A PORTFOLIO OF ACADEMIC, CLINICAL AND RESEARCH WORK

BY

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Cognitive style, Pain and Depression in Sickle Cell Disease.
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INTRODUCTION TO THE PORTFOLIO

This Portfolio consists of three chapters, Academic, Clinical and Research. Each chapter consists of a selection of work completed over the three-year duration of clinical training. A brief summary has been included at the start of each chapter outlining the contents.

In addition to the three chapters, there is a Clinical Appendix which contains five clinical case reports and activity logs and evaluation forms for the four core and two specialist placements.

References have been included at the end of each individual piece of work. The American Psychological Association guidelines for references have been followed throughout.
Academic Chapter
SUMMARY

This section contains five selected completed over the three years of the course. The titles are summarised below.

Adult Mental Health
What are the theoretical and practical limitations of the Cognitive model of depression?

Learning Disabilities
"People with Learning Disabilities are more at risk of being sexually abused and committing sexual offences". Discuss the contribution which Clinical Psychology can make to these issues in the context of societal attitudes.

Older Adults
What factors are involved in suicidal behaviour in older people?

Neuropsychology
Is neuropsychological rehabilitation effective?

Specialist
"There is some evidence that children with chronic physical health problems are at increased risk of psychological difficulties. However, the majority do not show psychological problems." Discuss with reference to at least two chronic conditions.
WHAT ARE THE THEORETICAL AND PRACTICAL LIMITATIONS OF THE COGNITIVE MODEL OF DEPRESSION?

In general cognitive models of depression are based on the premise that cognitive processes play a significant role in the aetiology and maintenance of emotional disorders. However, they may differ in their particular emphases and predictions. For the most part this essay will focus on Beck’s cognitive theory of depression as illustrative of this approach although references will be made to other related theories. Beck’s theory, which has been elaborated in successive publications (e.g. Beck, 1976), asserts that people may become depressed via a number of routes. However, once depressed they will share common features. The causal model of depression is said only to apply to “so-called reactive depression” (Beck, 1987). In other words the theory provides a description of the depressed state which is supposed to be universal but a theory regarding aetiology which is applicable only in some cases. The causal aspect of the theory can be usefully sub-divided into precipitation and maintenance. The empirical and theoretical status of the descriptive and causal aspects of the theory will be explored separately. Cognitive therapy as described by Beck incorporates both behavioural and cognitive techniques. Although in general outcome research has pointed to the efficacy of this approach, some behaviourist critics have disputed the theoretical underpinnings of cognitive therapy and the relative contributions of the cognitive and behavioural elements to successful outcome. Even amongst proponents of cognitive therapy there is debate as to the nature of the mechanism of change. Finally, there are practical problems associated with the approach which may limit the applicability of cognitive therapy to some groups of depressed people.

Beck’s description of the depressed state

In a recent thorough review, Haaga, Dyck and Ernst (1991) concluded that overall Beck’s description of the depressed state had received considerable empirical support. After outlining Beck’s description of the depressed state, the empirical evidence on which this conclusion was based will be reviewed. According to Beck, all depressed people are said to be characterised by a predominance of so-called negative automatic thoughts i.e. repeated thoughts which are not easily controlled. Negative thoughts are seen regarding the self, the world and the future, the so-called “negative triad”. It is also argued that the degree of negative thinking is related directly to the severity of other depressive symptoms. The empirical evidence suggests that Beck’s theory describes the depressed state accurately. Dohr, Rush and Bernstein (1989) compared 25 clinically depressed people with non-depressed matched controls on a variety of measures of cognitive style. Depressed subjects
scored more highly on all these scales than normal controls indicating greater negativity. Haaga et al cite evidence that depressed subjects score more highly on negativity measures than non-psychiatric medical out-patients (Hollon, Kendall & Lumry, 1986); remitted depressed patients (Dohr et al, 1989) or themselves when remitted (Dobson & Shaw, 1986). In addition, there is evidence that this negativity is characteristic of types of depression. For example, negative cognitions are equivalent in unipolar and bipolar (Hollon et al, 1986); primary and secondary (Hollon et al, 1986) and endogenous and non-endogenous (Eaves and Rush, 1984) depressions.

What of the cognitive triad? Relative to non-depressed controls, depressed patients appear to be more self critical (Blatt, Quinlan, Chevron, McDonald & Zuroff, 1982) and rate themselves as more discrepant from their ideal selves (Blatt et al, 1982). Depressed people appear to be more hopeless about the future than non-depressed or remitted controls (Dohr et al, 1989). Depressed patients also showed higher scores on the world, self and future subscales of the Cognitive Style Test than non-depressed controls and remitted depressed patients (Blackburn, Jones & Lewin, 1986). However, the conceptual status of the cognitive triad has been disputed, in that it has been described as "an unwieldy taxonomy with highly overlapping categories" (Haaga et al, 1991). For example it has been noted that the depressed person's negative view of the future is limited to the future of the self (see questions on Beck Hopelessness Scale, Beck, Weissman, Lester & Trexler, 1974). Blackburn et al (1986) noted high inter-correlations between the three subscales for depressed people. It is also not clear whether Beck sees it as necessary for depressed people to show greater negativity on all aspects of the triad or whether elevation on only one aspect is sufficient. There is therefore scope for clarification and possibly revision of this aspect of Beck's theory.

The evidence that degree of negativity is related to severity of depression is less clear and is confounded by the fact that many self-report measures of depression have a large cognitive component. However, there is evidence that self-reported cognitions are positively correlated with interviewer-rated depression (Dobson & Shaw, 1986). Haaga et al (1991) also cite evidence suggesting that the correlation between cognition measures and self-report depression scales remains after the removal of overlapping items.

One further area is worthy of comment. Blaney (1986) has highlighted the fact that Beck's use of the term automatic is not strictly in keeping with more conventional definitions, namely processes that place limited demand on attentional resources, can be initiated without
awareness and are difficult to inhibit. It has been argued that most depression research has not strictly tested the idea of automaticity, specifically looking at the degree of control over these thoughts and the degree of attention required.

**Beck’s theory regarding vulnerability to and maintenance of depression**

So on the whole Beck’s theory appears to provide an adequate description of the depressed state, although there are some areas where further clarification is required. What of the theory of causality outlined by Beck? This aspect of the theory is the subject of greater debate. Beck argues that those who are vulnerable to depression have so-called “depressogenic schemata”. Schemata are stored bodies of knowledge which guide the way people interpret incoming information. Beck has proposed that there are two sub-types of depressogenic schemata. Dependent or sociotropic schemata emphasise dependence on others for self esteem where as Self critical or autonomous schemata emphasise self worth as the result of achieving goals. These schemata are said to lie dormant until triggered by a congruent life event. The nature of the triggering event is dependent on the nature of the schemata. Thus someone with a sociotropic schema is vulnerable to loss events involving personal relationships where as someone with an autonomous schema is vulnerable to events affecting achievement e.g. being made redundant. Once activated these schemata override more adaptive schemata resulting in a negative cognitive shift. These depressogenic schemata influence the way in which events are perceived and introduce systematic negative errors or biases into information processing. Beck therefore assumes that depressed thinking is illogical and biased where as non-depressed thinking is rational and unbiased. The automatic negative thoughts referred to earlier are said to arise from these schemata. Once this pattern of thinking is triggered, other symptoms of depression e.g. behavioural (withdrawal); motivational (apathy) etc. ensue. A vicious cycle is established whereby the more depressed a person becomes the more negative their thoughts become leading in turn to an escalation of depression.

Thus from a causal point of view two issues need to be explored:

1) the impact of negative patterns of thinking on mood and the role of cognitive processes in maintaining depression i.e. the role of cognitive factors in the maintenance of depression;

2) Beck’s model of how some types of depression arise through the interaction of particular latent vulnerabilities and congruent life events, i.e. the role of cognitive factors in the onset of depression.
It should be stressed that Beck does not propose that cognitions cause depression. Beck (1991) argues:

"...it seems far fetched to assign a causal role to cognitions because the negative automatic thoughts constitute an integral part of depression, just like the motivational, affective and behavioural symptoms. To conclude that cognitions cause depression is analogous to asserting that delusions cause schizophrenia........However, I have considered the activation of the schemas to be a mechanism by which the depression develops not as the cause. The cause may be in any combination of biological, genetic, stress or personality factors, which also may be offset by any combination of such factors."

Fennell (1989) similarly argues:

"The fact that cognitions influence mood does not imply that negative thinking causes depression. Depression may be seen as a final common pathway for a range of biological, developmental, social and psychological predisposing and precipitating variables. Depressive thinking does not cause depression; it is part of it. Cognitions may, however, have some priority in the development of mood disturbance, and they can act to trigger, enhance, and maintain other symptoms."

The studies cited earlier suggest that there is a correlation between being depressed and thinking in a negative way. However, Teasdale (1983) suggests that in order to show that negative cognitions play any sort of causal role in depression, it also needs to be demonstrated that experimentally increasing negative thinking increases depressed mood and that experimentally decreasing negative thinking decreases depression. There is some evidence that increasing negative cognitions in depressed people does exacerbate their negative affect (e.g. Teasdale & Bancroft, 1977). A number of studies with normal subjects have employed mood induction paradigms in which non-depressed subjects are asked to read negative self-referent material, resulting in negative affect. However, often these mood states are quite mild particularly when compared with severe states of depression. In addition Beidel and Turner (1986) have queried the validity of using data from mood induction paradigm to support the cognitive model. They suggest that instructions given in such experiments focus on acquiring a particular mood rather than concentrating on the negative cognitions. They argue that this is contradictory to the predictions of the cognitive model which views negative affect as arising automatically as a result of negative cognitions.
There is also evidence to suggest that reducing the frequency or intensity of negative cognitions alleviates negative affect. Fennell and Teasdale (1984) compared the impact of a distraction condition (describing slides) with a control condition (looking at a square on the wall). Distraction was found to result in significantly fewer negative thoughts than the control condition with corresponding differences in level of depression, as measured by self-report and psychomotor measures. Thus level of negative thinking does seem to impact on mood.

Evidence from other studies has suggested that negative cognitions may play a role in the maintenance of depression. Lewinsohn, Steinmetz, Larson and Frank (1981) examined the relationship between questionnaire measures of cognition and persistence of depression. They found that those initially scoring highly on measures of negative thinking (e.g. attribution, locus of control etc.) were significantly more likely to still be depressed at follow-up than those with low scores on these measures. This difference remained on some of the cognitive measures after controlling for initial severity of depression.

