethics Coordinator
27 July 2001

Trainee Clinical Psychologist
Department of Psychology
University of Surrey

Dear Mrs

The experience of a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood (ACE/2001/60/Psvch) – FAST TRACK

Further to your recent submission of the above protocol to the Advisory Committee on Ethics, I confirm that this has now been circulated on the Fast Track procedure to the members of the Committee for their consideration.

In the meantime, I am returning the Protocol Cover Sheet for full completion, namely:
- your supervisor, Dr., should be included in part 2 as principal investigator;
- you should also be named as principal investigator;
- point 11, Checklist, should be completed;
- all investigators (including yourself) should sign part 12.

I enclose a blank Protocol Cover Sheet should you prefer to complete it instead of the form submitted, but it is also acceptable if you amend the current sheet as indicated. Please refer to the enclosed Guidelines which may be helpful. I confirm that completion of the Protocol Cover Sheet will not delay the approval process, but we will need the fully completed form before approval can be granted.

Please return the completed form to me. I look forward to hearing from you shortly.

Yours sincerely

Secretary, University Advisory Committee on Ethics

Cc: Dr. Supervisor, Dept of Psychology
    Dr. Co-Investigator, Dept of Psychology
Appendix 2

Information sheet for participants.
RESEARCH INTO THE EXPERIENCE OF A DIAGNOSIS OF ATTENTION DEFICIT HYPERACTIVITY DISORDER IN ADULTS (ADHD)

What is the research study about?

The study is being carried out to investigate what it feels like to receive a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood and given medication to help with the difficulties. There is currently very little research that looks at the way that people feel about receiving the diagnosis and the impact that it may have on how they feel about themselves. By listening to adult’s views about this, it is hoped that it will enable health professionals to learn more about how they can work with and help other people who have ADHD in the future.

Who will be doing the study?

The research study will be carried out by Mary Bond, Trainee Clinical Psychologist as part of her post graduate degree in Clinical Psychology.

Who will be in the study?

We would like to ask adults who have been diagnosed with ADHD and who are receiving medication for this.

Do I have to take part?

The study is completely voluntary and it is up to you to decide whether or not to take part. If you decide that you do not want to participate in the study, your decision will not affect your treatment in any way.

If you do decide to take part in the study, you will be asked to sign a consent form, saying that you would like to take part. You are free to change your mind at any time and again this will not affect the treatment or care that you are currently receiving. You do not have to give a reason if you wish to change your mind.

What will I have to do?

You will be interviewed by Mary Bond. The interview will last for about an hour and a half. It will take place at the ADHD clinic in the Hospital and it is hoped that this will be before your next follow up visit.

The interview will ask you about how you feel about the diagnosis and medication, how you feel it has affected you and how you feel you are coping with it. It will also ask you to talk about how you felt before you were diagnosed.

The clinic will be informed that you are taking part in the research. If something comes up in the interview that you would like to discuss further, a member of staff at the clinic will be able to discuss this with you.
Will the information I give be confidential?

Yes. The interview will be tape recorded with your consent so that the interview can be written down. The tape of the interview will be destroyed once the research has been completed. Your interview is confidential and all names and places that you mention will be removed. Instead of using your name when the research is written up, you will be given a code to ensure that you cannot be identified.

What do I do to get involved in the research?

I will shortly be contacting you by telephone when you have had chance to look over the information sheet and think about whether you would like to be involved. This will probably be in about two weeks time. It will also give you the chance to ask any further questions.

If you have any further questions about this study in the meantime, please contact:

Mary Bond
Trainee Clinical Psychologist

Contact telephone number:

Dr , Consultant Psychiatrist, Principal Investigator.
Dr , Chartered Clinical Psychologist, Research Supervisor.
Appendix 3

Covering letter sent to participants.
Dear

I am a Trainee Clinical Psychologist at the University of Surrey and as part of my post graduate course in Clinical Psychology, I am conducting some research into the experience of having a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood. Dr , Consultant Neuro-Psychiatrist at the adult ADHD clinic, at Hospital suggested that I write to you to see if you would be interested in helping with this research. I enclose an information sheet about the research, which describes a little about what it would involve.

I will be contacting you shortly by telephone when you have had a chance to read the information sheet and think about whether you would like to get involved with the research. I'd like to take this opportunity to thank you for considering this and for taking the time to read the information sheet. If you agree to participate in the research, the interview will be conducted before your next follow up appointment or at your home on a date convenient to you.

Yours sincerely

Mary Bond
Trainee Clinical Psychologist.
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<td>Consent form.</td>
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Major Research Project

CONSENT FORM FOR PARTICIPANTS

Experiencing a diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) in adulthood.

Principal investigator: Dr , Researcher: Mary Bond

Part A: To be completed by the researcher:

• I confirm that I have explained this study both orally and in writing to the participant:

Part B: To be completed by the participant:

• I confirm that I have read and understand the information sheet for the above study.
• I confirm that I have been given the opportunity to ask questions and discuss this study.
• I understand that I am free to withdraw from the study at any time and that my involvement in the study is voluntary. I understand that if I decide to withdraw from the study at any time, my medical care will not be affected in any way.
• I understand that my interview will be tape recorded so that the information I give can be processed for the purposes of this study. I understand that the tapes will be confidential, will be kept in a safe place and will be destroyed once the research has taken place.
• I agree to take part in this study.

Name of patient __________________________ Date ____________

Signature of patient __________________________

Researcher __________________________ Date ____________

Signature of researcher __________________________

Patient identification number:
Appendix 5

Background information sheet.
### BACKGROUND INFORMATION FORM.

**Participant information questionnaire.**

<table>
<thead>
<tr>
<th>Name</th>
<th>Date of birth</th>
<th>Participant number</th>
<th>Date of interview</th>
<th>What are your educational qualifications?</th>
<th>What is your current (or last) occupation?</th>
<th>Please (in your own words) describe your ethnic background</th>
<th>What is your current marital status?</th>
<th>Do you have any children?</th>
<th>If so, how many?</th>
<th>Date first diagnosed with ADHD</th>
<th>Date first prescribed medication for ADHD?</th>
<th>What type of medication?</th>
<th>When do you take the tablets?</th>
<th>Times of the day?</th>
<th>Weekends/week days or all week?</th>
<th>Are you receiving any other input for ADHD? E.g. counselling</th>
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Appendix 6

Interview schedule.
INTERVIEW GUIDE

Introduction

Introduce self and aims of the research project. It is important to gain an understanding of people’s views and ideas. Explain confidentiality procedures. Need to obtain the consent form for recording the interview.

Interview Outline

This interview will cover the following areas:

1. How you felt about yourself before the diagnosis of ADHD.
2. How you coped with the difficulties before the diagnosis.
3. The diagnosis itself and how it felt to go to the clinic to receive medication.
4. How you have felt about yourself since the diagnosis and what has changed.

Perception of problems before the diagnosis:

1. When did you notice that there was a problem / or you were experiencing difficulties?
2. What problems did you notice?
3a. How did this affect you when you were growing up?
3b. How did the difficulties affect your relationships when you were growing up?
4. What did you think was causing the difficulties?
5. What do you think other people thought was causing the difficulties?
6. Before the diagnosis, how did you feel about yourself?
7. How do you think others saw you as a person before the diagnosis?
8. What contact did you have with other services before the diagnosis?
9. Did it help explain any of the difficulties or help you to understand and deal with them?
10. It sounds as though you have had a lot to cope with over your life. What has helped you to deal with the problems?

**Perception of problems after the diagnosis.**

11. How did your diagnosis of ADHD come about?

12. How did you feel when ADHD was first diagnosed in adulthood?

13. How was it explained to you?

14. How did you explain ADHD to other people?

15. You said when you were first diagnosed with ADHD, you felt X, did your feelings about the diagnosis change with time and if so, in what way?

16. What things are different about your life now that you have been diagnosed with ADHD?

   (what has stayed the same?)

17. What do you think caused the ADHD?

18. What do other people think is causing the difficulties now?

19. In general, do you think your relationships have changed with people since the diagnosis?

20. Since the diagnosis and medication have you noticed any differences in the way that you view yourself?

21. Have other people noticed any differences in you?

22. Has the diagnosis changed your thoughts or beliefs about the future and what it holds for you?

23. What do you feel about taking medication for ADHD?

24. What changes have you noticed in yourself since taking medication?

25. Have other people told you about changes they’ve noticed in you since taking medication?
26. Do you notice any differences in yourself when you do not take the medication or when it wears off?

27. Since the diagnosis, has the way you cope with things changed?

28. Since the diagnosis, have you or are you currently receiving any input from other services?

29. What help would you like for the future?

Conclusions and reflections on the interview.

Can we just take a few moments to ask you how you felt about doing this interview?

Is there anything else you would like to add?

Thank you for your help and for taking the time to speak to me.
Appendix 7

Sample interview transcript.
When did you notice there was a problem or you were experiencing difficulties?

A: Um, I guess I would have had problems quite a lot at school particularly in my third year at school, but also in primary school just being someone who was always being told to pay attention. But I suppose as an adult it would have been at work where I realised in my second to last job that I wasn’t holding it together at all. I could intellectually understand things but I couldn’t get myself to sit down and produce the output but I was put in a position where I had to do that. I had to write a lot of detail about what I was doing and I started finding things becoming really really hard.

You mentioned a little bit about the sort of different stages of that when you noticed the problems I wonder if you could tell me in a little bit more detail about the sorts of problems in perhaps your childhood that you actually noticed.

A: Right ok. Ooh long standing family joke about me running around a lot, um you know if we got to a wide open space I would just be off and there would always be someone allotted to run after me. Um, lot’s of funny stories about me running off and falling down muddy slopes and into holes and things like that and airports and beaches and things. But also when I must have been about three between nursery and kindergarten my parents were at their first parent teacher meeting and they sort of made a comment about me being a little bit backward. My family thought you know “not my daughter” and they said she’s really not interested, she keeps herself separate from the rest of the class and doesn’t get involved, it’s very hard to get her interested and we think that she’s just not quite as bright as the others perhaps. And Dad said “but she can read” so they took a bit of a look at it and I ended up to be the youngest kid ever to read the lesson in prayers when I was four or something like that cause I used to sit with my Dad and just used to read away or maybe he was forcing me a bit or maybe not, you know it was just something we used to do. So that I guess is the sort of very earliest one. Just something people couldn’t quite put their finger on and I think at the time you know the puzzled parents think their child’s a genius but wasn’t, just bright and scatterbrained but not quite genius level. Then when I was about eight or nine, yes about eight or nine, I had tantrums because I used to go off into my own little world and I used to build things in my desk, little structures and stuff, um, when I got fed up. That year we had a teacher who wasn’t quite as calm and composed as the others and she used to pick on me a bit. And you know if I was caught not paying attention and for building things, she would kind of make fun of me. And on quite a few occasions I would throw the entire contents of my desk or I think once I actually threw the desk over and ran out of the front door because we weren’t aloud to go out and down the drive and try and get home. I keep in touch with a couple of old school friends and you know they said if they had a really boring lesson or something they would think you know (name of participant) is going to throw a tantrum today and also I don’t know, just being very good in a whole crowd when there’s lots going on but not being very good at making good friends or having very many close friends. Everyone else seemed to team off with best friends or a gang of two or three and I couldn’t do that, never quite got the knack of that.

Why do you think it was then that you found difficult to do that?

A: I think, I don’t know it just seemed that everyone else knew how to keep everything constant and smooth and I just seemed to, I don’t know, probably be quite an intense girl I think, quite intense kind of a bit moody as well. I’d go off into my own little dreams and stuff, spend a lot of time on the piano and things like that, solitary things, if you can play pop songs on the piano that’s good you can be popular but before that I just never used to quite get the knack of the social things that were going on.

So that was difficult for you to work out for you?

A: Yes, yes um it’s funny, in year seven I started coming first in subjects. I can remember the in crowd, the group of girls that always came top who were also quite cool because they were good at sports and so on. And they said “oh get (name of participant) over” and they said “did you know you came first in English you know you’re definitely in the top five you might be in the top three” and that was quite something, me as an outsider being asked into that it felt a bit weird.

What did you make of it as a child when you were looking at yourself against other children?
A: Um, what did I make of it as a child? I don’t know. I think I used to be very conscious and I probably still am and I’m aware of it as an adult. I think I still am actually as an adult but very conscious of other peoples moods and observing. I always felt a bit of an observer. I always felt like I was watching a film that wasn’t quite in. And also don’t know, I don’t know, just really that other people had some knack that I didn’t, that they were sort of perfect and I wasn’t, that there must be something wrong with me but I don’t know it’s kind of confusing to tell what’s... I mean I had a bit of a rough year when I was seven to eight because we left the family home after my parents split up and you know it all happened very suddenly and nothing was really explained so I didn’t get the chance to say goodbye to my Dad. Then we went to live in a medical residence in a psychiatric hospital so, you know the things like going to somebody’s house for tea or them coming to yours for tea, that stopped because people didn’t really want their kids wandering around that hospital at the time, that was late sixties early seventies you know tried to be open minded but weren’t terribly open minded. I think I was actually quite a depressed wee girl. I did a lot of wandering around by myself and that sort of thing, it’s hard to know if it was that or if it was the ADD or whatever.

Is there anything else you wanted to say about how this affected you when you were actually growing up?

A: Yes definitely, yes definitely. Um I was really really bad at sports and I could never work out why and the games mistress, we had the same games mistress all the way through school, and she used to be alternately encouraging and really disparaging you know ‘you’re really scatter brained and you have to stop this business of forgetting your gym stuff’. You know I think I was about 12 or 13 you know ‘just pull yourself together just see to it’ you know I found it really upsetting. There was a lot of that sort of that sort of thing just being scatterbrained and gangly just not feeling as co-ordinated as everyone else. So lots of trying really hard. You know I could get a really high grade or something. I would just throw everything into doing that. And then with the other stuff I could understand intellectually but I couldn’t get a good grade in the exam - stuff with short-term memory stuff I struggled with. I used to do an awful lot of last minute cramming before an exam and get some results from stuff like last minute cramming and just regurgitate it on to the paper. So a lot of that. But also really especially in secondary school I had a real sense of frustration that I could track everything that was going on and get a lot of the teachers interest for asking good questions and things but then not able to follow through. My school reports are full but aren’t everyone’s of ‘could do better’, ‘try harder’ that sort of thing or also ‘what happened here?’ And also we have a sort of family word which is used a lot about me and sometimes about my sister which is (inaudible) which I think is made up, it’s either made up or it’s a Scottish word which means you’re in a dream. But it’s more than in a dream.

How did it affect you actually as a person with yourself?

A: OK. Um, I think I’ve always thought myself as a bit of a weed, you know at school there was kids who were the in crowd and then there was sort of and I always felt I was a weed. Erm, I suppose since school from flashes of inspiration I’ve been trying not to be one. I’ve tried to be that ‘shiny’ together sort of thing and expecting that if I just got myself together, you know if I just pulled it all together I could be that. You know there must be some sort of enlightenment that’s under a rock. Here I am at 38. You know you’re not just going to turn into, that sort of polished and composed sort of thing is not going to happen, which is funny because I always thought it was there, just really a sense of not having done myself justice.

How did it affect your self-esteem and your self-image?

A: Ok, I think, I know I’ve got huge problems with self esteem and close friends and people who just say things without thinking too much and you know in all sorts of different phases of life you know school, university they would say ‘you’ve got problems with self-confidence or self esteem, you know you should value yourself more’. And boyfriends and so on would say ‘you don’t do yourself justice you know you’d enjoy yourself so much more if you knew how much other people valued you’. But I’ve got such a stack of unfinished stuff or stuff that I’ve made a mess of and then everything just seems to trail away into a mess. So I feel that I haven’t achieved anything very much. And the whole time management thing, that is just a nightmare. For years I’ve been annoyed with the rest of the world. I just thought people were trying to score points by saying that they were really good at it and everyone
else had to tow the line but now I know in adulthood I’m really really bad at it. Except when I’m in charge and I’m running a meeting or something and I get, for the last few years I haven’t had so many experiences or opportunities to do that. I suppose early thirties late twenties I had a few jobs where I was doing lots of chairing and stuff and I could be really really focused but I think everything kind of went to pieces in the last two or three years.

*How much control do you think you had over the problems when you were growing up?*

A: I don’t think I really thought about control. I suppose when I was studying for exams I did a couple of piano pieces for a music festival and stuff. Um I was very applied so I suppose I felt that I had control.

*In terms of whether you felt able to stop things happening to stop the problems happening?*

A: No I just always felt a bit dipsy and just always wondered, I always wondered if I had some sort of problem and at school (inaudible) and that kind of stuff.

*So did those sorts of things affect your self-esteem?*

A: Oh yes definitely. I mean it can still do, there’s one old school friend still thinking she’s being funny she can still say one of those things and I can’t. You know I just feel I’d really crumble.

*You might have answered this a little bit partly but what did you think was actually causing the difficulties?*

A: Um I think I felt I thought it was partly me and partly because my parents were divorced and also that I was really disorganised.

*So you thought it was something about you?*

A: Yes definitely

*What did you think other people thought was causing the difficulties?*

A: Um, good one. I don’t know apart from kids round about eight, nine ten saying ‘you’re mental’ and that kind of thing. I think a lot of people thought that home was a bit chaotic so there was a bit of that. I think my Dad thought, although I only saw him once a week with access rights and things, I knew from my stepmother that he thought I didn’t have enough time to play and you know I think other people in the family would say structure, it’s all about structure, more discipline, structure and everything will be fine.

*What about teachers?*

A: I think they just thought I was scatterbrained and oppositional and ungrateful you know because so many people were putting so much effort into my education, you know, I wasn’t returning the effort which felt really unjust because I was. I felt like I was struggling quite hard. And then of course every so often you get a really blinding run of brilliance but sadly lacking on other occasions, you know those sorts of things. God, they really ingrain into you these sorts of things don’t they? Yes I suppose, yes the games mistress saying ‘a lot of people and your poor mother is having to work very hard in order to keep you in school so just pull yourself together’. I think a lot of people just felt I was scatterbrained, scatterbrained, scatty, dipsy maybe a bit sort of unbalanced, really negative stuff yes and then the really funny sort of counter balance stuff every so often where people say “you know we think you’re a bit of a genius”. I’d think, “where am I in all of this”? and every so often I’d get a really high grade in something. I got over 90% in French once, yeah lots of times around my A’levels I got some really high grades. For my MBA I did an international finance course which I should never have done because it’s all about reading things and then having to regurgitate figures and things. I just know I was absolutely brilliant in the classes and seminars, people used to come to me for help and things and then I got to the exam and I failed so I had to re-sit and I only scraped through. Um, you know so it was just really disorientating, thinking ‘what’s going on here?’, you know, kind of, having quite a lot of
academic pressure to live up to my potential and failing it all the time, feeling that I'm just jumping over hurdles or that I'm just not succeeding.

Before you were diagnosed how did you feel about yourself?

A: Um I thought what was wrong with me you know there must be something badly wrong with my stability or something?

What about as a female how did you feel about yourself as a female?

A: Um I guess I kind of fluctuated in between being academically competitive with the guys when I did engineering um to you know being a kind of dippy bimbo, you know people used to say "don't play up that dumb blond thing, you don't have to do that". But you know it's just how I am and partially it's just a kind of I suppose you'd call it a kind of humorous defense, you know that slightly bimbo thing and that can cover up if I ever just lose the thread in conversations and stuff like that. Um so I suppose a bit of that. But also lots of other girls would be really good at keeping relationships constant and things like that. I always felt really sort of what's the word, you know I'd have periods where I'd have really good friends and I'd put a lot of effort into it and then they'd just go and I'd think what's wrong with me why can't I keep them, so a bit of that. And you know the kind of feeling that's something that I really ought to be able to do how was it that everyone else can do that and I can't. And also being much more scatterbrained when my periods were on a sort of PMT thing, in fact I was banned from washing up dishes as a teenager.

What sort of things did you like or dislike about yourself as a person?

A: OK, um I guess physical composure and not being as graceful as other girls. I've always felt why can't I do that or going along to an aerobics class and being able to follow everything then not being able to do it myself you know you're sort of seeing it but you can't get it to follow through and not understanding that. Are you thinking about problems?

Just things about really how you saw yourself.

A: Um just always that I had, I didn't value myself much at all. But sometimes I'd kind of adopted a kind of attitude where I kind of put myself in a secure position because I'd think 'it's all going on inside my head and these people don't that' and so I'd be a bit aloof sometimes. Erm, but just generally thinking I was just a bit of a failure. And also thinking that at some point it's all going to kick in and just waiting for it to kick in and you know, that sense of things beginning to kick in and reading 50 self-help books but just thinking 'why is this happening?', that kind of thing. Um things like clothes you know getting clothes organised and stuff like that. You know how comes I know people that throw their clothes together and get the look, I would have to spend a lot of money and a lot of time and have some really good advice before I could do that and the rest of the time everything was really kind of flung together. I always looked as though I'd been pulled through a hedge backwards. Um or spending too much time on my appearance you know, having people like my sister saying you know 'don't preen so much you know there's no need to be vain' and that sort of thing. You think I need to do that or being lazy or whatever. Um spending too much time on my appearance you know, having people like my sister saying you know 'don't preen so much you know there's no need to be vain' and that sort of thing. You think I need to do that or being lazy or whatever. The other thing was finding firewood at camping trips I could beat all the boys hands down. A few years ago a bunch of thirty somethings camping you know a couple of the guys were real boy scouts dyed in the wool and we had a real fire wood crisis on day two and I just knew exactly where to look and they were so hugely, hugely mythed it was hysterical and I just knew, I knew what I was doing. Yes founding mud fires or stuff like flora or you know if there's one orchid in the middle of a three mile meadow you know I'll find it.

How do you think others saw you as a person before you were diagnosed?
A: Um, eccentric unachieved genius would be how my friends saw me. I had a friend from school who would say 'you were always the mad professor one you know we always thought you would be going to go off and invent something you know, go to the chemistry lab and come back with some kind of cure all or something'. Um kind of animated, you know being full of action and kind of important so I think up until I think probably up until my thirties um, I was kind of, I think there was a kind of charm to the eccentricity and impulsivity and action and you know come on let's just do this. Um but there's a point where you have to just drop that and become very reliable and I found it really hard to get into that sort of role but I think while you're sort of all through my twenties it was cute, I got away with it. Some people kind of enjoyed it because I was never boring. They would say "you've got a really interesting angle on things" so, it could be something that my friends really valued but they'd also get, particularly the very organised ones, would get very impatient, you know 'get (name of participant) out of the house first and then we'll all follow'. It was a bit like I was a problem child.

How did it affect your relationships then?

A: Oh how long have we got!? Um.