As noted earlier Beck argues that a crucial factor in the maintenance of depression is the fact that depressed people show negative biases in their information processing. The evidence for this hypothesis is mixed. There is evidence that depressed people show negative biases in their recall of information. Lloyd and Lishman (1975) tested recall when subjects were suffering from severe depression and when they were in remission. Subjects were given two lists of neutral words and were asked to recall pleasant and unpleasant memories. In remission (mildly depressed mood) subjects recalled unpleasant and pleasant memories at roughly equal speeds. However, when subjects were depressed they recalled unpleasant memories significantly faster. Thus during depression negative memories appear to become more accessible. Clark and Teasdale (1982) tested subjects who were depressed but showed diurnal variations in their mood. They found that subjects were less likely to retrieve positive memories to neutral cue words and more likely to retrieve negative ones when in the more depressed phase of their diurnal cycle than in the less depressed phase. Subjects also tended to rate the hedonic tone of the memories recalled as being less positive or more negative in their more depressed phases as compared with their less depressed phases. This finding was interpreted as being concordant with the predictions of Beck’s hypothesis. It was argued that the greater accessibility of negative memories and the tendency to view these memories in a more negative way was likely to contribute to the maintenance of the depressed state. Drawing on findings by Tversky and Kahneman, in which judgements regarding the probability of a given outcome depends partly on how easily that outcome is
brought to mind, it was argued that the greater accessibility of negative memories in the depressed state would serve to maintain expectancies of future negative outcomes. However, whilst this study provides evidence for a correlational link between greater depression and greater accessibility of negative thoughts and provides evidence of a possible mechanism of maintaining the depressed state, it is not clear what causes the original escalation of depression.

The evidence that depressed people show biased and distorted thinking as compared to normals is also not conclusive. Alloy and Abramson (1988, cited in Haaga et al, 1991) defined a distortion as a “judgement or conclusion that disagrees or is inconsistent with some commonly accepted measure of objective reality” where as a bias may be seen as “a tendency to make judgements in a systematic and consistent manner across times and situations”. Haaga et al (1991) conclude that whilst there may be some evidence for cognitive biases in depression, there is less evidence that depressed people show cognitive distortions. As noted earlier there is evidence that depressed people tend to show a bias towards recall of negatively valenced information. However, this bias seems to be less pronounced when depressed samples are compared with psychiatric controls rather than normal controls (Dobson & Shaw, 1987).

There is also evidence that depressed people are more likely to draw strong negative conclusions, going beyond the information presented in hypothetical situations than non-depressed controls (e.g. Krantz & Gallagher-Thompson, 1990, cited in Haaga et al, 1991) and psychiatric controls (Dobson & Shaw, 1986). Contrary to the idea that depressives show universally distorted thinking, Garber and Hollon (1977, cited in Beidel & Turner, 1986) found that whilst depressed people predicted that negative outcomes would result from their own abilities or performance, the explanations that they generated for another’s performance were identical to those generated by non-depressed individuals. In other words the bias seemed to be limited to information pertaining to the self. Beidel and Turner (1986) suggest that to explain this in terms of a cognitive processing bias, one would have to postulate two separate processing systems, one for the self and one for others. Power and Champion (1986) argue that this is not the case, demonstrating how this discrepancy could arise within the framework of Johnson-Laird’s mental models approach.

Evidence of group differences between depressed and non-depressed individuals does not necessarily demonstrate that depressed people show negative or indeed irrational cognitive processing. It has been argued that the group differences observed in such studies may
actually be attributable to the fact that controls are distorting the evidence in a positively self-enhancing way whilst depressives are actually being realistic. Thus it seems that depressed people may be “sadder but wiser” than non-depressed individuals in some instances. Power and Champion (1986) have questioned Beck’s assumption that normal people are rational, suggesting that “To presuppose that thinking is logical is irrational”. Dykman and Abramson (1990) have also highlighted recent research which points to the existence of schema based processing, resulting in biases in normal subjects which, they suggest, contradicts Beck’s argument that schema driven processing only occurs in depressed/pathological individuals.

The evidence discussed so far suggests that negative cognitions and negative processing biases may play a role in exacerbating or maintaining depression. However, attempts to demonstrate the validity of Beck’s theory of the aetiology of depression have not proved particularly successful. The evidence regarding so called negative cognitive vulnerability to depression is mixed. It has been suggested that on cognitive measures which access more enduring beliefs, such as the Dysfunctional Attitude Scale (DAS), remitted depressives would be expected to show some resemblance to currently depressed individuals. However, it would be expected that such similarities would not emerge on measures of negative thoughts. Eaves and Rush (1984) found that whilst DAS scores declined in remission, remitted depressives scores still remained elevated as compared with normal controls. However, Dohr et al (1989) and Hollon et al (1986) failed to find any differences between remitted depressives and normal controls on these measures. Hollon et al (1986) attribute the discrepancies between their own findings and those of Eaves and Rush to the fact that they required longer periods of remission before assessment and that the remitted depressives in Eaves and Rush’s study showed higher scores on the BDI than their own group. They concluded that whilst DAS scores may take longer to return to normal levels than some other measures, there is no evidence that scores remain permanently elevated between depressive episodes.

Lewinsohn, Steinmetz, Larson and Franklin (1981) conducted a one-year longitudinal community study in which they assessed participants using a range of cognitive measures, some measuring transient cognitive factors and some measuring more enduring beliefs. Whilst these measures differentiated those who were currently depressed from non-depressed individuals, those who were to become depressed during the course of the study could not be identified on the basis of the pre-morbid measures. Reviewing the evidence from this and similar studies, Beidel and Turner (1986) concluded that “depressive
cognitions are correlates of depression and not causal factors. However, whilst the so-called Reformulated Learned Helplessness model argues that attributional style biases should persist between episodes of depression, Beck makes no such claim. Rather within Beck’s theory it is proposed that depressogenic schemata remain latent between episodes of depression until they are triggered by congruent life events. Lewinsohn et al (1981) made no attempt to assess life events as part of their study. Thus it could be argued that findings that the thinking of depressives returns to “normal” in remission are actually consistent with Beck’s theory. However, the concept of latency does make the causal aspects of Beck’s theory difficult to test, in fact Beidel and Turner (1986) argue latent schemata can never be empirically determined but must be accepted on faith alone. This is not necessarily the case and there have been attempts to test the predictions of Beck’s model. Haaga et al (1991) argue that it may be possible to prime these structures and thereby make them accessible to measurement, although it is not clear how this would be achieved.

Some more sophisticated studies have attempted to assess both cognitive vulnerability and life events. Hammen, Marks, de Mayo and Mayol (1985) asked subjects to give examples of events where they felt good and bad about themselves, dependent on others and critical of themselves. On the basis of this information they were rated as sociotropic or autonomous. Subjects were given regular life event assessments over the course of four months and were assessed for depressive symptomatology. It was found that dependent individuals tended to become depressed following negative interpersonal events but not achievement events. The reverse was true for self critical individuals although to a lesser extent. Hammen, Ellicott, Gitlin and Jamison (1989) assessed groups of uni-polar and bi-polar depressed patients using the Sociotropy-Autonomy scale, using the resultant scores to allocate them to predominantly sociotropic and predominantly autonomous groups. Participants were followed up over six months, with regular assessments of life events and symptomatology. They found that for the uni-polar depressives, symptom exacerbation was significantly more likely if preceded by congruent life events and experiencing more congruent life events was associated with more depression, especially for autonomous participants. Whilst this study provided some support for Beck’s model, it should be noted that it was not a full test of the model of causality, given that participants were already depressed.

Thus, there is little conclusive evidence to support Beck’s model of the aetiology of depression. However, few of the studies in the field have adequately tested all of the key variables, assessing both cognitive vulnerability and life events.
Beck’s theory suffers from a number of other theoretical limitations. Firstly, Beck does not make it clear where the cognitive biases which are said to characterise depression come from, apart from general references to faulty information processing. Beidel and Turner (1986) argue that:

"the aetiology of this deviant processing is not defined, although the implication is that it is one of genetic or physiological differences, and that the processes function outside the laws of learning".

If this were the case then it would seem foolish to attempt to modify hard-wired biases using techniques derived from learning theory. Secondly, there is a lack of clarity regarding the nature of schemata and how these differ from attitudes and beliefs. In addition, there is a lack of delineation between cognitive structure and content and cognitive processes and the products of these processes, both of which are referred to as cognition (Beidel and Turner, 1986). Some authors have attempted to propose clarifications of these issues based on developments in experimental cognitive psychology (e.g. Power and Champion, 1986) but there still seems to be considerable confusion within the literature and a lack of consistency in the use of terminology.

**Effectiveness and limitations of Cognitive Therapy**

Beck’s Cognitive Therapy, derived from the cognitive model, combines traditional behavioural techniques such as pleasant event scheduling and graded exposure with specific techniques designed to challenge patterns of negative thinking and to replace them with more positive ways of looking at events. Beck (1970) whilst acknowledging the parallels between behavioural and cognitive therapies, has stressed that the key difference is the latter’s emphasis on the importance of cognitive processes.

Recent reviews seem to largely concur that cognitive-behavioural therapy for depression is effective. Hollon, Shelton and Loosen (1991) in their review concluded that in controlled trials comparing cognitive therapy with tricyclic treatments, the two were roughly comparable in terms of outcome in the treatment of an acute episode. There was also evidence that cognitive therapy reduced the risk of subsequent relapse. Robinson, Berman and Neimeyer (1990) found evidence that a variety of therapeutic approaches were effective in treating depression. Although outcomes for cognitive therapy did not appear to differ reliably from either a behavioural approach or a cognitive behavioural approach, there was some evidence that cognitive behavioural treatments produced more improvement than behavioural techniques alone. However, they also found that once the influence of
researcher allegiance was controlled, there was no real evidence for the superiority of any one approach.

Behaviourist critics have argued that Beck's approach does not add anything significant to existing behavioural approaches. Latimer and Sweet (1984) in their comparative review argued that there was evidence that the cognitive aspects of this approach were less potent than established behavioural methods and that the success of CBT was derived from the success of previously established behavioural techniques. Beidel and Turner (1986) argued that in outcome studies cognitions were rarely directly altered and that the focus was rather on changing behaviour, with cognitive change perceived as a secondary corollary. They also claim that the use of techniques derived from both theoretical approaches is "hopelessly confound(ed)" so that no firm conclusion can be drawn. They argue that all the main cognitive therapies can be re-framed from a behavioural perspective. For example cognitive challenging strategies can be formulated as stimulus discrimination.

Alternatively some cognitive theorists have argued that all effective therapies are effective through cognitive mediation. Some studies have found that cognitive therapy and pharmacotherapy produce similar cognitive changes in that negative thoughts and attitudes become less negative as mood improves, irrespective of the type of treatment (for example Simons, Garfield & Murphy, 1984). However, DeRubeis, Evans, Hollon, Garvey, Grove and Tuason (1990) found that while such cognitive change predicts improvements in later sessions of cognitive therapy, it does not seem to predict improvement with drug therapy. Thus cognitive change may play a mediating role in cognitive therapy but not in pharmacotherapy.

Specifically focusing on cognitive therapy, Barber and DeRubeis (1989) have suggested three possible mechanisms underlying the effectiveness of cognitive therapy. Firstly, CT may operate at the level of underlying schemata, specifically modifying the content of these schemata. This hypothesis is difficult to evaluate since existing measures of schemata may be unreliable and prone to the influence of transitory mood changes. However, Barber and DeRubeis conclude there is little evidence for the accommodation model since changes in cognition are not unique to CT. Secondly, negative schemata may be de-activated whilst adaptive schemata are activated. Whilst this may be the mechanism underlying the effectiveness of medication which produces temporary change it does not explain the effectiveness of CT in preventing relapse. A final proposal, favoured by the authors is that CT provides a set of compensatory skills for example problem solving and distraction which
can be used to deal with negative cognitions when they arise. It is proposed that with repeated practice over time, change may also occur at the level of schemata but that this is unlikely in the course of a typical short course of therapy. This model concords with other recent proposals for change mechanisms. Teasdale (1985) argued that providing patients with information and teaching compensatory skills alleviates “depression about depression” in the early stages of therapy by increasing the perceived control which patients have over their depression. Simons, Lustman, Wetzel and Murphy (1985) found that subjects high in so called Learned Resourcefulness, i.e. those who already have some skills in their repertoire for monitoring and controlling unpleasant internal events responded better to cognitive therapy than those with low scores on this measure. However, those receiving pharmacotherapy showed the reverse pattern.