Whether with family or partners

A: Family relationships were really volatile, lots of very intense rows and lot's of slamming of doors, lot's of big shouting matches where everything just builds up and builds up and the pressure just goes and everyone starts shouting and slamming doors very loudly and things like storming out of the house, a lot of that. A lot of you know mum's voice ringing in my ear saying "Think! really spitting it out, Think!". I think all the time for goodness sake 'what do you mean think' and now I can see that what she was saying was, think of the consequences of your actions before you do something, just think it through. Um, so finding it easy to be a live wire in the crowd and the center of attention, that was what was appropriate on a social occasion but finding it very difficult to be someone who could have nice joined up conversation, do that sort of thing. Gosh, um with lots of relationships not being able to stick at anything you know just finding it very difficult to stick with it and being kind of lured off into other things, looking like I wasn't, mmm, it's a Jane Austen type of word, but looking like I wasn't constant, having constancy. Um, so relationships, um one or two relationships, I mean untold relationships that have been wrecked by either saying things impulsively or not knowing what was going on, thinking there was something wrong with me um, or you know kind of being attracted while people are flirting quite a history of that sort of thing. So I mean my sort of three main relationships where I just know my impulsivity, inconstancy and not thinking about the consequences has really affected things. I got married very young, at twenty two and stayed married for two years and was divorced very quickly and I think the whole marriage was impulsivity that whole thing was just not thinking things through. Um and then the next relationship that was three or four years, we lived together for a couple of years the whole thing was very difficult and I just found myself eventually going into melt-down. He was a very organised person, a real project manager type and he would get really frustrated and say he would take it as a kind of insult to the relationship or to him. When I was going off at tangents he would see it as a sign that I wasn't committed, which was far far from the truth. My most recent relationship happened last year, that happened as well, you know bits of my brain would be going off into different places. We talked a lot about the ADD and you know we read a couple of articles, you know I sat him down and made him read about it and relationships and things. And then we had this sort of wonderful time when we were very conscious of sort of working around it which was a really just a lovely thing to do but then it became very easy just to get very, you know just to say things or get a bit of commitment phobia and then get very impulsive about what I said and ended up trashing the whole thing. This whole thing of self sabotage, completely sabotaging relationships is a real pattern, you know probably because not so much that I don't trust them I don't really trust myself to stick with it. You know you go off and you drink a lot and eat a lot of chocolate and read a lot of Jane Austin and you get this word constancy and you think that's it! That's what I don't have! And it's not that the heart isn't there, it's the stuff that comes out of my mind and it's kind of driven by little gremlins saying you can't trust, can't trust, can't trust. I'm feeling very sorry for myself. Keeping in touch with people over the years people I've got on with very well and then sort of
coming back to them, people have literally said, “where did you spring from”? That sort of bad penny thing, you know, you haven’t been in touch with them and suddenly you turn up um you know there’s a lot of that kind of thing. On Sunday night I went through my filofax thing and I was literally looking at every name in there and thinking how well have I maintained that relationship and it’s so hard to find any apart from a couple of school friends. Some people who were more scatty than me, apart from those it’s really really hard to find things that I do have a real twinge of guilt. Things like cleaning out drawers of memories with letters and cards and things is always really hard because your full of all these knotted up, not properly sustained things which makes you feel that something isn’t right. And also a hugely annoying problem to put so much in to things and then to find your not getting that sort of reliability back. Also, it’s a problem at work as well. Professionally, relationships you know as you grow up in business development being able to keep a large network of contacts on the go. You know I guess if you’re ADD that should be a bit of a gift because you should be able to say “ah I know what so and so is about” and be able to build bridges and that sort of stuff. But because you haven’t got the constancy in your relationships and because of not being able to, that kind of farming, gathering, a bit like gardening yeah, farming I’m not very good at that at all. I’ve done a lot of market analysis jobs particularly being a girl, you tend to get thrown into the centre of the job, you get pushed forward a lot more and I got put in the spotlight as a bit of a highflier. But again that constancy with keeping up relationships wasn’t there everything you know it’s like a house of cards everything just starts to collapse, that’s one of the things that happened in my last but one job.

What contact did you have with other services before you were diagnosed?

A: Right back to earlier years? Getting very stressed about exams and fainting a lot and mum trotted me along to have a scan and an EEG so I had one of those and then went to see a (inaudible). The computer said that there was something that they couldn’t quite recognise on the EEG but it was so slight and I think it was something they couldn’t recognize, like it was a petit, petit petit mal epilepsy and I think it was more to say you know that’s the only thing that we could possibly think it was. Um, so a bit of that. Then what else? Um, I got very stressed and constantly fatigued. I had a bad fever and my GP said it might be helpful if you were to talk to the practice counsellor, she’s a sort of psychotherapist in training and a qualified practice counsellor as well she was really good. She was very good and asked me if I was having problems with attention and I thought ‘yeah, yeah, it’s an attention problem’ and she said you know have you heard of this thing ADD she just started talking about it. She said why don’t you take it back to the GP so that was how it started.

It sounds as though that last contact with services did kind of move you towards the diagnoses that they were suggesting but before that did any of the contact help explain any of the difficulties?

A: No not in the slightest. No.

It sounds as though you’ve had a lot to cope with over your life but I wondered before you were diagnosed what sort of strategies what sort of helped you to deal with the problems?

A: Um, gosh things like eating whole packets of sweets I would really pig out on sweets um actually my ex husband used to sort of throw a plate of toast and honey at me when I would be losing the plot a bit so a lot of that um yes studying. I had to be very focused when studying or report writing or something or highlighting reports or something the best place to do that was on a moving train! Um it was you know just one of those sort of things where there was two or three people around and there was just this huge sense of coming to focus um don’t ask me how that worked but it worked. Um, or curling up with a book and just really trying to focus. Literally curling up. I did that much more as a kid, much much less able to do that as an adult. Um, thousand of books and papers and things on how to study, how to get yourself organised, time management for dummies etc everything and never quite getting it to click in. I think every employer I’ve ever worked for has sent me on a time management course and using lots of highlighter pens, making use of a lot of colour and keeping things in different
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piles and using small size of post it’s to mark up. When I was writing a dissertation, to mark up subjects because I couldn’t find my way to them because you don’t have that sorting mechanism so you’d let the post it notes do that and put post its on things like quality and statistical measures and to pull the whole thing together, you’d just sort of play hunt the post-it. I can remember actually the really organised long term ex-boyfriend. I can remember him walking into the room, he’d actually let me borrow the flat in order to help me write up my dissertation. He had cleared his flat in Aberdeen and said just have the flat. He put beautiful flowers in a vase on the table, lots of coffee. I was there all night. Reference books, about 30 reference books I had them laid out in different piles, you know marked out in different chapters and stuff with the post-it system and he walked in the room and said ‘you know I’m really worried about you doing this MBA about how you’re going to go forward’. I said “what do you mean?” He said ‘well I just don’t think you’ve got what it takes’. You know it was a really fired, tell it like it is moment ‘I just don’t think you’ve got what it takes to pull this stuff together, you’ll be a nightmare trying to manage things and will need to be really careful how you do that’. And yet, I thought my system was really clever because I had chapter 1, chapter 5 and chapter 6 laid out.

What was helpful and what wasn’t helpful in the strategies you used?

A: Um time management courses you know people oozing great presentation skills standing up there telling you stuff that just wasn’t going to work. You sit there and think this is great everyone else is so enthused but I just you know as soon as I left as soon as I was on the tube or the train or something you know I couldn’t hold that so those sort of things weren’t much use. Um being shouted at you know lots of strict comments, um, you know that shout that has a bit of criticism in it um that definitely didn’t work. Um what else? I remember reading in a book about ADD with kids that’s a bad thing to do and other peoples systems don’t work at all.

How did your diagnosis of ADD come about?

A: After being referred from the GP’s practice therapist he said “(name of participant) sometimes I just cannot follow your stories they are so complex and we’re always loosing the thread”. I think she was trying to work out whether it was an avoidance thing, you know what else is going on. So after that referral my GP had a think and she said yes I think there’s something in this so she did some research and found a doctor. That’s where is came from.

What were your thoughts before you went about the possibility of being diagnosed?

A: Um a kind of mixture of trepidation and excitement and strangely a kind of ‘oh this could be really good this could unlock everything that’s wrong with me and that must be fantastic’ and also a real fear of going into this you know where having been to see a psychiatrist there was a real kind of fear around that. Oddly, at the time that my GP asked me you know she said “you will have to go and see a psychiatrist are you happy to do that”? You know at the time I was just so desperate to get everything sorted out and to find out what was wrong with me. I was really thinking that I was having some sort of breakdown or maybe Alzheimer’s or something. Everything was going horribly wrong and people were starting to think she’s not as good as she thinks she is.

How did you feel when it was first diagnosed?

A: Um brilliant, just sort of phew there is something, it’s got a name. I’m not mad and there is hope and you know, you know you read all these really upbeat American books and articles and think oh this could be alright really! And then!! After that elation of great there’s this thing and guess what maybe Einstein had it too. Back to that little girl whose parents thought she was a budding child and oh I can be one of those you know. Then it kind of kicks in. You know you start the Ritalin and I think the first
Ritalin tablet I took before choir rehearsal and it was just fantastic because the conductor was always
you know just like being back at school giving me hard stares and things and that time it was just
amazing because it was a really difficult second soprano part and I just sailed through it. My sight
reading was great and then I went to the pub and I was able to instead of loosing the conversation just
sit there and hear noise from all the different conversations. Before this, a couple of people had begun
to get quite bitchy about my conversation skills, suddenly realizing I could have this really focused
conversation. I can remember walking back and saying “I’m not really supposed to talk about it but
guess what?” and telling a couple of my close friends what was going on and it felt really exciting and
gosh this is how it’s going to be. And then getting to work I’d been given some time off from work by
my really understanding boss in order to re-frame. And coming back and being I don’t know quite
hyper and quite sort of don’t know just feeling that in a way the Ritalin was driving me rather than
something just there to help me and suddenly thinking there’s much more to having this – it’s not just a
case of ‘off you go’. And thinking this is actually much harder and things like making mistakes with
the dosage - forgetting I’d taken one at lunchtime and taking two. I had a dreadful experience when I
did this.

How was it explained to you when it was diagnosed?

A: Um a lot of focus on the inattentiveness and impulsivity um and the idea that hyperactivity tended
to taper off as you got older or that possibly for women hyperactivity maybe worse because we’re
trained to be more demure or something. Um but the yes the impulsiveness and inattentiveness and you
know sort of not a huge amount of explanation about it not a huge amount.

When this was sort of explained to you what were your thoughts about you know about the possibility of
having ADD on an ongoing basis for the rest of your life?

A: Huge thought about what about this medication, do I really want to be doing this, is it going to be
doing my body any good, a bit of a worry about the medication in the long term. Also, the kind of a bit
of there’s something wrong with me you know it did feel a bit like yes I do have a bit of a not a
disability. Not like being deaf or loosing my sight and kind of being handicapped, just you know the
general sense that I really have been playing life with one hand tied behind my back here and a sort of
can I stop everything and just you know really think and then going back in my mind and thinking this,
this, this and this and then going through that full cycle of that needn’t of happened if I’d known
about this and this huge sense of having wasted a lot of years.

It sounds that from the time of that initial elation you know the feeling about the diagnoses actually
changed?

A: Yes really markedly, really markedly um cause I think one of the things I had was this real
expectation that everything suddenly would be wonderful, that I’d suddenly be able to get the hang of
everything. I thought I’ve got a good brain and good education and everything should suddenly kick in
and I had some really understanding colleagues. I actually had three colleagues who had a very
detailed and very accurate understanding and I felt gosh with this job I’ve landed in heaven and you
know I should be able to slice through complex markets in half the time that anyone else does you
know this is just fantastic. You know the perceptiveness in Ritalin, that means you can tune into
someone you know even if they’re in the corner that kind of perceptiveness. I thought this is fantastic
and then the realization that there’s so much more to it than you know. I had so many habits that I had
to unlearn. Um, I went on a fantastic very well run, very well grounded course at (name of course). It
was facilitated by people who really knew what they were doing and they sort of did things like, partly
by assertiveness partly by getting you to sort of just walk into a circle, you know get other people to
sort of say how well you were doing, so you walked into the circle being assertive um and also public
speaking being persuasive using three different influences and styles of being persuasive you know.
Gosh, the feedback from the other 15 or 16 people in the room was ‘gosh you’ve got a real gift for that
you know throw away the notes that’s one piece of advice they give you throw away that piece of paper you just talk you can do that’. I came back from that course back into the office thinking you know now I’m fired up and completely equipped to do really well here. Yet I still couldn’t do it cause I had too much to unlearn and I wasn’t in that very supportive learning environment. So I could do brilliantly in the courses and things. And I’d come back and it just didn’t kick in and a lot of it was to do with my relationships with other people. Um, I haven’t, I still haven’t quite got that sorted out yet and although it might be due to other things as well, the whole sort of consistency or constancy thing wasn’t there and that underpins everything. And when you’re on a training course it’s sort of a short time and you can have a lot of impact in a short space of time, you can follow through. But in a large team over a long period of time and people start to say “you’re not giving as much back from her”. Um so I think I haven’t really thought that one through but I think that’s the main thing that’s so disappointing in being in this wonderful ADD heaven job and so frustrating because I was so lucky to have landed it to have got into that firm. There was also some nice people and nice people are I think quite rare.