Simons et al’s results suggest that cognitive therapy may not be equally effective for all depressed individuals. CT is a pro-active method of therapy which requires active involvement from the client, for example in completing homework, to maximise results. Many of the symptoms of depression such as apathy and social withdrawal are likely to mitigate against active compliance and co-operation with therapy. Hollon (cited in Lindsay & Powell, 1987) suggested that scores on four or more of the following items predicts poor outcome:

- Beck Depression Inventory score >30;
- Duration of current episode >6months;
- Prior poor treatment response;
- More than one previous episode;
- The presence of psycho-pathology other than depression;
- Overall impairment estimated as moderate or severe;
- Poor estimated tolerance for life stress.

However, recent studies have suggested that cognitive therapy can be effective with chronically depressed in-patients (Scott, 1992) and with patients who multiple/entrenched problems (Young, 1989). With such patients the traditional therapeutic techniques may need to be modified. For example, Scott involved nursing staff in incorporating CT techniques into the in-patient programme and sessions were also held with families. Sessions were kept short and were held three times per week. Young recommends combining emotive, interpersonal, cognitive and behavioural techniques, for example utilising a number of gestalt techniques. This eclectic approach, however, will make identification of effective components difficult. As yet there is little outcome data evaluating the effectiveness of this approach.
Conclusion
So, in summary Beck’s cognitive theory of depression seems to provide an accurate description of the depressed state, although there is scope for refinement of the cognitive triad. Evidence for the causal aspects of the theory is more mixed. Whilst there is some evidence suggesting that negative cognitive factors and processing biases may play a role in the maintenance of depression, there is less evidence which clearly supports Beck’s theory regarding the interaction between cognitive vulnerability and life events. Research in this field is hampered by the lack of adequate measures for schemata. The theory also lacks clarity in terms of defining the nature and origins of schemata. Whilst there is fairly good evidence that cognitive therapy is effective and is particularly helpful in preventing relapse, the mechanisms through which change occur is not yet clear. There is, however, evidence to suggest that the teaching of compensatory skills may be important. Recent developments suggest that cognitive therapy may be used with chronically depressed patients with appropriate modifications. However, further research to evaluate the effectiveness of such approaches is much needed.
REFERENCES


LEARNING DISABILITIES
ESSAY

YEAR 1

PSYCH.D.
PEOPLE WITH LEARNING DISABILITIES ARE MORE AT RISK OF BEING SEXUALLY ABUSED AND COMMITTING SEXUAL OFFENCES. DISCUSS THE CONTRIBUTION CLINICAL PSYCHOLOGY CAN MAKE TO THESE ISSUES IN THE CONTEXT OF SOCIETAL ATTITUDES.

The question assumes that people with a learning disability are at more risk of being sexually abused and of committing sexual offences. Before discussing the contribution which Clinical Psychology can make in these areas, it would seem important to clarify whether these assumptions are valid. If they are valid it would also seem important to identify the factors which contribute to this increased vulnerability and so identify those areas which should be the targets of intervention by Clinical Psychologists. In other words it would seem to be important to delineate the nature of the problem and develop a formulation before moving on to discussing possible intervention strategies. Consequently, part of this essay will concentrate on reviewing prevalence studies in these two fields and discussing some of the hypothesised vulnerability factors. In the light of these findings, possible areas in which Clinical Psychology can make a contribution will be discussed at three levels: societal, service and individual. For the sake of clarity the two aspects will be discussed separately but clearly there are a number of issues which are pertinent to both areas.

Prevalence of sexual abuse amongst people with a learning disability

A number of recent studies have investigated the prevalence of sexual abuse amongst people with a learning disability, exploring factors such as the type of abuse; perpetrators; mode of disclosure or discovery etc. There are a number of methodological difficulties in establishing prevalence. Studies using archival methods can only be based on the number of reported or discovered incidents and as Turk and Brown (1993) point out, a number of "filters" exist which minimise reporting. Different areas seem to have different procedural policies regarding reporting of abuse. Turk and Brown (1993) noted considerable variations between districts as to the number of reported incidents. Whilst this may in part be attributed to multiple offences by a single perpetrator, variations in policy and degree of staff expertise in detecting abuse may also be critical. Alternative methodologies also have their limitations. In the child sexual abuse field, for example, retrospective studies using community samples may be used to attempt to determine the extent of under-reporting. However, amongst people with a learning disability this can be complicated by difficulties around memory and communication. A second difficult issue is the definition of abuse used in studies. Prevalence rates vary depending on whether a study focuses solely on penetrative
abuse or includes other types of contact and/or non-contact abuse. Abuse is always non-consensual. However, establishing whether or not a person with a learning disability consented to a particular act may prove difficult if they have communication difficulties, limited concepts around assertiveness and saying “No”, etc. This issue is even more complex with people with severe learning disabilities who are deemed under law as being unable to give consent.

Bearing in mind these difficulties, some of the recent prevalence studies will now be reviewed. Dunne and Power (1990) conducted a three-year incidence study of reported abuse amongst adults and children served by one community service (population: 1500). The study does not define what the authors meant by abuse. 13 cases were identified although this is likely to be an under-estimate due to the retrospective nature of the study and the lack of skill and awareness of reporting abuse in the area at the time. There was an equal split amongst victims between male and female and the majority had a mild-moderate learning disability. However, this may have been due to biases in ability to disclose rather than a true reflection of incidence. All the perpetrators were male and known to the victim; 5 were members of the family. 5 of the offenders had a known or possible learning disability. Abuse was most often disclosed to staff at a day/residential unit or to parents.

Turk and Brown (1993) looked at the incidence of abuse in one Health Service Region over a two-year period. They offered a clear definition of abuse including both contact and non-contact abuse. Questionnaires were sent to the main statutory service providers in the Region. 119 cases were reported. The majority of the victims (73%) were female; 40% had a severe/moderate or moderate learning disability and 40% had a mild or borderline learning disability. 70% also had additional difficulties e.g. communication difficulties; psychiatric/behaviour problems. In 67.9% of cases the initial allegation that abuse had occurred came from the abused person themselves. 98% of perpetrators were men and several had committed multiple offences against several individuals. In 87% of cases, the perpetrator was known to the victim and 42% of perpetrators also had a learning disability. It was suggested that this may be a distorted figure because people with a learning disability may be more likely to commit more public offences and there may be a greater reluctance to disclose abuse by a family member or staff member than by a peer. In 48.2% of cases no action had been taken against the perpetrator and in 43% of cases the perpetrator still had some continued access to the victim.
Furey (1994; Furey and Niesen, 1994) also used a broad definition of abuse including contact and non-contact abuse. Over a 5 year period 461 cases were reported of which 37% (n=171) were confirmed. As in previous studies, most victims were women (72%) and fell in the mild-moderate learning disability range. Most perpetrators were known to the victim (92%) and in 42% cases the perpetrator also had a learning disability. However, it was noted that the perpetrator with a learning disability was only deemed culpable in less than half of the cases. Focusing more specifically on abuse between people with a learning disability within this data set, Furey and Niesen (1994) noted that both men and women were equally likely to be victims (56% women and 44% men). Female victims tended to have a mild learning disability where as male victims were spread across the disability spectrum. In 82% of cases the abuse occurred within the residential placement. 94% of perpetrators were men, mostly with mild-moderate learning disabilities. 81% of perpetrators were still living in large residential settings.

Stromsness (1993) interviewed 14 women with mild learning disabilities who had responded to mailings asking them to take part in the study. 80% had been sexually abused at least once. It was noted that only 45% had received sex education before they were 21 years old where as much of the abuse had taken place before victims were 18. Most of the perpetrators were acquaintances or members of the family. Although most of those who were abused had disclosed prior to the study, in only two cases had legal action been taken against the perpetrator. In one case the judge disregarded the woman’s testimony because he could not understand her. In the other case the perpetrator had been jailed. Nine out of eleven women who had been abused had developed strategies such as keeping doors locked to try and prevent a repeat of the abuse which they believed would happen. One woman made a poignant comment about the vulnerability of people with a learning disability to abuse:

“They figure a person who is handicapped with retardation is not going to testify or even tell and even if they did tell, the system would just ignore the complaint because this person is retarded or handicapped.”

Kempton and Stanfield (1988, cited in Stromsness, 1993) argued that people with a learning disability are four times as likely to be sexually abused as non-disabled peers. Data from other studies (e.g. Hard, 1987; Sumners, 1987, cited in Stromsness, 1993 and Turk & Brown, 1993) suggest that between 70-90% of people with a learning disability are sexually abused before their eighteenth birthday.
Whilst most of the studies cited have methodological flaws, for example biases in the sample due to recruitment method (Stromsness, 1993) or inadequate definition of what is meant by abuse (Dunne and Power, 1990), the picture which seems to emerge from these studies is that people with a learning disability are at risk from being abused both by other people with a learning disability or by staff or relatives. Whether they are at more risk of being abused than the general population is more open to debate and would probably depend in part on the general population sample used as a basis for comparison e.g. adult, child etc. However, it would appear that people with learning disability are at a higher risk of being abused than their non-disabled peers. In addition in would appear that abuse by strangers is comparatively rare, although it has been suggested that amongst parents fear that their disabled “child” would be abused by a stranger is common (Furey, 1994). Of course the rarity of this type of abuse could in part be attributed to warnings by staff and parents not to talk to strangers or restrictions placed on people’s freedom to go out alone, thus limiting their possible contact with strangers. It would also seem that action against perpetrators is a rare although the reasons for this are likely to be complex. For example, where the perpetrator has a learning disability they may not be deemed culpable for their actions or competent to answer charges; staff may seek to protect people from the rigours of court and so not report incidents to the police etc. Alternatively there may be insufficient evidence that abuse has occurred; difficulties may arise in establishing whether or not the victim consented; or doubts may be cast over the victim’s capacity to testify or their reliability as a witness.

Factors contributing to increased vulnerability to abuse
A number of authors have suggested factors which may contribute to the increased vulnerability of people with a learning disability to being sexually abused. This would appear to be a vital area for research so that effective preventative strategies can be developed. However, most of the proposed factors are largely speculative and have not been subjected to rigorous empirical testing. Despite these reservations, some of the current suggestions may act as useful guidelines for possible intervention strategies.

There would appear to be two main types of factors, although these are related and overlapping; firstly, characteristics of people with learning disabilities either arising directly from their disability or indirectly as a result of the way in which they are treated; secondly, characteristics of the way in which services and society in general respond to issues around the sexuality and abuse of people with learning disabilities. Craft and Craft (1981, 1983) argue that people with a learning disability are often lacking in assertion skills and may tend
to be compliant, particularly with people in authority. This was also stressed by Walmsley (1989, cited in Furey, 1994):

"...people with mental handicaps tend to 'obey' rather than challenge their caregivers. They tend to have less choice and frequently have not been educated to believe that they have any control over what happens to them."

Brown and Craft (1989, cited in Turk & Brown, 1993) argue that because people with learning disabilities have a low status in society, somehow abusing them is believed to be less reprehensible and easier to get away with. Kempton and Gochros (1986, cited in Furey, 1994) suggested that key vulnerability factors included: a tendency to be more trusting; deficits in ability to discriminate appropriate from inappropriate behaviour; greater compliance; inability to defend themselves; and inability to report the abuse due to communication difficulties or lack of appropriate vocabulary. Stromsness (1993) suggests people with a learning disability often have difficulty judging the motivations behind other people’s behaviour and that given the fact that they often lead isolated and emotionally deprived lives, they may interpret any expression of intimacy positively and therefore be less likely to resist.

Some authors have argued that a lack of knowledge regarding sexuality and relationships means people with learning disabilities are more vulnerable to suggestion and may not be able to distinguish positive from negative sexual experiences. Studies investigating the sexual knowledge of people with learning disabilities suggest that they tend to be more conservative than their non-disabled peers (Watson and Rogers, 1980) and that their sexual knowledge is often “partial, inaccurate, inconsistent and even improbable”. Lindsay, Michie, Staines, Bellshaw and Culross (1994) assessing the sexual knowledge of a group of adults with mild-moderate learning disabilities prior to a sex education programme found that:

- 28% of the experimental and 25% of the control group thought that you had to go out on a date if you were asked;
- 67% of the experimental and 54% of control groups thought that if someone kissed you that meant they loved you.

A combination of lack of knowledge and a tendency towards trusting compliance are likely to make people with a learning disability particularly vulnerable to exploitation.

In addition to personal vulnerability factors, service and societal responses to the sexuality and abuse of people with learning disabilities may serve to increase their vulnerability. Firstly, at a service level. A number of factors may mitigate against the identification of
abuse within particular settings. Staff may not regard people with learning disabilities as sexual beings and may be ignorant of the prevalence or effects of abuse. As with other unpleasant incidents, there may be a tendency to deny that such an awful thing could happen.

A number of authors (e.g. Furey, 1994) have highlighted cases of institutional or service neglect where there has been a failure to protect vulnerable individuals from exposure to clients with a known history of offending behaviour. Sundram and Stavis (1994) have argued that service providers in the USA often fail to recognise when individuals are at risk, detect incidents and take action against abusers. They argue many staff feel confused as to their role regarding issues of sexuality, given the sometimes conflicting demands of a normalization philosophy which promotes autonomy and sexual expression and their legal obligations to protect vulnerable individuals particularly those who are legally deemed unable to give consent. For example, in seeking to promote sexual expression and autonomy and avoid intrusion, staff may be aware of sexual activity between two clients but may take no action to ascertain whether this activity is consensual.

Societal failure to acknowledge and act following disclosures of sexual abuse also serves to reinforce vulnerability. As the quotation cited earlier suggests, given the low status of people with a learning disability within society, action against those who abuse them may be less rigorous than action against those who perpetrate abuse against other groups. Again there may be widespread denial that people regarded to be "asexual" could be subjected to sexual abuse. Even if people with a learning disability do disclose there is no guarantee that their story will be believed or that action will be taken against the perpetrator. Sobsey and Doe (1991) point out that although the identity of the abuser is known in 95.6% cases, only 22.2% of alleged offenders were charged and 8.5% convicted. Sobsey and Mansell (1990) suggest that the prosecution of offenders is critical in preventing further abuse. However, this may not be feasible where the offender has a learning disability and not deemed to be competent to stand trial or where other factors may be deemed influential in abuse occurring.

Where legal action is taken against perpetrators difficulties may arise around the testimony of the abused person. Valenti-Hein and Schwartz (1993) suggest that in the USA the law is often sceptical as to whether people with a learning disability will meet criteria established for witness competency. Even where competency is proved, it is argued that jurors and judges often doubt the reliability of their testimony and may not see people with a learning disability as credible witnesses. Valenti-Hein and Schwartz suggest that beliefs about people with learning disabilities' credibility as witnesses are based largely on distortions and inaccurate myths. A recent Panorama programme highlighted the difficulties around this area and cited a number of cases in which judges had been reluctant to permit the extension.
of arrangements made for child witnesses to adults with learning disabilities. In a number of cases witnesses had subsequently been discredited under cross-examination.

**What contribution can clinical psychology make in this area?**

In the light of the previous discussion, what contribution can Clinical Psychology make? Clinical Psychology would seem to have a role at the three levels of societal attitudes, service policies and responses and the individual person with a learning disability, both in the prevention of abuse and responding to abuse after it has occurred.

A key role would appear to be in ongoing research to explore the prevalence and impact of sexual abuse as well as critiquing previous studies. It is vital also that the findings of this research are made known so that prevailing myths about people with learning disabilities are challenged. Clearly there is also a need to raise public awareness regarding the prevalence of abuse amongst this population and the impact which this has on individuals. One important role would appear to be in consulting as to whether the law as it stands provides adequate protection for people with learning disabilities. Gunn (1990) suggests that the law in this area is in need of revision and, drawing on their knowledge of the research in the field, Clinical Psychologists surely have a consultative role to play in this area. There may also be scope for the profession to advise on issues around witness competency and arrangements around giving testimony both on a national level and in individual cases. Valenti-Hein and Schwartz (1993) suggest that there is a need to develop more standardised and reliable methods of establishing witness competency. Again Clinical Psychologists could play a role in developing such instruments, drawing on their knowledge of the research on suggestibility, memory, communication difficulties etc. In specific trials, Clinical Psychologists also have a role to play in acting as expert witnesses where they may have been involved in assessing whether abuse has taken place and commenting on the psychological impact on the victim.

Clinical Psychologists could also advise at a national and regional level on the importance of providing adequate sex education for all people with learning disabilities. This should include education around good and bad touch, saying “No” to unwanted approaches etc. As Gunn (1990) points out there is already statutory provision for such a move within the 1986 Education Act.

At a service level clinical psychologists could have an important role in ensuring that their services have sex policies which embody positive attitudes towards sexuality but also
include clear guidelines on protection from abuse and procedures to be followed when incidents come to light. Koheeallee and Dustin (1989) noted that many service providers did not have clear policies in this area. It would seem vital that such policies should emphasise the importance of providing therapeutic support for victims as it would appear that this is often absent. As well as helping the victim to cope with the trauma such an approach may also help to prevent the victim going on to become a victimiser. Policies also need to provide guidelines as to what action should be taken against perpetrators of abuse to ensure consistency. This may prove particularly complex where perpetrators also have learning disabilities and once again clinical psychologists clearly have a role in shaping general policy but also in advising on specific cases. (See later discussion)

Care staff in residential and day care settings have a critical role as they can shape opportunities for sexual expression and in many cases abuse is disclosed to them first. Thus it would seem important that they receive training so that they are aware of sex policies in their area and the practical implications of those policies. Such training clearly needs to address issues around abuse, possible signs which might suggest abuse is occurring and clear guidelines about how to respond. A number of authors have described such packages and evaluated their effectiveness (e.g. Rose and Holmes, 1991).

For those individuals who have not had adequate sex education or who are still considered vulnerable to abuse, Clinical Psychologists, along with other professionals, have a role to play in running sex education programmes which should include issues around good and bad touch, saying “No” and who to tell when bad things happen. McCabe and Schreck (1992) suggest key areas which need to be covered in sex education programmes. Haseltine and Miltenberger (1990) describe a largely successful programme to teach self protection skills. However, the focus within this group was on dealing with approaches from strangers and paid little attention to approaches from other groups who would appear most often to abuse people with learning disabilities. Thus there would appear to be scope for broader approaches to self protection and assertiveness training. However, as Haseltine and Miltenberger point out this needs to be balanced with ethical concerns around causing distress through suggesting staff might abuse people. Clearly this is an issue which needs to be sensitively addressed.

Finally, Clinical Psychologists have a role in developing, evaluating and providing therapeutic input for victims of abuse, an area which is currently very much in its infancy.
Prevalence of sexual offending behaviour in people with learning disabilities and factors contributing to vulnerability

Studies of the prevalence of abuse amongst people with learning disabilities have highlighted the fact that in many cases the perpetrators also have a learning disability. However, less research has been conducted into the prevalence of sexual offending behaviour of people with learning disabilities and the factors which contribute to the development of offending behaviour. Furey and Niesen (1994) conducted a study of 49 people who had sexually abused other people with learning disabilities. 94% were male; 57% had mild learning disability; 25% moderate and 12% severe. They highlight a common link between being the victim of abuse and becoming an abuser, particularly for men, suggesting that:

"with inappropriate or non-existent role models and sexual experiences which include sexual abuse, residents in institutions may be learning that sexual victimisation is not only acceptable but the norm and the cycle of sexual abuse continues."

Although historically low I.Q. has been associated with criminality and people with learning disabilities has sometimes been viewed as "hypersexual", Turk (1989) argues that recent evidence has pointed to a more complex picture in which social and environmental factors are also important. However, a number of authors have argued that people with a learning disability are more likely to commit some types of sexual offences. Hunter (1979, cited in Turk, 1989) claims that people with a learning disability more frequently commit arson and sexual misdemeanours, usually exhibitionism, than their non-disabled peers. He argues that this is related to difficulties in obtaining partners and diminished awareness of the significance of the behaviour. It is also likely that people with learning disabilities are more likely to admit to offences under interrogation, possibly in some cases falsely, because of the tendencies towards suggestibility and acquiescence which are associated with lower I.Q.

Gilby, Wolf and Goldberg (1989) surveyed the incidence of sexual offending behaviour amongst adolescents with and without a learning disability in in- and out-patient settings. Amongst out-patients, the learning disabled adolescents showed a similar proportion of sexual offences but different patterns. People with learning disabilities were more likely to show nuisance behaviours, less likely to engage in consensual but illegal acts and as likely as their non-disabled peers of showing assaultive behaviours. Amongst in-patients, a slightly higher proportion of people with learning disabilities had a history of offending behaviour than their normal peers. The pattern of types of offending behaviour was similar to that observed in the out-patient sample. Closer examination of a small sample (n=10 in each
group) suggested that 80% of learning disabled offenders had committed paedophilic offences in addition to other types of offence. 90% of normal I.Q. offenders had committed paedophilic offences. In 60% cases learning disabled offenders knew their victims and this was less often than non-disabled peers, who knew their victims in 90% of cases. For the learning disabled group, a history of sexual abuse was recorded for 20% of offenders and 30% had a history of physical abuse. The authors suggested because of their method of data collection i.e. referral to records, this was probably an underestimate.

Swanson and Garwick (1990) highlight the confusion that exists within the literature regarding the prevalence of sexual offending amongst people with learning disabilities and how this compares to the non-learning disabled population. They suggest that in their area only 3% of people who receive services from the learning disabilities team show severe sexual aggression problems. However, they do not define either the nature of the population who receive services nor what is meant by “severe sexual aggression”. Swanson and Garwick go on to argue that “there are no data to indicate that the proportion of sex offenders is even as high among people called ‘mentally retarded’ as within the general population”.