How do you explain ADD to other people?

A: Um, if they’re unlikely ever to have heard of it I call it ‘butterfly mind’ um, and I also talk about it being something that has to travel around you and moves but doesn’t and it’s the thing that helps the majority of people in the world to understand time and to structure themselves. But with someone with ADD um, that kind of doesn’t move around as quickly as it should so it’s not doing that kind of executive function thing and filling in time sheets and tax forms is an excruciatingly difficult task, it’s ten times more difficult for an ADD person. Usually for people who do time sheets it’s easier for them to understand.

What things are different about your life now that you’ve been diagnosed with ADD?

Um, I don’t have a job! Sorry um I’m trying to make light of it but I mean that is a really serious thing you know I’m really seriously thinking about what on earth it is I should be doing for a living and but I think the main thing that’s different is I’ve stopped trying to do things I know I’m not really equipped to do. I’ve stopped pushing myself in a way that’s just making me stressed and ill and I’m very glad not to be doing that. I’m allowing myself time just to curl up on the settee with a duvet and a good book and to flick from the Simpsons to the News or whatever. Also having, you know I’ve had this long search since the diagnosis for someone I knew was really going to help me and to be able to understand the ADD context and be able to coach me on that. And now thank goodness I’ve got someone who’s doing that um and who doesn’t believe in too much you know this isn’t going to be done by kindness and sympathy. But which is a school of thought that say’s it has to be a physiological shock you know so she really slammed the door on me. She had a really over staged period where I was really furious with me and it hasn’t been the same since. But also to be able to deal with all my other stuff in an ADD context and what I’ve been doing is looking for help for all my other stuff you know, some of which might be to do with may be the ADD context and the family. But you know to be able to help me from a psychotherapeutic point of view you know with all my stuff in the context that I have ADD. Because I don’t think anything, you know without having that diagnosis would work because people would be putting on labels and stuff.

Anything different in terms of relationships with others?

A: Yes, hugely. Um I think with some people I’ve talked about it and with some people it’s kind of gone over their head and with those people I’ve changed my, I’ve changed the value I put on the relationship. So if somebody doesn’t really take it in and refer back to it again then I just think then maybe you don’t value me. The other thing is that I take pains to explain it to people. Um, and in my last relationship which finished for all sorts of reasons but it wasn’t helped by not feeling understood, but in that relationship it was really good to talk about it you know, ‘I do this and that’s what I do’ and he could start to adjust, as a very thoughtful person he could start to say ‘OK’ ..... We did this lovely
thing, being very positive for each other and I've never had a relationship where both of us had worked at raising each others self esteem and it was really rewarding.

What things have stayed the same?

A: Um, I still find it really difficult. I keep coming up with new systems for organising things but I still have my dining room table which is covered in heaps of stuff which has some order to it but you know it would take half an hour to clear it up even if I had to just clear it without doing anything. So I've still got a real back log of stuff and my Bank Manager is still on my back. I've explained it to him and he was very understanding. He'd heard of it and he you know when I've had difficult things like you know re-mortgaged and he explained it to the re-mortgaging people and I got someone who knew about it to take me through the paperwork and um it was great you know just to have that. It was really good but my approach to banking and stuff is still not what it should be.

What do you think caused the ADD?

A: I think it was just there. I think I was bom with it. Um, it was funny, mum used to talk about how when she was pregnant with me she'd have one dram every night to help her sleep and that she didn't stop smoking and she said when we had an argument "I'm very glad that I did both those things because I could never keep up with you if you were any more bright" which was a nice thing for mum to say. But, I do wonder about that. The other thing I wonder about it being hereditary in the family because we've got a whole history of people dying tragically in very similar circumstances, um journeys to work. Three people in two generations actually. My maternal grandfather was killed at the same zebra crossing as one of my uncles. My mum had an accident while driving to work. So I think it just seems such a coincidence those three things, not one but three – it starts to make a trend. And also dad really understood about my reading- You know he understood I had a brain that could take a lot in and lots of different faces and that focusing was difficult and we used to have this lovely very quiet focus time where he'd just sit with me and I read Gulliver's Travels out loud when I was three just sitting on his knee. And you know he really understood it was something that the reading task I could be very good at if I focused.

What do other people thinks causing your difficulties?

A: Um some of them still think that I'm just, that I think too much about myself, scatter brained, haven't quite got my act together um and others are as relieved as I am to know there is something and concerned about the medication the sort of long term thing. There's one person in the family we haven't told because they would have a huge tantrum you know shame would be heaped on generations of the family and doors would be slammed.

You said that some people still think that you might be scatter brained that would be sort of colleagues or people you didn't know so well?

A: Some colleagues and some less forgiving friends.

What about the more forgiving friends what did they feel?
A: Um, gosh must think more about that. I've got a lot of friends who've said that they have found me different now - more focused, um particularly two of my old school friends and I do wonder you know I really do wonder actually three old school friends so there must be something in that.

Do you think life would have been different if you'd received the diagnosis of ADD in childhood?

A: Oh gosh yes, oh yes hugely. I think there would have been a kinder approach to getting me to be disciplined and structured. I think everyone would have been much more focused on building up a structure that I could stick to and I think some of the unpleasant experiences I went through you know I would have been more enlightened about them. I think I could have chosen my subjects better and I would have focused rather than doing lots of little bits of things um so that would have been good. I might have done much more with music which is a huge regret. I would have done much more on the creative side of English cause I always used to have my essays read out in class and it's funny but a lot of people do think that I will write, it's one of the things that I've been throwing around in the last month or so you know now that I'm not in this fantastic job any more what am I going to do? I could do it on a small scale or I could choose to do something completely different and something much easier. And even with terribly conservative older people when I've said I could write, they've just snapped on it and said 'yes you must do that', you know, so I'm taking my self much more seriously um how I'm going to follow through with some of my creative things.

Since the diagnosis and medication have you notices any differences in the way that you view yourself?

A: Yes definitely. Um I can see where I need to polish up my self esteem, which is not the same thing as something going ping.

Can you tell me a little bit more about that?

A: I'll try. I'm more forgiving about my sort of general coordination um and about whether I just sort of get myself out of the house in whatever happens to be clean or whatever. I'm less worried about trying really hard to look a 'such and such' you know. I'm not doing that so much any more um and I think I've taken on board much more with the communication lessons I've got through training courses and things. So although I haven't been doing it very much I'm much more aware about how I can use that you know. I've got methods I can use to get my point across and also biting my tongue much more and not saying as much. I'm much much less impulsive and I've also got a huge barrel of self pity I'm really wallowing in that one. I am processing a lot of guilt and remorse and stuff and just like processing I'm lucky I've got the time to do that so I'm able just to do that.

What about things like self control, we talked a little bit about the fact you didn't feel you had very much self control, has that changed?

A: Um not as much as I'd have thought. Um not nearly as much as I'd have thought. I mean I've got all sorts of stuff that isn't ADD that can't be explained by ADD, you know, environment and stuff. Um and stuff about me that I haven't quite got in order yet that I'm adjusting to um and I'm never very sure when things have gone wrong. You know I'm never very clear whether it's been me not managing my work properly or it's been underlying depression stuff or I really am a hopeless scatterbrain.

So there are lot's of thoughts going through at the moment?
A: Oh there are lots of different things. Yes, a huge amount of guilt at the last job, you know, having some really extraordinarily understanding people behind me um but not quite having just not quite having got it right and not really understanding that. But you know that job would have been you know to get in to it now it’s a hugely complex, um, you have to have a really good degree from a really good university plus masters and stuff and then some. And I was in there and I was adjusting to my ADD and my diagnosis and I had people who understood that I still couldn’t get it to click in so um you know after being given every chance in the world I still couldn’t get it together. But that you know at the end of the day that might come back to how much control do I have of this? I still don’t have that control and I still you know I’m still adjusting to all the new stuff as well.

How do you think other people see you as a person since the diagnosis?

A: Um, sorting her life out would be one thing. Um someone in the family whose very successful kind of sails through things said when I explained to her recently about the ADD she said “I didn’t know you had that”. “I didn’t know you had ADD”. I said “yes I’m sort of adjusting to the medication”. She said “I didn’t know you had problems like this you know”. And she started talking in a very informed perspective as though she had it and she was talking about public speaking in a very public forum and to a very high standard um in her career and talking about how she had to focus and stuff. How sometimes it was a gift and sometimes it was a handicap and she really understood it. I thought, you know ‘what’s wrong with the picture?’. She’s got that and I have it and I’m sort of limping along feeling, you know and what’s the difference?

What about in terms of labeling and stigma in terms of other peoples perception of you?

A: Yes I think I’ve overdone that one I think. I’ve talked too much to people about it. Um, I think I’ve been too quick to want to tell people um in a work environment. Particularly, I should have only kept it to superiors and I shouldn’t of mentioned it to people of my grade I really shouldn’t have done that. Um, because it is um you know it’s a big bad world, some careers it doesn’t matter if you show weakness and in some jobs it really does.

And in your job you found it did?

A: Yes I wasn’t doing myself any favors and also it also looked like I was making excuses. Um and I probably told too many people in choir about it so it then becomes difficult to not be seen as anything other than the person with that. And also for other people who for very good reasons might not want to talk about the ADD you know they might find it’s kind of challenging them to talk about it and they may not want to for all sorts of good reasons.

How’s the diagnosis changed your thoughts about the future and what it holds for you?

A: Yes. I haven’t a clue what I’m going to do for a living and in some ways I’ve kind of lost faith in my own ability to spot what it is I can do. Um, cause I’m going through a real ‘let’s face reality thing’ um you know confronting what it is I do and what I don’t do so I’m really concerned about that. I’m really burnt out thinking about it you know. I’m not really capable of doing much more than curling up with a good book.

Just taking time out?
A: Yes, I mean going to the supermarket. I'm really not up to it. I can do a quick run through or I can do little bits of shopping but I can't do the full supermarket thing but I think that's also part of the processing stuff.

*What do you feel about taking medication for ADD?*

A: Um, partly very scientific about it you know, great if there's one chemical I can take that sorts everything out then this is worth doing. And also experiencing the whole thing and becoming very conscious of it and what it's doing to me um and worrying about it, quite a lot of anxiety really. And also kind of you know, being given, being handed that prescription, that sort of golden moment when it was handed over you know that smile on the doctors face when they hand that over and it's sort of saying you don't know how much everything is going to be alright now. You've got this magic piece of paper. It should be possible for everything to click into place and then suddenly realising for me it's been quite a roller coaster and that I've have some really bad really depressive moments in the last couple of years. You know, thinking how much of this is medication and how much of this is my own mind. Or how much of it's medication and how much of it's constitution and how much of it is controlling you. I actually had an experience a couple of weeks ago. I got on a train and had to be by the sea and I wasn't sure if I was just going to quietly sit down by the sea or whether I just wanted to run away from it all and see how it was away from everything. I had a sort of day where I really absconded and I had two days without Ritalin just to see how it felt.