In contrast Day (1993, cited in Bowden, 1994) suggests that the incidence of some types of offences is higher amongst people with a learning disability. Bowden (1994) suggests that part of the confusion arises because people with learning disabilities who commit sexual offences rarely go through the judicial process, particularly in cases where the victim also has a learning disability. A further factor which contributes to the confusion is highlighted by Hingsburger, Griffiths and Quinsey (1991). They point out that what appears to be sexually motivated behaviour may in fact serve a very different function. They list eleven hypotheses for “counterfeit deviance” including attention seeking; side effects of medication; sexual behaviour occurring in public because of a lack of private space and a lack of understanding regarding how to form relationships. Thus careful assessment of the nature and function of behaviour is essential prior to its being labelled as a “sexual offence”.

Thus there would appear to be some disagreement as to whether sexual offending behaviour is more common amongst people with learning disabilities or not. However, clearly some people with learning disabilities do offend and it would seem important to try and identify factors which may contribute to the manifestation of such behaviours. Swanson and Garwick (1990) argue that that continued reluctance to acknowledge the sexuality of people with learning disabilities combined with inconsistent attitudes and behaviour by staff within and between settings, can lead to considerable confusion for people with learning disabilities as to what is and is not acceptable behaviour. The response to initial, often minor offences
may also reinforce this ambiguity. Swanson and Garwick suggest that the typical response to an initial offence is a minor scolding but little therapy or education. This conveys the message that the behaviour is “not too bad”. Only when carers’ tolerance levels are exceeded by increasingly serious behaviour or by repeated minor offences is firm action taken. Swanson and Garwick argue that offenders are “typically desensitised gradually to the gravity of the offences and then unexpectedly punished”.

Bowden (1994) suggests that many people with learning disabilities have experienced many years of restriction being placed upon their sexual expression so that they have little opportunity to develop appropriate patterns. Consequently, people, particularly those who have experienced long periods of institutionalisation, may have learned inappropriate models from peers or developed inappropriate compensatory behaviours. A number of authors have discussed the link between being abused and becoming an abuser, particularly for men. This process may involve learning to associate abuse with sexual arousal and modelling in what may be the sole experience of intimacy. It should be noted that no clear causal link has yet been established.

A further factor identified by Charman and Clare (1992) may be ignorance or confusion regarding the laws and social mores around sexual behaviour. Even if the person with a learning disability knows, for example, that it is illegal to have sex with a person under 16, they may have difficulty in establishing the age of other people. Charman and Clare found considerable evidence of ignorance in this area amongst a group of learning disabled sexual offenders although these gaps did not appear to relate clearly to their specific offences. It should also be noted that as no control group was included it is not clear whether ignorance amongst offenders is any greater than amongst people with learning disabilities who do not sexually offend.

**What contribution can Clinical Psychology make to these issues**

As the previous discussion has shown, there is clearly still room for more research on the prevalence of offending behaviour amongst people with learning disabilities and reasons for this behaviour. Such research would appear vital if Clinical Psychologists are to be able to give effective advice as to how to respond to offending behaviour and if effective intervention programmes are to be developed.

On the basis of existing work it could be argued that a more positive approach to sexuality in which people with a learning disability have access to sex education in its broadest sense and
also opportunities to learn about sexuality in more normal ways, may reduce the occurrence of such behaviours.

For those who are already offending, or who may continue to offend in the future despite more positive attitudes, clinical psychologists may contribute in a number of ways. Firstly, in contributing to sex policies on how to deal with inter-client abuse and other cases where offending behaviour takes place. Secondly, in assessing particular individuals. Given the fact that individuals may show behaviour which appears to fall into the category of sexual offending for a variety of reasons, careful assessment of the contributory factors and a comprehensive functional analysis would seem vital. Bowden (1994) provides guidelines for the areas which need to be covered in such an assessment. On the basis of such assessments advice may be given as to what further action is required. In cases where the police are involved, clinical psychologists may advise on appropriate questioning to take account of tendencies towards suggestibility or acquiescence. They may be able to comment on competency to stand trial, comment on mitigating factors which need to be considered, conduct risk and neuropsychological assessments and comment on the most appropriate line of action to take if someone is found guilty. In cases where the police are not involved, it would seem that action also needs to be taken to protect other vulnerable individuals and to minimise the likelihood of further offences. Clinical Psychologists have a role to play in discussing what action should be taken, once again drawing on the literature regarding different approaches. Depending on the nature of the offence this may include in or out-patient treatment. A number of studies have been published describing approaches to the treatment of offenders. For example, Swanson and Garwick (1990) outline a group treatment approach which included sex education and social skills and an emphasis on the negative impact of abuse on victims. The recidivism rate was 40% and 13% were re-arrested. Day (1988) describes an in-patient treatment approach for offenders including practical and social skills programmes and token-economy strategies. They reported largely positive outcome particularly for sex offenders with 70% of people in the well or reasonably adjusted category at 1 year follow-up. Hames (1987) outlines a residential programme including counselling, social skills training and sex education. 3 out of the 5 cases discussed had not re-offended at six months follow-up. Clearly there is scope for more work in developing and evaluating treatment approaches and Clinical Psychologists have an important role in this.
Conclusion

Sexual abuse and sexual offending amongst people with learning disabilities are both complex and emotive subjects. Whilst there has been much speculation regarding the reasons for vulnerability in these areas, few of these suggestions have been empirically tested. Clearly there is a need for ongoing research lest interventions and advice be based purely on speculation rather than on empirical findings. In addition clinical psychologists could contribute in a number of ways at societal, service and individual levels in both these areas.
References:


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OLDER ADULTS ESSAY

YEAR 2

PSYCH.D.
WHAT FACTORS ARE INVOLVED IN SUICIDAL BEHAVIOUR IN OLDER PEOPLE?

INTRODUCTION
The government white paper "The Health of the Nation" (1992) has identified reduction in suicide rates as a key area of health gain. Given that suicide rates are highest amongst older adults (over 65), consideration of the factors contributing to these rates and the implications for service provision is vital.

The main focus of this review will be on completed suicide. However, reference will be made to the literature on attempted suicide. There is some debate as to how these two groups relate but a number of authors have highlighted the commonalities in risk factors (Merrill & Owens, 1990; Zweig & Hinrichsen, 1993), suggesting that elderly attempters and completers may constitute separate but overlapping groups. Others (e.g. Lyness, Conwell & Nelson, 1992; Conwell, Rotenberg & Caine, 1990) have highlighted the benefits of studying attempters given that they are at high risk of subsequent completed suicide and that studies of attempters avoid the retrospective biases inherent in most of the studies of completed suicide.

It should be noted that studies in this field are hampered by the fact that official statistics typically under-report elderly suicide (Blazer, Bachar & Manton, 1986; Lapierre, Pronovost, Dube & Delisle, 1992). In particular, cases of indirect self-destructive behaviour, (McIntosh, Santos, Hubbard & Overholser, 1994), where, for example, self neglect or abuse of medication may hasten death, often remain unreported.

After a brief review of the epidemiological data, the evidence for some of the main contributory factors identified in the literature will be reviewed. Few authors have proposed models which encompass multiple risk factors but some examples have emerged in recent years and these will be discussed briefly. Finally, the implications of this research for clinical practice will be explored.

Epidemiological findings
Studies from the USA, Britain and other countries have indicated that rates of completed suicide are highest amongst the elderly population, typically defined as those over 65 (McIntosh et al, 1994; Conwell, 1995; Cattell & Jolley, 1995). The old-old, defined as 75 and above, show higher rates of suicide than the young-old. Evidence from the USA has
also revealed racial differences, with the highest rates occurring amongst Caucasians and other racial groups showing variable rates. At all ages, men are at higher risk for suicide but this trend becomes even more marked in the elderly. Canetto (1992), in her review of theories proposed to explain the gender disparity in suicide rates, has argued that women are at lower risk because they show more flexible coping styles, possibly acquired in response to the multiple role changes they experience in their life course. In addition, she argues women are more likely to seek appropriate help for psychological distress. In contrast, she argues, men experience fewer role changes prior to retirement, show less flexible coping styles and are more likely to resort to destructive coping strategies such as alcohol abuse. Much of the evidence she cites in support of her argument is indirect but this suggestion is worthy of further research.

For parasuicide or attempted suicide the pattern is somewhat different. Rates of attempted suicide are lower amongst the elderly than amongst younger adults, rates being highest amongst adolescents. In general, the elderly are much more likely to be successful in a given suicide attempt. The ratio of attempts to completed suicides among all ages is about 10:1, but in those over 65 it is 1:1. (Frierson, 1991). McIntosh et al (1994) suggested that this lower ratio was due to a combination of factors including greater desire to die, use of more lethal methods, the physical changes associated with ageing which increase the likelihood of death following self harm and greater social isolation which reduces the chances of discovery. McIntosh et al (1994) note that although at all ages, rates of attempted suicide are higher amongst women, the gender difference becomes less pronounced with age.

KEY RISK FACTORS FOR SUICIDE IN OLDER ADULTS

LIFE EVENTS

A number of studies have examined the role of various life events in precipitating suicidal behaviour in older adults most commonly focusing on retirement, bereavement and physical ill health.

Retirement

Poor adjustment to retirement has been cited in a number of reviews as a risk factor for suicide (Lapierre, et al, 1992; McIntosh et al, 1994). However, the evidence is somewhat mixed.

Miller (1978) argued that retirement was a major factor in his study of elderly, white male suicides. He suggested this group were particularly likely to experience detrimental effects
after retirement because of the predominance of the Protestant work ethic and a tendency for this group to define themselves in terms of work. In contrast, Atchley (1980, cited in McIntosh et al, 1994) argued that retirement did not have a significant impact on male suicide because there is no sharp increase at or in the year following retirement. However, this is not a convincing argument as not everyone retires at the same time and it could be argued that the implications of retirement do not sink in immediately. One might expect a honeymoon period followed by disillusionment in cases where meaningful ways of filling ones time or alternative ways of defining one’s identity have not been found. Certainly, Ekerdt, Bosse and Levkov (1985) in their study of adjustment to retirement, found significantly lower levels of life satisfaction and reduced involvement in leisure and physical activities amongst second year compared to first year retirees.

It could also be argued that the circumstances surrounding retirement may influence the nature of adjustment and thus impact on suicide risk. Parotti and Wilson (1979) interviewed 140 residents of a retirement hotel comparing the impact of voluntary and involuntary retirement. They found that those who had retired involuntarily showed higher levels of emotional instability, had fewer interpersonal relationships and contemplated suicide more often. However, they also found that regardless of the circumstances of the retirement, those with good interpersonal relationships and a high degree of emotional stability contemplated suicide less frequently. Thus social support and emotional stability seemed to be more important in predicting contemplation of suicide than nature of retirement. Shepherd and Barraclough (1980) in a sample from across the life span, compared the work histories of 75 completed suicides and 150 controls, matched for age, sex and marital status. They found no significant differences in the proportions of those retired in the two groups. There was a non-significant trend for suicides to have retired early. However, in several cases this was due to a psychiatric problem which would have been expected to increase the risk of suicide anyway. It was noted that more of the control group were likely to maintain some kind of employment after the age of 60. This has been interpreted as indicating that gradual retirement may have a less detrimental effect than sudden retirement.