*How did that feel?*

A: By day two it felt eccentric but ok and I actually wonder if part of what I was doing without being subconscious of it, part of what I was doing was just saying right what am I, who am I and how does that feel? Let's just scrape away all this old chemical stuff and just see what was there. And I had a lovely pottery day where I just walked along the beach and I thought 'stuff it I've got this condition and I'm probably completely mad into the bargain'. And I took my shoes off and walked, you know like a completely eccentric person, walked along the beach probably a three mile walk from where I was staying back into the town um and just thought 'I'm going to go paddling, who cares it's October, I'm going paddling, it's a glorious day'. And I didn't actually disappear into the sea and I did that lovely walk and I just thought anything that I could think and allowing myself to do it. You know, just being completely batty and dizzy. And I went round clothes shopping but instead of going to all those shiny glamorous places, I took a fixed sum of money out and said ok I'm going to spend as much of this as I can on things that I really like and I got some, we had a lovely feedback system which we just set up for projects where a person we were working for would set out your project brief and would give you instant

*What are the main changes you've noticed in yourself since taking medication?*

A: My internet searches are much more focused. I'm much more successful and I really enjoy them and I got some, we had a lovely feedback system which we just set up for projects where a person we were working for would set out your project brief and would give you instant
feedback on. After you produced the final report xx wrote down in block capitals 'research really good, able to get to all sorts of obscure facts out of all corners of the world' and then he wrote 'and really enjoys it' with three exclamation marks. You know because I think, because they just see me being so grumpy and miserable and think you know she must be in the wrong job what does she like to do? So the research things much better and I can read newspapers much more and I can do puzzles, crosswords and stuff but I'm also in a funny way I haven't lost the wiredness and in some ways that feels accentuated. I seem to be much more anxious. I've noticed that I've got a real anxious hand thing that I'm doing. So I've noticed I'm doing that more, um and a bit more shaky sometimes. Um but predominantly much more able to focus and concentrate and able to package what I've got to say. So I'm much more able to fit a quart into a quart pot. So I did some catering for a party for the choral society and it was a much easier task, which is really nice and much more able to sight read which is great.

Have other people told you about changes they have noticed in you since you have been taking the medication?

A: Yes. I got some very positive feedback from the way I handled some business meeting. Being able to apply the assertiveness and talking very objectively like putting emotions into what I was saying. Um I've got some very positive feedback from that (....inaudible....).

What about from friends and family have they notices changes in you since the medication?

A: Yes my sister's really worried about me um but worried about me in a very constructive way. She sort of, we had a long chat last night and she said that she's much more reassured at the way things are sounded. She's medically qualified, she's an anesthetist and she said "xx I'm so much more reassured that you've got the medication in place, that you've got you know that you're talking about things" she said "you know it sounds like you're really getting a grip on things".

Has she noticed any changes in you though?

A: She wouldn't really say that. No, she's not a, um, no other than saying you know you're sounding good, you're sounding like you've got yourself together a bit, you know, maybe a bit of that. Um, yes I think people in the choir have noticed that my conversation skills are better and my ex boyfriend can tell the difference um I'm just trying to think....

Do you notice any differences in yourself when you don't take the medications and when it starts to wear off?

A: Yes definitely, definitely. Um yes I mean I talked about this drop in my mood and but also there are some things that I can do equally well. Um, flitting around a party and talking to people um you know if I'm doing a multiplicity of lots of little things that's fine I can do that ok. But I'm very aware that I can't focus on selecting, sorting and structuring. The nightmare task is a report. Um you know the whittling of 30 slide presentations down to 10 slides and pulling out the key points that whole thing. And I tried that once at work um and I had slides everywhere and I was trying to get a colleague to understand me so I was saying that 'the thing I cannot do is, I cannot, you know, I'm looking at all these and they are all equally important'. You know I'd got them all sorted with post-its and was trying to label them and I said, "you know your brain is going to be able to collate them", "I cannot collate things, my brain will not collate things". I could have three double espressos from star bucks and you know three packets of sweeties and that would get me half way there but I still can't do it that structuring thing. Choosing menus is funny. I can surf around my cookbooks for recipes. The kitchens just a mess but I can surf around cookbooks for recipes and really fit the people and the occasion...
without the medication. With Ritalin I can produce a perfect meal on time with everything. You know I haven’t forgotten to get the potatoes ready and bring everything together which is great, fantastic.

Do other people notice when the medication is wearing off?

A: Yes, definitely yes. I mean my ex’s classic line about 9.30-10.00 at night if we’re on the phone and everything starts to get a bit wobbly he says ‘are you taking your Ritalin you know like speaking to a child.

So his reaction would be slightly sort of negative?

A: Yes. There would be, I’d start to lose the plot more which he isn’t so worried about because he’s you know arts background, creative and hugely tolerant. But he’s yes, but I get sort of anxious and angry. I get this sort of kick back anger thing. It’s like the opposite of the calm warm. There’s a sort of warm, calm rosy glow that sort of kicks in after an hour you know everything’s ok in the world and I can see the sunshine so I can notice nice things. There’s more of a warm glow and then everything starts to get bleak and lots of things are hammering for my attention and I think the word in the family would be jangly you know where everything is snapping at me. You know I have that sort of list of bills coming snapping at me and dust on the carpet you know bits that are dusty or the piano has not been properly polished and CDs not been tidied.

Has the way that you deal with things changed since the diagnosis?

A: Yes definitely. I kind of threw all my coping mechanisms up in the air and they are now beginning to come down in order. So I’ve got this wonderful diary system which I really believe in. I think it’s really working. You know those quite retro bar pens with four different colours, it’s a survival kit but that is really important and a highlighter pen. So I go through the diary (it’s a week on a page diary) and I go through that and the drop everything just do this stuff is in red and the fun stuff is in green and the kind of important just need to do at anytime is in black and blue. And the general rule is that you strike them off with a highlighter pen so that you can see what you’ve done so you don’t score them out, you don’t scrape them away. You highlight the stuff that you’ve done so that you feel positive about it so I really started using that and I’ve actually got a small wipe board, sad person that I am in my bedroom. And I’ve got a lovely sort of embroidery thing and it’s above that and it says take your tablets, keep calm and then in red do your ‘to do’s’. And it’s up there like a Victorian piece of moral thing so it’s just there and every time I get up in the morning I look at it.

What about are there any other sort of coping strategies?

A: Yes a rubber band! Apparently, it’s like a little physiological shock and you just ping it when you divert when you’re supposed to be focusing on a task, you ping it so that’s good. And choosing colour more and trying to simplify. I’m just trying to simplify everything to fit on my to do’s. I have six or seven threads of activity, sort of house, job whatever that’s going to be or job search, social and family, spirit and health and garden that’s right. So I’ve got those six things and I list all my to do’s under them as I think of them and then I put them in the proper place in the diary as I’m going to do them. And there’s another thing as well. I use colored index cards and I don’t use my memory at all because that’s why I got so tired and stressed. So I’m trying not to use my memory at all and that’s actually a really nice feeling and also set my alarm to remind me that I need to take my medication.

Are there any things that you do that you don’t find helpful and coping strategies that you use that are not particularly constructive?
A: Yes, um planners and other peoples planning systems, filofax and time management systems. I think there's all sorts of different trade names because they don't work. I've stopped them, as the only thing is to use the diary.

Sometimes people sort of turn to drinking or?

A: I can't do that, I can't drink anymore it's really boring! I'm at the age where I ought to be doing wine tasting and things but I can't and I love my food and I'm really interested in that whole thing and I can't drink. I can do one unit after two that's one thing I get feed back from friends on you know drinking. I think you're not meant to do more than two on medication anyway and the anti-depressants. But I was finding that as the alcohol kicked in I could get myself in a very dark place, not being embarrassingly drunk or anything I would get myself into a really downward spiral.

Are there any things that other people have said or done which were helpful or not so helpful?

A: Um, yes positive reinforcement. I've got two cousins who are both professional artists. They teach and they do sort of arty stuff and I think they are both ADD as well because they don't live in this country. But they said oh when I mentioned it at first they said "oh you're one of the people who really manage that quite well" and that their whole household is just a wonderful place to be because they really believe in positive reinforcement. And you know I just spend ten minutes in there and I feel like I could conquer the world and so that's really good. The other cousin on the other side of the family is completely unrelated to her and she's got a very successful job. And her positive stuff is really helpful. She understood it — if she can do what she's doing. And both those sides of the family are completely unrelated and yet they are both doing really good things. It should theoretically, if you get a grip on things at the right age, it should be possible but I think I've kind of come to it a bit late.

Anything that people do or say that isn't helpful?

A: Yes. Cross, scolding by anyone other than scary psychotherapist about ADD is really not helpful and the snap out of it thing um I could really flip when people do that. Um, what else isn't helpful? Um, oh god, at a committee meeting of the choir people started throwing numbers around to try and work out different formula for tickets and things and I got really uncomfortable because I wasn't sure if it was paranoia or but I just couldn't do it — it's a real Achilles heal. The patronising thing. People can become patronising particularly if they know you have ADD. Because you've got these little sparks of real giftedness if you're on the right kind of task and you're focused. You know you're so much better than the other 96% of humanity and it's so annoying to have, sorry that sounds arrogant but it's so annoying to have that and then get someone patronising you.

You said that you're receiving some input at the moment are you receiving anything else or just the scary psychotherapist?

A: Just the scary psychotherapist that knows about ADHD.

And is it helpful I know you said she's quite scary?

A: Yes I think so. I've got a sense of working on all the different things from the right order. She's, although we seem to have done a lot, she's pitching things at the right level. She's not, you know, I
feel she's kind of engaging my brain which is always a good thing to do isn't it? It's lovely when that happens and she's also dealing with one thing at a time and sort of crystallising and prioritising different things, which are really important. So the first thing was you know the first big thing was take your medication! Um we did that and really forced this idea you know get the prescription don't mess around with it take it, get it in the diary, don't ever allow yourself to run out. Um, the second thing was lateness, I remember slamming doors and being absolutely furious. I actually walked out of that session but it worked. And the other one was not diverting a task if you need to do it and the diary system. And then, you know, talking about the kind of attention seeking problem child behavior, you know and saying when are you going to grow up and join the rest of us you know we shouldn't have to tolerate this, it's an imposition on other people. Um, getting you to think not so much about the way other people are treating you but saying sort yourself out first then you can start to criticize other people. And being absolutely rigorous in almost a religious way in getting you to think first yourself and then others.

What help would you like in the future if any?

A: Um, other people in a similar context or of a similar need um to talk. To not so much, you know, in a well facilitated session that would just be wonderful. Um and a kind of quality control reading list, cause I think it's easy to go off on the internet and hit all sorts of weird stuff and I think everyone should be warned not to read this stuff. Also, a sort of idiots guide to handling the medication right at the beginning. Some guide to say 'look this is a controlled substance'. I had a really funny altercation in the pharmacy when I was handed the prescription. I said "what about alcohol" and he looked at me like a was a three headed monster um and said "is it for your child?" He obviously thought I was anesthetizing my ADHD child you know a wee drop of brandy or something. Things like that. Things like, you know, be aware that it's a classified drug. Be careful who you talk to about it that sort of thing. Just a practical handy hints in a very friendly informal way. And also some sort of quality control on where to go for help because again because there is so much stuff on the internet but to have something that is coming from an English or Scottish culture because there is so much of an American spin on everything and not that there's anything wrong with America but I think to be able to fit it into the kind of English reserve.

Alright well thanks very much that's the end of the questions I just wondered if there was anything that you wanted to ask or anything I should have asked you?

A: Timescales I guess. Maybe to say that the whole concept of time is very difficult and how does that impact and also maybe to dig into some more questions about the different female experiences with ADHD.

When you say the timescales what do you mean?

A: How long does it take to get to grips with medication, you know that sort of thing. Having some idea of adjustment time would be really helpful to be given some guidance on that. To actually understand that there will be a bit of a learning curb to understand how long it takes to refrain and the sort of things to look out for. You know, to be aware that your relationships at work might be difficult, a kind of warning list would be really helpful.

Was it ok to answer all these questions how did it feel?