Overall, there does not seem to be any conclusive evidence that retirement, in and of itself is a significant risk factor. It is more likely that the circumstances and meaning of retirement to the individual are important and this is worthy of further study. The role of retirement as a broader risk factor for example in reducing social contacts and as part of an accumulation of stressors also cannot be ignored.
Bereavement and Widowhood
Bereavement and widowhood are also commonly cited as risk factors for suicide (Lapierre et al, 1992; Conrad Glass & Reed, 1993; Conwell, 1995) particularly amongst men. Bunch (1972, cited in DeLeo & Ormskerk, 1991) found evidence of an increased risk of suicide amongst men in the first year after the death of their spouse. However, by four years post bereavement this risk dropped to normal levels. Cattell and Jolley (1995) in their study of 100 completed suicides found that marriage was a protective factor against suicide for men with higher rates amongst widowed and single men. However, no such difference was found for women. Li (1995) in a historical cohort study based on information from an official census and death certificates, found evidence for a higher rate of suicide amongst widowed compared to married people. There was an interaction between sex and marital status in that widowed men were three times as likely to kill themselves as married men where as the difference in suicide rates between widowed and married women was small. With adjustment for housing quality, education etc., widowed men were five times as likely to kill themselves as married men where as the relative risk for women was near unity.

Thus there is some evidence of increased risk of suicide following widowhood certainly for men although the reasons for this are not yet known. Canetto (1992) suggests that men may have relied more on their wives as their sole source of emotional support where as older women are more likely to have a network of friends. Some studies have found evidence that widowers tend to be more withdrawn and less communicative than widows of the same age (Kirsling, 1986) which could exacerbate their risk of suicide. Canetto (1992) also suggests that men may have to take on additional, unfamiliar responsibilities following the death of a spouse but this is just as likely for women. A further factor may be that women, who tend to have a higher life expectancy than men, are more likely to be widowed and are therefore more likely to “anticipate” widowhood and have peers who have experienced widowhood.

The relationship between being widowed and the increase in suicide risk is likely to be complicated. Rates of depression and alcohol use are also known to increase after bereavement and these are also risk factors for suicide. In addition, widowhood is likely to impact on role, social isolation and living circumstances. Thus it is not clear whether loss per se or loss combined with these other related factors contributes to this increased risk.

Physical health
Poor physical health is another commonly cited risk factor where the evidence is mixed (Lapierre et al, 1992; McIntosh et al, 1994).
Frierson (1991) reported that amongst elderly suicide attempters, 48.5% had chronic illnesses and many others had transient illnesses. They argued that for their group the most common precipitant for an attempt was ill health, particularly diseases such as lung and heart problems and chronic pain syndromes which often necessitated significant life style changes. Cattell and Jolley (1995) in their retrospective study of 100 cases of elderly suicide found that 65% had recorded ill health at the time of death, of whom 23% had been hospitalised within the previous year. 27% had complained of “pain” which was reported to be severe in 16% of cases. However, the interpretation of this data is complicated by the retrospective, third party nature of the data and the lack of a control group. Rich, Wasradt, Nemiroff, Fowler and Young (1991) interviewed friends, family and professionals to ascertain frequency of life events in 202 cases of suicide across the life span. They found that the relationship between life stressors and suicide varied across the life span. Where as for adolescents and younger adults interpersonal problems were most pertinent, illness and physical health problems became most salient amongst older adults. However, interpretation of the significance of this data was complicated by the lack of normative data for these different age groups. In addition, no attempt was made to ascertain the severity of life events or how different types of life events had a cumulative or interactive effect.

Clark (1993) has argued that there is no evidence that people who commit suicide are in worse health than their peers. Perhaps, therefore, rather than a direct link between physical health and suicide, other factors are also important. Dorpat, Anderson and Ripley (1968, cited in Lyons, 1984) found that amongst their sample of suicide completers aged over 60, 85% were ill and for 69% their illness was deemed to have contributed to their suicide. Dorpat et al (1968) suggested that the relationship between illness and suicide was mediated by depression and also that individual characteristics may interact with experience of illness to increase risk. For example, illness may be particularly difficult for those for whom activity and independence are important. De Leo and Ormskerk (1991) suggested that hopelessness in the face of ongoing illness or illness which is perceived as untreatable may be critical in increasing risk of suicide.

The relationship between poor physical health and risk of suicide thus appears complex. Even where evidence of a link is found this can be explained in a number of ways. For example physical health problems may engender an attitude of hopelessness and depression which in turn increases risk of suicide; physical health problems may reduce mobility and
increase social isolation thus increasing risk etc. There is certainly scope for further work to elucidate the nature of this connection.

**Suicide as a response to an accumulation of life events**

Many authors have argued that elderly suicide is not typically a reaction to a single event but is rather a reaction to an accumulation of life stressors and losses (Conrad Glass & Reed, 1993; Osgood, 1991). Achte (1988) suggests that these repeated life events co-occur with reduced internal and external coping resources to increase suicide risk in the elderly. Leenars (1992) in his study of suicide notes reported that many detailed such an accumulation of stressors to such a point that the person no longer felt able to cope. He cites Farberow and Scheidman (1957) who claimed:

"The older suicide is tired, bitter of life or of pain and suffering and he writes that he is physically or mentally exhausted".

However, an accumulation of difficult experiences may not constitute the whole answer. Clark (1993) reported that using a standardised life and social stresses scale designed specifically for older adults, there was no evidence that people committing suicide had experienced significantly more life stresses than controls. Perhaps there is scope for a consideration of personal and social factors which may impact on response to life events.

**SOCIAL ISOLATION**

Social isolation is another factor commonly cited as increasing the risk of suicide but again the evidence is complicated.

Lyons (1985) found evidence that suicide rates are higher amongst those who do not belong to any social, cultural or religious organisation, confirming earlier findings by Miller (1979). However, this may be confounded by other variables such as levels of depression and physical disabilities given that both are likely to reduce inclination and ability to participate in such groups. Miller (1979) found that elderly persons who committed suicide had only been visited once a month or less, compared to non-suicidal elderly persons who were visited more than once per week.

There does not appear to be any consistent evidence to suggest that those who live alone are at higher risk of suicide. Cattell and Jolley (1995) found 49% of their sample were living alone at the time of the suicide. However, this did not emerge as a significant variable as it was estimated from census data that 50% of the people of pensionable age living in the area were also living alone.
Lyons (1984) has emphasised that quality of interactions and contact may be more important than frequency in terms of adjustment and protection from risk of suicide. Lyons (1982, cited in Lyons, 1984) found no differences between suicide attempters and controls in terms of frequency of visits and phone calls. However, 73% middle aged and elderly attempters reported feeling lonely where as only 37% of controls did. Darbonne (1969) in a study of suicide notes found evidence elderly suicides emphasised loneliness and isolation more often than younger suicides.

One final study of interest is that of Abrahams and Patterson (1978). They found that where social isolation was a lifelong pattern, elderly people were not distressed by it. However, for those unaccustomed to isolation, for example those who were recently widowed, isolation was more distressing.

Thus the role of social isolation in suicide is likely to be complex and may depend in part on how that isolation is viewed i.e. as something which is unpleasant versus something to which one has grown accustomed to. Quality of social support is also likely to interact with other factors. For example, isolation is likely to be exacerbated by physical ill health and depression. Lack of support may become a particular problem where the individual is experiencing significant stressors and needs help to cope with them. Finally, reduced social contact may decrease the chances that someone identifies clues that the individual may be contemplating suicide and also reduces chances of detection after an attempt, thus increasing the likelihood that the person will succeed in killing themselves.

**DEPRESSION AND ALCOHOLISM**
The most commonly cited and most frequently explored risk factor for elderly suicide is depression (Conwell, 1995; Lapierre et al, 1992; DeLeo & Ormskerk, 1991; Osgood, 1992).

Rich, Young and Fowler (1986) found evidence that elderly suicides were most often diagnosed with affective disorder or organic brain syndrome, whilst younger suicides were more often diagnosed with substance abuse disorder or antisocial personality disorder. Clark & Clark (1991, cited by Osgood, 1992) carried out psychological autopsies on 72 cases of suicide aged 65 and over, found that 65% of subjects qualified for diagnosis of major and minor depression in the weeks preceding death. Caution needs to be exercised in interpreting this retrospective data given that it is difficult to ascertain how much third party reports are biased by hindsight. Frierson (1991) in a retrospective chart review of 95
people over 60 who were assessed within the psychiatric services following a suicide attempt found that 50% of people had diagnoses of major depression without psychotic features. Amongst younger attempters, depression is less common although other diagnoses, especially adjustment disorder, schizophrenia and personality disorders, are common. Cattell and Jolley (1995) found that 60% of their sample were clinically depressed.

However, several authors have pointed out that many older adults who are depressed do not commit suicide. Lindesay (1986) suggested only 0.5% of elderly depressed people commit suicide. A number of authors have argued, that as for younger adults (Beck, Kovaks & Weissman, 1975), hopelessness is a key mediating variable (Lyons, 1984; De Leo & Ormskerk, 1991). Indeed, Hill, Gallagher, Thompson and Ishida (1988) found evidence that hopelessness was a major predictive factor of suicidal intent amongst depressed elderly people. Greene (1981) found evidence that hopelessness was monotonically related to age, with older individuals expressing greater hopelessness. Loss has been shown to be related to hopelessness (Slater & Depue, 1981) and as has often been pointed out, older people face multiple losses. Frierson (1991) suggested that the precipitants identified for a suicide attempt amongst older adults were more likely to be irreversible than those for younger adults. Such a situation, it is argued, engenders a heightened sense of hopelessness.

Osgood (1991, 1992), along with others, has argued that alcoholism is a major precipitating factor in later life suicide. Barraclough, Bunch, Nelson and Sainsbury (1974) found that those who have habitually used alcohol to cope with problems are particularly at risk of later life suicide. However, this may be confounded by other variables, for example co-morbid depression and anxiety and coping with the social and financial consequences of alcohol abuse. Other studies suggest that, given that alcoholism is a self-limiting disorder, alcohol and other substance abuse tend to occur less often among suicide completers (Conwell et al, 1990) and attempters (Lyness et al, 1992) with increasing age.

**PERSONALITY**

Few studies have looked directly at the role of personality traits in elderly suicide. Conwell (1995) has suggested that “a neurotic, emotionally constricted personality style” is a risk factor for suicide, citing a psychological autopsy study by Duberstein, Conwell and Caine (1994). Data was gathered on 52 suicide completers of all ages using an interview and review of medical and other records. As part of this study they used an informant based measure of personality which they report to be “standardised” and “well validated”. Data was also gathered for age and gender matched normal controls. They found elevated levels
of neuroticism, particularly self-consciousness and pessimism, amongst completers of all ages. There was no evidence that completers were high on impulsivity or hostility. Whilst the are some complications in the interpretation of this finding, it was suggested that completers may generally be more considered than attempters who are often characterised by impulsivity. On the Openness to experience sub-scale, suicide completers obtained lower scores than controls and older completers had even lower scores than younger completers. Whilst there are some limitations to this study, particularly the small size of the sample and cross sectional design which makes interpretation of age differences difficult, it does offer some interesting preliminary pointers as to personality factors which may be key in increasing suicide risk. There is certainly scope for more work of this kind.