A: OK but I was surprised how many chips I've got on my shoulder yes but it was ok.
Appendix 8

DSM-IV criteria for ADHD.
DSM-IV Criteria for ADHD (APA, 1994).

A. Either (1) or (2):

(1)
Six or more of the following symptoms of inattention have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Inattention:

- Often fails to give close attention to details or makes careless mistakes in schoolwork, work, or other activities.
- Often has difficulty sustaining attention in tasks or play activities.
- Often does not seem to listen when spoke to directly.
- Often does not follow through on instructions and fails to finish schoolwork, chores or duties in the workplace.
- Often has difficulty organising tasks and activities.
- Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort.
- Often loses thinks necessary for tasks or activities.
- Is often easily distracted by extraneous stimuli.
- Is often forgetful in daily activities.

(2)
Six or more of the following symptoms of hyperactivity-impulsivity have persisted for at least 6 months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity:

- Often fidgets with hands or feet or squirms in seat.
- Often leaves seat in classroom or in other situations in which remaining seated is expected.
- Often runs about or climbs excessively in situations in which it is inappropriate.
- Often has difficulty playing or engaging in leisure activities quietly.
- Is often on the go or often acts as if driven by a motor.
- Often talks excessively.

Impulsivity:

- Often blurts out answers before the questions have been completed.
- Often has difficulty awaiting turn.
- Often interrupts or intrudes on others.

Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before age 7 years.

Some impairment from the symptoms is present in two or more settings.

There must be clear evidence of clinically significant impairment in social, academic or occupational functioning.

The symptoms do not occur exclusively during the course of a Pervasive Developmental Disorder, Schizophrenia, or other Psychotic Disorder and are not better accounted for by another mental disorder (e.g. Mood Disorder, Anxiety Disorder).
Literature Review

The Assessment and Treatment of Attention Deficit Hyperactivity Disorder (ADHD) in Adults.

Year 2
The Assessment and Treatment of Attention Deficit Hyperactivity Disorder (ADHD) in Adults.

1.0 Introduction to ADHD in adulthood.

Until fairly recently, ADHD was viewed as a childhood disorder in which the core symptoms of hyperactivity, impassivity and attention difficulties were thought to dissipate during adolescence and adulthood. However, prospective studies that have looked at the long-term outcome of childhood ADHD, suggest that ADHD is a disorder that does persist into adulthood (Weiss, Hechtman, Milroy, & Perlman, 1985; Mannuzza, Klein, Konig, & Giampino, 1989). It is now generally agreed that about one third of children diagnosed with ADHD continue to indicate some core symptoms of the disorder in adulthood, as well as experiencing substantial “associated psychosocial difficulties” (Young, 2000) (p191). Estimates of persistent symptomatology have varied from 10 % (Schaffer, 1994: cited in Jackson and Farrugia, 1997) to 79% (Weinstein, 1994), however this seems to be dependant on the criteria used to diagnose ADHD in adulthood and the way the criteria is used (Barkley, 1997).

Of course, not all adults who have been diagnosed with childhood ADHD continue to show symptoms in adulthood. Those who do may vary in the severity of their symptoms. Three categories of outcome for childhood ADHD have been proposed (Hechtman, 1991). These include: individuals who are able to function normally during adulthood, those who have persistent emotional, social, impulse control and concentration problems (the largest group identified) and finally those with more serious anti-social or psychiatric pathology.

Current research supports the developmental course of ADHD into adulthood. Yet it is still considered an “underdiagnosed and undertreated adult psychiatric disorder”, particularly in the United Kingdom (Young, 2000) (p197). This literature review will towards this end identify current thinking about the assessment and treatment of adult ADHD and identify the significant gaps in our knowledge of the disorder.
1.1 The core symptoms of ADHD and progression into adulthood.

The three core symptoms of childhood ADHD include: hyperactivity, impulsivity and inattention. However, these seem to be expressed in a different way as the disorder progresses into adulthood (Jackson & Farrugia, 1997). Weiss and Hechtman (1993) suggest that the symptoms of hyperactivity tend to decrease with age, impulsivity changes in quality, attention problems generally remain the same but may become more disabling for the individual with the increase in workplace demands. These changes will be briefly outlined below (Weiss, Hechtman and Weiss, 1999).

**Attentional difficulties.**

Attentional problems tend to remain the same for the adult with ADHD so that they experience difficulty focusing on a task and shifting the focus of attention as necessary. However, many may have developed compensatory skills to deal with their inattentiveness, such as working in a job which does not require prolonged attention (Wender, 2000). For those who have not developed compensatory skills, inattentiveness can impact on success in most areas of adult life for example, social and occupational areas.

**Impulsivity.**

Impulsivity in childhood and in adulthood in ADHD seems to be closely linked to a low tolerance of frustration. This core symptom appears to be a stable and enduring characteristic of adult ADHD as well as childhood ADHD. However, the consequences of impulsivity appear to be more serious in adulthood. Decreased impulse control, combined with a short fuse can cause more road traffic accidents, and speeding tickets. Impulsivity may imply a focus on immediate gain, which may in turn lead to impulsive buying and more short-term relationships.

**Hyperactivity.**

Hyperactivity tends to reduce over time as the disorder progresses through the life span. By adulthood, hyperactivity has usually diminished and is perceived as either an objective or subjective sense of restlessness. In this case, the individual may report
a dislike of sitting still and relaxing. Weiss et al., (1999) suggest that the restlessness may become more purposeful and adaptive for the adult with ADHD as it might lead to a more active job or the ability to work longer hours. However, the increased restlessness might also lead to marital discord, as the spouse may feel exhausted by their partner’s inability to relax.

Wender (2000) also describes several additional symptoms of ADHD in adults. These include: frequent and rapid mood swings (distinct from the emotional disorders often associated with adult ADHD), low stress tolerance, poor organisation and a difficulty completing tasks. In addition, a number of authors have highlighted a range of problems associated with the disorder, but which are not necessary for the diagnosis (e.g. Nadeau, 1995, Young, 2000, Weiss & Hechtman, 1993, Ratey, Greenberg, Bemporad & Lindem, 1992). They may be viewed as consequences of the core symptoms of ADHD and have been described in various ways for example, “social and emotional sequelae of ADHD in adulthood” or secondary characteristics (Young, 2000). They include: mood lability and a sense of failure, low self-esteem, impairment of social skills, poor interpersonal relationships, substance abuse, criminal behaviour, emotional difficulties, low educational and occupational achievement.

2.0 Aetiology of ADHD.

The aetiology of ADHD remain as yet uncertain and a number of possible causes have been suggested.

2.1 Neurological studies.

1. The catecholamine hypothesis.

This was put forward in the 1970’s by Kornetsky, (1970: cited in Quinn, 1995). The hypothesis suggests that there is an impaired functioning of the two neurotransmitters, dopamine (DA) and norepinephrine (NE) in ADHD. This is supported by the relative effectiveness of the stimulants commonly used in the treatment of ADHD. Stimulants such as methylphenidate serve to increase the levels of DA and NE in the brain.
Caution needs to be taken in the interpretation of the Catecholamine hypothesis as later studies have revealed rather more inconsistent results (e.g. Zametkin & Rapoport, 1987). Quinn, (1995) concludes that there is a dysregulation of the neurochemical balance in the brain of people with ADHD, but the exact dysregulation remains unclear.

2. Brain abnormalities.

Several studies have implicated structural differences in the brain of individuals with ADHD. Of note, abnormalities have been found in the anterior right frontal regions (Aylward, Reiss, Reader, Singer, Brown, & Denckla, 1996: cited in Barkley, 1998). The caudate nucleus and globus pallidus regions have been found to be smaller in children with ADHD (Castellanos, Giedd, Eckburg, Marsh, Vaituzis, Kaysen, Hamburger, & Rappaport, 1994; Filipek, Semrud-Clikeman, Steingard, Renshaw, Kennedy & Biederman, 1997). Some studies have also found evidence for a decreased cerebral blood flow to the prefrontal regions and relevant connection pathways to the limbic system (Lou, Henrikson & Bruhn, 1984: cited in Barkley, 1998). These abnormalities all share the connection of the frontal and prefrontal region of the brain.

3. The theory of frontal lobe disinhibition.

This theory was put forward in the 1980’s (Chelune, Ferguson, Koon & Dickey, 1986). It suggests that ADHD is caused by disinhibited/ dysfunctional frontal lobes. These disinhibited frontal lobes are unable to control emotional reactions and behavioural impulses or provide appropriate psychological and/or cognitive responses (Quinn, 1995). Support for this theory has been found in studies which have noted more frontal lobe deactivation in individuals with ADHD (e.g. Amen, Poldi & Thisted, 1993: cited in Quinn, 1995). Evidence that there is decreased blood flow to the frontal lobes of children with ADHD would also provide support for this theory (Lou et al, 1984: cited above).
4. Neuropsychological studies.

Support for the role of dysfunctional frontal lobes in ADHD also comes from neuropsychological studies, which indicate deficits in this area. The results of neuropsychological testing suggest difficulties in working memory, motor sequencing, verbal fluency and planning as well as a "disinhibition of behavioural responses" (Barkley, 1998) (p165).

2.2 Genetic factors.

A body of research supports the idea that ADHD has a strong genetic predisposition (Toone, Clarke & Young, 1999). Support for the genetic aetiology of ADHD rather than an environmental cause has come from twin studies. Twin studies have demonstrated greater concordance for symptoms of inattention and hyperactivity between identical twins compared to non-identical twins. An earlier study by Gilger, Pennington and DeFries (1992) found that agreement for ADHD was 81% in identical twins compared with 29% in non-identical twins when one was diagnosed with ADHD. Family studies have also provided support for the heritability of ADHD. Recent research has suggested that the risk to a child being born to a parent with ADHD is 57% (Biederman, Faraone, Mick, Spencer, Wilens, Kiely, Guite, Ablon, Reed, & Warburton, 1995).

2.3 Psychosocial factors.

Psychosocial factors (e.g. poor parental management, family discord etc) have all been put forward as aetiological causes of ADHD. However, the general conclusion seems to be that whilst they may exacerbate ADHD they are unlikely to form a primary aetiological role (Toone et al, 1999). Environmental factors such as dietary additives and pre- and postnatal insults have also been put forward in the search for the cause of ADHD, however, they appear to account for only a small number of cases (Weiss, Hechtman & Weiss, 1999).
The implication of this research into the aetiology of ADHD is that a range of genetic and neurobiological factors can lead to the disorder. These multiple aetiologies "give rise to the disorder through disturbances of a final common neurological pathway in the nervous system" (Barkley, 1998) (p176). This final common pathway appears to be based around the prefrontal network. The role of social and/or environmental factors appears unlikely to be a causal one, although it may well be that these factors either contribute to or maintain the persistence of the symptoms.

3.0 Assessment of ADHD in adults.

ADHD is now recognised as a disorder present in adults, however existing diagnostic criteria provide little guidance for adult assessment of ADHD. There is a general consensus that a reliable and valid assessment procedure for adults needs to be found (Young & Toone, in press) (p4).

There are a number of reasons why ADHD is difficult to diagnose in adults (Murphy & Gordon, 1994).

1. Many symptoms of ADHD are typical of normal behaviour and are present to a greater or lesser degree in the "average population".
2. Some of the symptoms of ADHD are also present in psychiatric disorders. Murphy and Gordon describe inattention as "a universal symptom of mental illness that in isolation, it provides little diagnostic direction" (p347).
3. ADHD is viewed as representing one end of the continuum on a normal curve. As such, the identification of ADHD involves an element of subjective judgement to determine whether someone falls into the area defined as "abnormal".
4. The diagnosis of adult ADHD relies in part on history of childhood functioning. This means that professionals are often reliant on the memory of the patient or his/her family. Retrospective data is subject to problems of distortion, and inaccuracy. As such, the reliability and validity of the data can often be questioned. An earlier study found that patient's recollection of childhood showed little agreement with parental recall, however parental recall
appeared to be more effective in predicting treatment response (Wender, Reimherr & Wood, 1981: cited in Young & Toone, in press).