A BRIEF REVIEW OF MULTI-FACTORIAL MODELS

Lester (1994) has argued that the research on suicide has not identified any variable or combination of variables which is necessary or sufficient to the aetiology of suicide. It seems more likely that multi-factorial models are needed which encompass personality, coping style, life events etc. and the interactions between these variables. Development of such models seems to have been largely absent from the literature. However, two recently proposed models are worthy of some discussion.

Clark (1993) argues that many but not all elderly suicides have an invisible, life long character fault, specifically they lack the capacity to adapt to the ageing process and resolve the associated conflicts (Erickson, 1963). In response to an accumulation of earlier unresolved conflicts and the normal losses and stressors associated with age, such individuals experience a “narcissistic crisis of ageing”, manifested for example in angry denial and refusal of help. This is exacerbated where the person has chronically abused alcohol or psychoactive substances and/or experiences a period of depression. Exposure to a final, possibly fairly innocuous, triggering event precipitates a suicidal crisis and act. This model represents an admirable attempt to try and combine some of the key risk factors identified earlier. However, the notion of the “lifelong character fault” is poorly delineated and little evidence, beyond anecdote, is provided to support the model.

McIntosh et al (1994) describe a cognitive behavioural model in which psychosocial stressors, limited social support, problem solving deficits and cognitive distortions feed into and maintain mood disturbance (specifically depression and irritability) and hopeless. The co-existence of mood disturbance and feelings of hopelessness is thought to result in the desire to die. Availability of method and reduction in self control are amongst the factors
believed to contribute to high risk of an attempt. This model encompasses many of the risk factors discussed earlier and makes some attempt to look at the interactions between factors. There is, however, scope for more rigorous testing of this model and particularly research on the role of cognitive biases and hopelessness.

**CONCLUSIONS AND IMPLICATIONS FOR CLINICAL PRACTICE**

The evidence in this field highlights a number of factors which appear to contribute to increased risk of suicidal behaviour in the elderly. Whilst evidence regarding many of these factors is equivocal, there is strong evidence to support other factors such as widowhood in men and depression. It would also seem important to explore more thoroughly the role of cumulative life stressors. The areas of hopelessness and personality traits which may contribute to vulnerability could also be explored further. Few attempts have been made to develop and test multi-factorial models and this would seem to be a vital area for future research. Such models would be invaluable for Clinical Psychologists seeking to identify and assess those considered to be at high risk. In addition, such models would be helpful in the development of appropriate services and interventions for high risk groups and individuals.

In terms of clinical practice, a number of issues are worthy of note. At a societal level, little attention is given to suicide in the elderly and the associated risk factors. Clinical Psychologists have a role to play in disseminating the existing research and in providing appropriate teaching and training for those who work with the elderly. Whilst Cattell and Jolley (1995) and others have found that few of their sample of suicide completers were in contact with specialist services, Vasilas and Morgan (1993; 1994) found that 68% of their over 65 sample consulted their G.P. in the four weeks prior to their death. Cattell and Jolley (1995) suggest that G.P.'s often fail to detect depression in their elderly patients. Training for G.P.'s in the detection and appropriate treatment of depression would seem to be a potentially important way of reducing elderly suicide. Training for all primary care and specialist professionals working with the elderly to raise awareness of risk factors may also be helpful.

As noted earlier, the existing research has pointed to some specific risk factors and high risk groups. It would seem vital to take account of these findings in planning service provision and to develop creative ways of providing services for these groups. Given that men are at particular risk yet often do not seek help, ways of targeting services more effectively for this group need to be identified. A number of authors have suggested that retirement preparation courses may be useful in promoting successful adjustment to retirement and thus reduce the
potential risk of suicide. This could address issues around planning for graded retirement, activity planning after retirement and exploration of issues around identity. Men also seem to be particularly at risk after the death of their spouses. Consideration of how to make services available and accessible to this group seems key. Such services may need to address issues around practical as well as emotional support.

Finally, development and evaluation of therapeutic interventions for older adults, specifically for hopelessness and depression, is also vital.
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NEUROPSYCHOLOGY
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PSYCH.D.
IS NEUROPSYCHOLOGICAL REHABILITATION EFFECTIVE?

Introduction
Hanlon (1994) from an American perspective has highlighted the recent growing demand for neuropsychological rehabilitation. He points out that approximately 500,000 people per year in USA require hospitalisation for head injury and an additional 500,000 new victims of stroke are treated per year. Similar trends have been noted in Britain (Wilson, 1995). These figures need to be considered within the context of increasingly sophisticated medical technology which is resulting in higher rates of survival. In addition, in Britain recent health reforms have emphasised the need to evaluate efficacy of treatment provided.

In seeking to evaluate the effectiveness of neuropsychological rehabilitation, two definitional issues need to be addressed. Firstly, what is meant by rehabilitation and secondly, what is meant by effectiveness. The two are clearly related as the model and aims of rehabilitation which are adopted will influence how effectiveness is defined and evaluated. The Oxford English Dictionary defines rehabilitation as a procedure that “helps a person who is physically or mentally disabled to re-adapt to society”. Miller (1992) contrasts two different intervention approaches that could be used with impairments resulting from traumatic brain injury. Firstly, the curative approach which attempts to remove or reduce the basic impairment directly. The alternative is the rehabilitative or compensatory approach. Miller suggests this approach:

“places the emphasis on reducing the impact that the impairment may have on the individual’s everyday functioning while accepting that the basic impairment itself will remain unchanged”.

Hanlon (1994) suggests:

“The primary objective of neuropsychological rehabilitation is to improve the quality of life of individuals who have sustained neurological insult, which may involve cognitive, behavioural, emotional, and social factors. Any and all of these factors may affect interpersonal, marital, vocational, educational and recreational domains, in addition to functional independence in activities of daily living”.

These definitions suggest that generally rehabilitation is seeking to compensate for rather than cure deficits. In addition, rehabilitation should aim to improve everyday functioning and quality of life. As Hanlon (1994) points out, rehabilitation needs to address emotional and social functioning as well as cognitive and behavioural. These definitions also suggest that in evaluating effectiveness, attention needs to be paid to generalisation of skills to
everyday functioning and that measures of outcome should include social and emotional factors.

An additional factor in this field, highlighted in much of the literature, is the heterogeneity of the head injured population (Wilson, 1991, 1993). As Wilson highlights this heterogeneity has implications for the type of methodologies which are likely to be useful. She argues that group designs have an important role in the field but also stresses that, given the diversity of deficits within the population, interventions need to be individually tailored. This necessitates use of single case methodologies in which improvements are measured in the individual’s level of functioning.

Reviews of neuropsychological rehabilitation (e.g. Wilson & Powell, 1994; Hanlon, 1994; Mateer & Ruff, 1990; Ruff, Niemann, Troster & Mateer, 1990; McGlynn, 1990) highlight the diversity of target problems and approaches used within the field. Gross and Schutz (1986) summarised the main treatment models used in neuropsychological rehabilitation as being: environmental control; stimulus-response conditioning; skill training strategy substitution; and the cognitive cycle model. Environmental control is a behavioural approach in which the environment is restructured to elicit or eliminate specific behaviours. The second approach is based on the use of behaviour modification techniques. Skills training is an educational approach in which repeated rehearsal of a skill is used to improve tasks performance. Strategy substitution involves incorporation of alternative sensory and cognitive systems to perform tasks normally mediated by the damaged system. Finally, the cognitive cycle model involves training in the implementation of a structured organisational sequence that may be repeated and modified as needed to complete tasks requiring complex problem solving skills. Gross and Schutz (1986) suggests that these models comprise a functional hierarchy, with environmental control being appropriate for those with the most serious deficits and the cognitive cycle model being appropriate for those who have more intact cognitive functioning. Hanlon (1994) describes an alternative classificatory system for the main approaches to cognitive rehabilitation consisting of four main divisions. The general stimulation or direct re-training approach consists of routine engagement in repetitive drills. The substitution transfer approach involves training in the substitution of an intact or comparatively intact system for an impaired cognitive function. Functional compensation and adaptation involves use of a variety of internal and external strategies and devices to compensate for deficits. Finally, behavioural approaches are derived from learning theory and behaviour modification principles.
Rather than attempting to cover the areas of functioning that can be addressed within neuropsychological rehabilitation, this review will focus on the selected areas of memory, attention and executive functioning as illustrative of the range of approaches used in other fields. The final section will look at studies evaluating the effectiveness of treatment programmes encompassing different elements.

Memory

Although estimates of the prevalence of memory deficits vary, a number of authors agree that it is one of the most common sequelae following brain injury (Wilson & Powell, 1994). Wilson (1995) suggests that 36% of people with severe head injury will have significant and permanent memory impairment. A variety of different approaches have been used to treat such deficits and the findings of the outcome studies suggest differing degrees of success.

One approach, derived from the direct retraining model, is to use rote repetition or drilling. Miller (1992), citing evidence from studies by Glisky and Schacter (1986), argue that there is little evidence to suggest that such an approach has any beneficial effect.

A second approach derived from the strategy substitution approach is to teach people to use internal memory strategies to maximise their residual memory function. A variety of specific techniques have been evaluated, largely using single case methodologies, with varying degrees of success. Hanlon (1994) in his review of these studies suggested that whilst many reported task specific improvements, reports of successful maintenance and generalisation are less frequent.

Jones (1974) reported on a group study of use of a visual imagery technique to aid in learning unrelated word pairs. Three lists of word pairs were used, one for measuring baseline performance, one for teaching the strategy and one for post-training testing. Unexpectedly, delayed recall of all three lists was tested after two hours. As it was decided that it was not reasonable to bring everyone to a criterion performance, an arbitrary standard of three learning trials per list was used. Those groups receiving mnemonic training showed improved performance on the later lists. Although this study points to the potential benefits of using visual imagery, the task used was very artificial and it is not clear how far these results would generalise to more naturalistic settings. Other studies of visual imagery training have produced more mixed results. Glasgow, Zeiss, Barrera and Lewinsohn (1977) describe an uncontrolled case study of a patient assessed as having average intelligence and
mild overall impairment. The patient received 19 sessions training him to use a visual
imagery technique to facilitate memory for people’s name. Within the lab, no benefit was
found in using the imagery procedure as compared with his standard strategy, partly because
the patient tended to develop very complex images. A simplified imagery technique was
used in vivo and after 7 weeks practice there was a decline in number of names forgotten
daily as compared with baseline levels.

Wilson (1987) conducted a study in which the interaction between severity of impairment
and ability to use various strategies to facilitate paired associate recall was assessed.
Subjects were allocated to three groups depending on the severity of their memory
impairment. For each group, baseline performance was compared with two visual imagery
conditions, one in which imagery was provided by the therapist and one in which imagery
was self generated. A significant Group x List interaction suggested that whilst all groups
could benefit from the therapist provided imagery, only those with mild impairments
benefited from self generated imagery. However, Benedict (1989) suggested that recall for
all groups may have been improved if subjects had received more than the three trials with
each strategy used in this study. This study does, however, highlight the importance of
considering individual variables such as severity of impairment when considering the most
appropriate strategy to be used.