5. Adults with ADHD are particularly prone to developing a range of comorbid conditions. These may have developed as secondary conditions to "years of ADHD-related frustration and failure" (Murphy, 1995) (p136). A number of outcome studies have demonstrated the range of co-morbid conditions often associated with ADHD. These include anxiety disorder, depression, personality disorder and conduct disorder (Murphy & Barkley, 1996: Shekim, Asarnow, Hess, Zaucha & Wheller, 1990). The difficulty with co-morbid conditions and the diagnosis of ADHD is determining the primacy of the condition.

6. Some psychiatric disorders can mimic the core symptoms of ADHD and these need to be ruled out before a diagnosis can be made.

7. Impairment can be more difficult to determine in adults than children. For children, a range of ratings and observations can be obtained from all aspects of the child's life (school, home etc.). However, it is generally not possible to obtain the same range of information in the adults life. It may be necessary for the professional to turn to other sources, such as the patient's partner or the use of cognitive/neuropsychological measures (Nadeau, 1995).

Despite these apparent difficulties, the diagnosis of adult ADHD still needs to be made. A number of areas are thought to be important in the diagnosis (Goldstein, 1997).

1. A childhood history of ADHD symptoms.
2. Current ADHD symptoms.
3. Evidence that these symptoms are causing the individual significant impairment in their everyday life (e.g. relationships, job, emotional adjustment).
4. Assessment of the existence of co-morbid conditions. It may well be that the co-morbid condition(s) is impacting more on the individual's life than the ADHD and as such, it may need treatment first.
Murphy & Gordon (1998) suggest that assessment should also rule out the possibility that the symptoms can be accounted for by a condition other than ADHD.

3.1 DSM-IV criteria.

The DSM-IV criteria (APA, 1994) are considered to be the most widely accepted and scientifically verified criteria for determining whether or not an individual meets the diagnosis of ADHD (Murphy & Gordon, 1998). It is used to formally determine the presence of existing symptoms in adulthood and retrospectively the presence of symptoms in childhood.

The DSM-IV criteria separate ADHD into three types, namely predominantly - inattentive type, predominately - hyperactive - impulsive type or combined type which is a mixture of the two. This distinction is a particularly important one to be made in the diagnosis of adult ADHD as the developmental progress of ADHD seems to imply a decrease in hyperactivity (Biggs, 1995). To receive a diagnosis of predominately-inattentive type or predominately-hyperactive-impulsive type, the individual needs to have met six out of the nine criteria specified. To receive a diagnosis of combined type, the individual need to fulfil six criteria from both of the above. In addition, the symptoms need to have been present for at least six months and there must be evidence of the symptoms before the age of seven years.

There are a number of difficulties with DSM-IV (APA, 1994). The first stems from the definition of the predominantly inattentive subtype. Some authors have suggested that the criteria for this subtype are not specific enough. This is because a number of other disorders are also associated with problems with attention. Unless considerable care is taken to rule out the existence of the other conditions, there may be a higher rate of false positive diagnoses (Weiss, Hechtman & Weiss, 1999). A second criticism of DSM-IV is that it does not provide "adult appropriate manifestations" of the core symptoms of inattention, hyperactivity and impulsivity. Hyperactivity may not be defined as "always on the go" when manifested in adulthood but may instead be present in the form of obsessive exercise regimes (Weiss, Hechtman & Weiss) (p93).
3.2 Clinical interview.

The clinical interview is considered to be an important part in the assessment process (Nadeau, 1995). The aim of the interview is to identify such areas as childhood symptoms and behaviours, past school history, type and frequency of behaviour difficulties, previous social relationships, work history, medications, family history of ADHD, current functioning, substance abuse and self-esteem. The general aim is to ensure that consistency of symptoms over time is demonstrated and across a range of settings (Murphy & Gordon, 1998). A further aim is to increase the reliability of assessment techniques used in the diagnosis (e.g. Barkley & Murphy, 1998).

The clinical interview is subject to the same problems of retrospective memory, outlined above for the adult with suspected ADHD. Therefore it is recommended that several informants are present to provide more global descriptions and information (Biggs, 1995).

3.2 Questionnaires/rating scales for adult ADHD.

Another method used in the assessment of ADHD in adults is screening questionnaires/rating scales. These often necessitate structural interviews as “initial diagnostic steps” (Jackson & Farrugia, 1997) (p314). One of the most widely used is the Wender Utah Rating Scale (Ward, Wender, & Reimherr, 1993). The rating scale is based on the idea that for the person to be diagnosed with ADHD in adulthood, it must have been clearly identified in childhood. Therefore before the rating scale is completed, retrospective information is obtained about the person’s childhood experiences from a range of sources (self-report, informants’ reports etc.). The aim is to establish that the adult would have met the criteria for ADHD in their childhood (Nadeau, 1995). The rating scale is then completed which examines the presence of core symptoms of ADHD and additional ones, such as affective lability and stress intolerance.

There are a number of problems with the Utah rating scale. The first is that there is a lack of normative data, which means that total number of symptoms needed for a cut-
off is arbitrary. There is also the suggestion that one of the symptoms listed, stress intolerance, should not be categorised as a primary symptom but may instead be an associated symptom (Weiss & Hechtman, 1993). Another fundamental problem with the scale is the assumption that hyperactivity should be demonstrated in childhood and currently in adulthood. This means that only those individuals with persistent hyperactivity would be able to receive a diagnosis. The criteria is not supported by the diagnostic criteria of the DSM-IV which delineates between three subtypes of ADHD, including the predominantly inattentive type.

One scale that provides a normative basis for the assessment of adult ADHD is Brown’s ADD scale (1996: cited in Weiss, Hechtman & Weiss, 1999). This scale is thought to be helpful in assessing a more broad range of problems associated with ADHD in adulthood and as such can be used to compliment the DSM-IV. The scale was designed to assess five separate dimensions in adults or adolescents with suspected ADHD. The dimensions include: sustaining attention and concentration, sustaining energy and effort, managing affective interference, organising work and working memory. There are a number of perceived advantages to this scale. Normative data is available which means that a more meaningful score can be obtained. The scale has been found to be sensitive to change and as such can be usefully used as a pre-and post outcome measure in treatment. Finally, the scale appears to tap the wide range of attention difficulties that cause considerable problems for adults with ADHD.

3.3 Psychological testing.

Neuropsychological testing is often used as part of the assessment of adult ADHD, however it is clear that it should only be used a part of an overall package of assessment (Biggs, 1995, Weiss et al., 1999). Current research suggests that no individual or battery of tests has an “adequate predictive validity or specificity to reliability make an ADHD diagnosis” (Barkley, 1998) (p358). The general consensus is that testing should be used to back up information already obtained from childhood, current functioning and rating scales. It may also help to confirm or disconfirm a
clinical diagnostic impression or indeed suggest areas for treatment planning (Biggs, 1995).

Tests of attention and impulsiveness are commonly used in the assessment of adult ADHD as they are two areas that ADHD adults typically find difficulty with. The most commonly used is the Continuous Performance Test (CPT), (Connors, 1998: cited in Murphy & Gordon, 1998). This is a computerised test of sustained attention and response inhibition. A low score on the test will not in itself provide a diagnosis of ADHD but may support the other assessment data available. Similarly, clinicians may find it useful to observe the individuals as they carry out the test as additional qualitative information obtained may reveal difficulties that are not necessarily reflected in the score.

4.0 Treatment.

Treatment for adults with ADHD typically follows a pharmacological and/or psychological route. However, the choice of treatment plan needs to consider the individual needs of the person, particularly when co-morbid disorders are present. These may need treatment first before considering other needs (Toone, Clarke & Young, 1999). Most authors support the idea of a multimodal approach in the treatment of adult ADHD which may impact on the treatment process (e.g. Nadeau, 1995; Wilens, Spencer & Biederman, 1998).

4.1 Pharmacotherapy of adult ADHD.

The use of pharmacotherapy in childhood ADHD has been well demonstrated, however it is less established in the treatment of adult ADHD (Wilens, Biederman, Spencer & Prince, 1995). In comparison to 200 controlled studies of stimulant medication in child and adolescent ADHD, there are only two open and eight controlled trials in adult ADHD (Spencer, Biederman, Wilens, Harding, O’Donnell, 1996 & Griffin; Wilens, Spencer & Biederman, 1995).
Stimulant medication (usually methylphenidate) forms the mainstay of treatment across the ADHD lifespan. Controlled treatment studies of stimulants in adult ADHD range from a 25% success rate (Mattes, Boswell & Oliver, 1984: cited in Wilens et al, 1995) to as much as 78% (Spencer, Wilens, Biederman, Faraone, Ablon & Lapey, 1995). This somewhat extreme variability seems to be related to a number of factors, which include the criteria used to identify ADHD, varied stimulant doses, high comorbidity rates and different methods to determine level of response (Wilens et al., 1995).

As previously discussed, the treatment of adult ADHD should follow a multi-modal approach. The use of pharmacotherapy is unlikely to adequately deal with the range of social and emotional sequelae which often feature in adults with ADHD. As of yet, only one study has highlighted the possible benefits of a combined pharmacotherapeutical and psychological approach (Wilens, McDermott, Biederman, Abrantes, Hahesy & Spencer, 1999) (see later). However, more research is needed to determine the relative effectiveness of these two approaches when combined.

4.2 Psychosocial/ Psychological treatment.

There is very little evidence to support the effectiveness of non-pharmacological treatment in adult ADHD, which represents a huge gap in the literature in this area (Toone, Clarke & Young, 1999). The majority of authors provide anecdotal evidence about various non-pharmacological treatment approaches but at present their relative effectiveness has not been demonstrated. Several authors have proposed clinical approaches to working with adults with ADHD. However the conceptual basis of these do not seem to be grounded in existing therapeutic approaches. Nadeau (1995), for example, describes the various roles that the therapist should maintain when working with an adult with ADHD.

1. Therapist as supporter. The therapist should support the adult with ADHD in their transition from ‘victim to empowered’.
2. Therapist as Interpreter. The therapist should help interpret the specific pattern of the individual's ADHD. These can then be shared with the person's significant others to help them to accept the disorder.

3. Therapist as Structurer. When working with an adult with ADHD, the therapist should become more active and structured. This is to provide a base for working with someone who may have difficulty in planning, organising and focusing.

4. Therapist as Educator. The essential role of the therapist is to educate the individual with ADHD about the disorder. Education may be offered through reading, instruction, or ongoing as part of the therapeutic process.

Hallowell & Ratey (1994) have produced a range of tips for the management of ADHD in adults, which range from individual management to relationship problems. Their approach focuses on practical ways of dealing with everyday problems. The approach also places more emphasis on action as a means of addressing change (instead of thinking or feeling). However, it does emphasise the active role of the individual in therapy instead of a passive recipient (Weiss et al., 1999).

4.2.1 When is psychological therapy appropriate?

As previously discussed, the use of stimulant medication is not effective for up to 22% of adults with ADHD (Spencer et al., 1995). Similarly, for those individuals who have benefited from medication, they may still only experience a small remission in their symptoms (Weiss, Hechtman & Weiss, 1999). In addition, the high comorbidity in this group combined with the multiple secondary characteristics of ADHD may mean that the individual remains with a number of untargeted symptoms. Psychological therapy may be the "treatment of choice to address the secondary effects of psychosocial disability " (Weiss et al., 1999) (p190).

4.2.2 Psychoeducation and diagnosis.

According to Murphy (1998) treatment for adults “begins at the time they are diagnosed” (p584). Murphy and LeVert (1995) suggest that an adult passes through a
series of six stages when they have received a diagnosis of ADHD. These are initial relief/optimism, denial, anger/resentment, grief, immobilisation and finally accommodation. It is suggested that the way that the diagnosis is communicated to the individual is crucial in their understanding of the disorder and their future adjustment to the diagnosis (Murphy & LeVert, 1995).

Psychoeducation is a specific therapeutic approach which can be used from the start of the diagnostic process (Jackson & Farrugia, 1997). The general approach should be calm and non-judgemental and the aim should be to promote insight into the diagnosis of ADHD, the meaning of the diagnosis, and the impact it has had on the individual (Weiss et al., 1999). Murphy (1998) has proposed a framework to assist therapists in the psychoeducation process.

1. **Rationale for ADHD and Comorbid Diagnoses.**

The first part of the education process is to provide information about ADHD. Murphy (1998) suggests that often just the process of receiving the diagnosis will provide a sense of relief for the individual, as they are finally able to name and explain their long standing difficulties. Murphy (1998) suggests that the therapist should also help to explain the reason why the individual fulfils the criteria for a diagnosis of ADHD to enhance their understanding of the disorder. Education about medication is also important at this stage as many individuals may have preconceptions about the impact of stimulant treatment.

2. **Reframing the past.**

Murphy (1998) suggests that the adult with ADHD will have experienced a history of failure in all aspects of their life. Often the adult will have been given the message that he/she is stupid, lazy and unmotivated. The cumulative effect of this is often low self-esteem and a belief that the situation can never be changed (Murphy, 1995). However, by helping the individual to understand that ADHD has a neurological basis and is “not a character defect or moral weakness”, this should begin to provide the person with some hope (p585).
Throughout the psychoeducation, the aim is to install hope in the individual that he/she should be able to make progress with appropriate treatment, combined with hard work and support. This installation of hope needs to be offered in light of the information that there is no cure for ADHD. Treatment is aimed at coping with the disorder and maximising individual strengths.

4.2.3 **Cognitive-Therapy (CT).**

Cognitive-Therapy is to date, the only psychological treatment adapted for work with adults with ADHD and empirically validated (Goldstein, 1997). There are a number of challenges in the adaptation of CT for this client group (Barkley, 1998). The first is that adults with ADHD may have difficulty completing "homework" tasks for example, writing down thoughts. Secondly, the impulsive symptoms of ADHD seem to occur prior to cortical processing, therefore working with people cognitively could mean “working with what goes on after it” (Weiss et al., 1999) (p196). Young (2001) suggests that a cognitive approach is likely to be effective because it is structured. This should provide a focus for adults who may struggle with attention and organisational difficulties. Similarly, one of the important facets in CT is collaboration, as therapist and client agree agendas and therapeutic goals. For adults who may feel ambivalence about engagement with another clinician, CT will offer a degree of face validity.

Wilens, McDermott, Biederman, Abrantes, Hahesy & Spencer (1999) carried out a pilot study of 36 sessions of CT with a sample of 25 adults with ADHD. Over half of the group had comorbid problems and 85% were receiving medication for ADHD and/or co-morbid problems. The proposed CT model suggests that a history of rejection in adults with ADHD can lead to the development of core beliefs that they are unlikeable and a belief that any rejection will be catastrophic. The focus on rejection can instigate a cycle in which the selective perception of rejection confirms the core belief that they are unlikeable. Treatment uses a technique called the SPEAR technique (Stop, Pull back, Evaluate, Act and Re-evaluate).
Results of the pilot study found that CT was effective in improving the core symptoms and associated problems of ADHD in 69% of the sample. There were a number of limitations with the study. The study was an open trial with no control group or medication only group. Similarly, for those adults who were receiving medication specific treatment for anxiety and depression it is not clear whether their positive response could be attributed to pharmacological or psychological treatment or a mixture of the two. Despite these limitations the results do suggest that CT may potentially have an important role in the treatment of ADHD but more research is needed.

4.2.4 Interpersonal Therapy (IPT).

Interpersonal therapy requires the individual to choose a particular focus e.g. role transition difficulties and to address the difficulties around this issue in a structured series of sessions. As yet, there have not been any specific adaptations of this approach for adults with ADHD. However, Weiss et al., (1999) propose that IPT would make a good choice of treatment for adult ADHD as it is supportive, psychoeducational and orientated towards systems.

4.2.5 Psychodynamic Therapy.

Hallowell (1995) suggests that psychodynamic therapy requires specific adaptations if it is to be used as part of the overall treatment process in ADHD. He suggests that the therapist should play more of an active role in the therapeutic process and place some structure on the sessions. He recommends that the “fundamental rule of psychoanalysis” that the person should say whatever thoughts come to mind may be difficult for an adult with ADHD. The person may have so much information that comes to mind that they become “flooded” (p150).

Hallowell (1995) also suggests that the psychotherapist needs to develop a good understanding of ADHD as a disorder before using this approach. Interpretations of the individual may be made in relation to unconscious material or transference issues when instead they may reflect certain core difficulties of the disorder. Hallowell
provided the example of a client he was working with. He described how the client suddenly switched topics to discuss a problem with the lift in the building. As a therapist he may have interpreted this at an unconscious level, however it may well have reflected an inability to concentrate on one topic for a period of time. A similar point was expressed by Ratey et al., (1992). They found that psychodynamic therapists who had worked with ADHD adults had often interpreted their presenting symptoms as “defences against forbidden wishes” (p270). This approach had led to a negative effect with the individuals feeling frustrated and blamed.

4.2.6 Behaviour Therapy.

This draws on the idea that certain behaviours can be modified through the use of reinforcement and punishment techniques. It is usually reliant on the person’s ability to observe and record identified behaviours with the aim to monitor change. Some adults with ADHD may have difficulties around organising themselves to follow the behavioural programme and making observations about themselves. Similarly, some adults with ADHD may find difficulty with rewards system. Impulsivity could mean that they reach for the reward even if they are not entitled to it or may become easily frustrated if they feel that they are being deprived of something. This might also suggest difficulties in the maintenance of the behaviour programme over time. Weiss et al (1999) suggest that all of these difficulties need to be taken into consideration when designing a programme and discussed fully with the individual concerned. However, it might mean that Behaviour Therapy is not a particularly good option for adults with ADHD.

4.2.7 Group therapy.

Adults who have been recently diagnosed with ADHD may feel misunderstood and consequently isolated from their peers. A group format enables adults with ADHD to meet up, share information and feel less isolated. Individuals can validate their own experiences by sharing their thoughts with other adults with ADHD (Hallowell, 1995). The group also enables the development of a supportive network whereby skills can be rehearsed and acquired without judgement. Cognitive-behaviour therapy may be a
useful psychological treatment approach for a group format, as it is time limited and provides structured goals and themes. Open ended groups may not be appropriate for adults with ADHD as they are dependent on good organisation and time management skills. Adults with ADHD may also have some difficulty committing themselves to a process that they perceive as lengthy as it will not satisfy their need for immediate gratification (Young, 2001).

4.2.8 Marital work.

Marital work is considered helpful for addressing some of the relationship difficulties that may be present between adults with ADHD and their partners. Murphy (1998) suggests that some partners of ADHD adult’s report feeling unloved and frustrated and may find their partners unreliable and insensitive. Murphy suggests that education about the disorder may enable the couple to re-evaluate their problems in light of the ADHD and to work together to reduce the impact of ADHD on their lives.

4.2.9 Cognitive Remediation strategies.

Cognitive remediation strategies (or behavioural strategies) are an important consideration in treatment of adult ADHD to enhance memory, attention, and organisation in everyday life. Weinstein (1994) suggests that they are an “important active adjunct” to other psychological treatment interventions (p48).

Weinstein suggests that some therapists perceive cognitive remediation strategies as too concrete and based on common sense instead of a therapeutic approach. However, Weinstein agrees that they form an integral part of treatment as an adult with ADHD “will need psychological strategies to circumvent attention deficits” (p48). Weinstein concludes that the type of cognitive remediation strategies to be used can be ascertained by a person’s profile of strengths and weaknesses in a neuropsychological assessment. It may be that the person will benefit from learning attention strategies (e.g. try to do one thing at a time), memory enhancing strategies (e.g. rehearsal of information) or problem solving strategies. In addition, the adult with ADHD may
also benefit from stress control strategies or anger management (Toone, Clarke & Young, 1999).

Weinstein (1994) concludes that cognitive remediation strategies are not something that can just be presented to adults with ADHD. As previously discussed, many adults with ADHD have already developed some compensatory strategies to deal with the symptoms of ADHD. However they will also have encountered a life long history of failure which may prevent them from having the confidence to acquire new skills (and successfully execute them). An understanding of the person’s cognitions and self-concept is needed in order to work with these long standing issues.

4.2.11 Factors which may impact on psychological/ psychosocial therapy.

It may well be that the core symptoms of ADHD are the factors that cause difficulties in therapy. Adults who find difficulty focusing on a conversation or keeping to time limits may find difficulty coping with the structure of an hour long session. Adaptations to the therapeutic process will need to take account of these individual problems (e.g. shorter sessions). Rule governed behaviour can be difficult for some ADHD adults, which may mean difficulties turning up on time or adhering to appropriate boundaries. The role of the therapist in the early stages may be to clarify and re-clarify boundary issues and therapeutic rules (Weiss et al., 1999).

5.0 Conclusion.

This literature review has aimed to identify some of the current thinking around the assessment and treatment of adults with ADHD. Earlier research suggested that ADHD was a disorder that was overcome by the developmental process into adulthood. However, numerous prospective studies and clinically referred adults clearly emphasise that ADHD persists into adulthood (Weiss et al., 1985). Adults continue to show core symptomatology of ADHD, albeit in a slightly different presentation from childhood (Weiss & Hechtman, 1993). They are also substantially at risk for developing associated problems, such as emotional difficulties, anti-social behaviour and poor occupational achievement (Young, 2000). The exact aetiology of
ADHD remains unclear, however existing research suggests that a range of genetic and neurobiological factors can give rise to the disorder. These seem to be based around a common pathway indicated in the prefrontal network (Barkley, 1998). Clearly more research is still needed to determine the aetiology of ADHD in its various forms, as it will help to guide future diagnostic methods and treatment.

Existing diagnostic criteria appear to provide little guidance for adult assessment of ADHD. As of yet, there are numerous difficulties with current assessment procedures. The most widely accepted criteria used in the diagnosis of ADHD are the DSM-IV criteria (APA, 1994) but this does not acknowledge the range of manifestations of the disorder in adulthood. Clinical interview, additional rating scales and some neuropsychological testing are typically used in addition to DSM-IV. However there is a need for a reliable and valid assessment procedure to be developed.

Treatment for adults with ADHD typically follows a pharmacological route (particularly in the UK). However a number of authors advocate the need for a multi-modal approach based on a combination of pharmacology and psychological input (Jackson & Farrugia, 1997). Most importantly, the treatment package needs to take into consideration the individual needs of the adults with ADHD, particularly as it is a disorder which presents with core symptomatology as well as secondary associated problems and a high presence of co-morbidity. There is very little evidence to support the effectiveness of non-pharmacological treatment in adult ADHD. This represents a huge gap in the literature in this area. At present, discussion of non-pharmacological treatment has centred on anecdotal evidence, clinical impressions and suggestions for adaptations of therapy in adult ADHD. One study tentatively provides support for the role of Cognitive Therapy in the treatment of adult ADHD (Wilens et al., 1999). However this was a pilot study and contained a number of difficulties. The relative efficacy of a combined pharmacological and psychological approach still needs to be determined.

ADHD at present remains an "underdiagnosed and undertreated adult psychiatric disorder" (Young, 2001) (p197). This is particularly apparent in the UK where there are only two NHS clinics specialising in the treatment of ADHD. The increased
recognition of adult ADHD as a valid disorder is likely to place a huge pressure on NHS services in the UK over the next few years. Clearly, advances in our knowledge of aetiology, assessment and treatment are necessary in order to be able to provide some relief for those adults who have this frustrating and debilitating disorder.
References.


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