Glasgow, Zeiss, Barrera and Lewinsohn (1977) presented an uncontrolled case study looking
at the effectiveness of various techniques to improve memory for text. Following baseline
assessment with a neuropsychological battery and probe task, within lab conditions the
patient was taught to use either her normal strategy, rehearsal or the PQRST method to recall
key points from text. The PQRST proved to be more effective than the other strategies used.
Following baseline assessment, the patient was encouraged to use the PQRST technique with
articles and academic material. Although improvement in vivo was not as dramatic as in the
lab, the patient was able to apply the technique in a natural setting and felt confident enough
to return to college. It should be noted that this patient was assessed as having above
average intelligence and only mild overall impairment. Treatment consisted of 24 sessions
over 6 months.

Wilson (1987) compared the effectiveness of simple rehearsal and PQRST with a group of
eight patients. Group results suggested superior immediate and delayed recall for PQRST.
However, conclusions were limited by the lack of pre-treatment baseline.
Wilson (1982) used a multiple baseline methodology to compare the effectiveness of various memory strategies. The patient had recovered physically after a CVA and showed no intellectual problems (he was reported as functioning in the very superior range) but had severe memory difficulties. Four specific problems were identified and baselines taken on each area for four days. Different strategies were used for each task: rehearsal for learning a daily timetable; visual imagery for names and first letter mnemonics for shopping lists. For learning routes a variety of methods were used including rehearsal, a fading procedure, a letter sequencing cue and a letter/word mnemonic strategy. In addition the patient received general memory training. Re-testing on a variety of general memory measures did not suggest any significant improvement. However, high rates of success were reported on three of the target tasks although learning the routes remained a problem. At three months follow-up, high levels of performance were reported on the three originally successful tasks but route finding performance remained poor. Thus, tasks specific improvements were obtained and maintained. However, generalisation of these skills proved more problematic. Although no structured measures of generalisation were employed, Wilson (1982) reports that his life at home remained largely unchanged. With fairly intensive training, the patient was able to learn new information but the strategies did not help with constantly changing information in naturalistic situations.

In contrast to the majority of the reports in this field, which used case study or other single case methodologies, Ryan & Ruff (1988) conducted a well controlled group study. Subjects were either assigned to an experimental group (132 hours practice on memory strategies) or a placebo group (132 hours practice on video games and supportive group therapy). The rate of improvement on a battery of psychometric tests did not differ between the two groups. In addition, the analyses suggested that severity of injury was a significant factor in predicting responsiveness to memory remediation.

Berg, Koning-Haanstra and Deelman (1991) conducted a well controlled group study which produced mixed results. They note that in studies of effectiveness of particular training procedures care needs to be taken to control for effects of spontaneous recovery, test-retest and also for the effects of training, time and attention per se. 39 closed head injury patients who were screened according to fairly strict criteria participated in the study. It should be noted that all were living independently and half had returned to work/education. Participants were randomly allocated to one of three groups. The “strategy rehabilitation group” received 18 one-hour sessions over three weeks combined with daily homework practice to promote generalisation. Participants were given a book detailing memory rules.
and sessions focused on further delineation of the application of these rules. The “pseudo rehabilitation group” received equivalent input based around memory tasks and games with a focus on drill and repetition. The third group consisted of a test-retest control group. Two baseline assessments were taken during the first three weeks followed by a three-week training period and two post training assessments in the following two weeks. After a further three weeks of training, two further post training assessments were taken over three weeks with additional assessment at three month follow-up. Outcome measures included subjective measures, completed by participants and close relatives, and an objective test battery. This consisted of tests on which no improvement would be expected (a reaction time task) and tests on which improvement would be expected (an auditory verbal learning task, a face-name learning task and a shopping list task). On the subjective measures, both treatment groups showed similar patterns of positive outcome ratings. For the control task, no significant changes occurred for any of the groups. However, on the other tasks, whilst no significant effects were found for pseudo-rehabilitation, the strategy training had significant positive effects on all the memory performance measures, especially at follow-up. This was taken as evidence that participants were continuing to use the strategies they had learned. Thus evidence was provided that memory strategy training had beneficial effects which generalised to other tasks, were maintained at follow-up and were not attributable to spontaneous recovery or attention. However, it should be noted that only subjective ratings of generalisation to everyday life were obtained. More objective measures would have been beneficial.

Milders, Berg and Deelman (1995) conducted a four-year follow-up of the participants in their earlier study. Participants completed the same objective tests, rated their everyday memory problems and how well they coped with these difficulties. The results suggested that there were no significant differences between the three groups on either the memory task, the control tasks or the subjective ratings of memory difficulties. The authors suggested that this could have been partially explained by selective dropout, in that a larger proportion of those with poorer memory scores from the pseudorehabilitation and control groups did not return at follow-up as compared with the strategy group. Even taking this into account, however, relative to post-training, improvements were noted for the pseudo-rehabilitation and control groups whereas the strategy group showed a slight deterioration. The authors suggested that this may have been due to differences in strategy use. Although measures of strategy use were taken at four-year follow-up and revealed no group differences, no information on strategy use was available from previous evaluations. Thus, the benefits of strategy training observed immediately after training and at short-term follow-
up were not maintained at long-term follow-up. In part this may be attributable to the fact that initial intervention was fairly intense and that no booster session were offered.

A third approach involves use of external aids such as memory notebooks and environmental adaptations (Wilson, 1995). Hanlon (1994) describes a single case study by Sohlberg and Mateer (1989) detailing a structured programme for use of a compensatory memory notebook. In addition to the acquisition and utilisation of a compensatory memory notebook, they reported effective transfer to activities of daily living and work in a patient with severe memory impairment. Wilson (1995) describes a number of other case studies where external aids have been used successfully. In a study looking at outcome for people with severe memory problems, five to ten years after they completed rehabilitation, participants were asked about the numbers of aids, strategies and memory techniques which they were using. The most commonly used memory strategies were all external compensation strategies. It was also found that those using six or more aids, strategies or techniques were significantly likely to be independent than those using five or less.

Glisky and Schacter (1989) describe the use of the method of vanishing cues to teach severely amnesiac patient complex knowledge related to a data entry job. The task was broken down into a series of stages and each component was taught in the laboratory prior to transfer into a real world setting. The patient was initially accompanied in her job by an experimenter who monitored her performance and helped to resolve difficulties. Transfer to the work setting was initially accompanied by a slowing in data entry as compared with laboratory performance. However, after 5 weeks documents were being entered more quickly than they had been at the end of laboratory training. This study raises interesting possibilities for neuropsychological rehabilitation in that it demonstrates that some amnesiac patients can be taught new skills. Whilst there were some difficulties in generalising these skills to a novel setting, generalisation was eventually successfully achieved. However, the programme took several months to complete and was fairly intensive. It is unlikely that resources would be available to conduct programmes of this intensity within routine clinical practice.

Summary
There would appear to be little evidence to suggest that repetition or rote drilling is helpful in memory rehabilitation. Evidence regarding training in specific substitution strategies is mixed. Whilst short-term improvements have been observed, evidence for maintenance and
generalisation is often absent. Positive results have been reported for use of external aids but the authors stress that patients need to be trained effectively to use these aids. Gisky and Schacter’s study suggests interesting possibility but their approach is very labour intensive. A key theme, which emerges across studies, is that the type of approach which can be used effectively is likely to be influenced by the severity of the individual’s deficits.

Attention
Benedict (1989) comments that deficits in information processing speed and selective attention are common after traumatic head injury. Remediation in this area has focused on using tasks requiring patients to ignore distraction and maintain attention over time. Ben-Yishay and his colleagues have been instrumental in developing retraining programmes in this area and also evaluating the effectiveness of these interventions. The programme developed by this group is based around a series of hierarchical computerised tasks of increasing difficulty. The tasks cover visual reaction time, maintenance of focused visual attention, sustained and selective visual attention, time estimation and rhythmic response sequencing. Positive results have been reported for this programme. For example, Ben-Yishay, Piasetsky and Rattock (1987) (cited in Benedict, 1989) report a case study in which the patient received 62 hours of attention training. Improvements were reported on the training tasks, on a reaction time task and also on the Digit span subtest of the WAIS-R. In a further study with 11 people, improvements on training tasks were reported after training and also at 6 months follow up. However, lack of pre-treatment baseline limits the results and evidence regarding generalisation is limited. This package forms part of a comprehensive treatment programme and studies evaluating the programme as a whole are reported under the section on outcome of treatment packages.

Sohlberg and Mateer (1987) describe a process specific approach to rehabilitation. They have developed a hierarchical retraining package with tasks covering focused, sustained, selective, alternating and divided attention. They employed a multiple baseline design with four patients, using the PASAT as an outcome measure for attention combined with a visual processing task as a control. After baseline, patients participated in attention, visual processing and memory training programmes. For all patients, improvements on the PASAT were noted after attention training and the gains were maintained up to eight months after cessation of treatment. Anecdotal reports of improvements in everyday life were also noted.

Franzen and Harris (1993) used a modified multiple baseline design to evaluate intervention for attention skills related to memory and abstract reasoning / problem solving skills. The
Luria Nebraska Neuropsychological Battery was employed for the initial and follow-up assessment. Specific measures of attention and problem solving were employed combined with the Stroop Color and Word Test as an index of general cognitive efficiency. The initial phase of treatment consisted of seven sessions of training using four attention/concentration tasks along with daily home practice. The second phase consisted of nine sessions using two tasks requiring skills in planning, sequencing and problem solving. Performance on the attention test tasks improved more after Phase 1 than after Phase 2 and after Phase 1 greater improvement occurred on the attention tasks than on the problem solving tasks. After Phase 2, greater improvement was noted on the problem solving tasks than on the attention tasks. On the Luria Nebraska Neuropsychological Battery, which was re-administered at the end of treatment, at least limited improvement was noted on all scales. The authors noted that aside from the targeted scales, the greatest improvements occurred on those scales which had a significant attentional or memory component. Although anecdotal reports of follow-up and generalisation to everyday life are provided, there was no attempt to evaluate this systematically and this is a failing of the current study.

**Summary**

There is evidence that approaches targeting remediation of attentional processes can have some beneficial effects at least in the short term. However, the studies reported so far have not evaluated maintenance and generalisation to everyday life systematically. This is an area worthy of further exploration.

**Behavioural difficulties and executive functioning**

Benedict (1989) has noted that head injured patients often exhibit deficits in self regulation and impulse control. The associated behavioural problems can inhibit progress in rehabilitation.

Environmental manipulation and behaviour modification approaches are commonly used to deal with these difficulties. Eames and Wood (1985) report on the long-term outcome of a group of 24 head injured patients treated within a structured setting, which operated on a token economy. The programme combined positive reinforcement of appropriate behaviour using tangible and social rewards with time out for inappropriate. Mean duration of treatment was 12 months. Outcome measures included placement, activities of daily living, behaviour and ongoing treatment. The follow-up period ranged from 6 to 39 months after treatment. The authors report generally positive results. For example, two thirds of patients showing improvements in placement after treatment and in most cases this was maintained at
follow-up. Comparing behavioural ratings for post-treatment and follow-up, the authors concluded that there was little tendency for treated behaviours to reappear after discharge from the structured setting. Thus, this study suggests that positive improvements in behaviour can be achieved even with very difficult patients in a structured environment and that these changes were of sufficient magnitude to permit the patients to move to less restrictive settings. However, the authors note that one quarter of the sample failed to benefit from treatment, most of whom had very diffuse injuries and one of whom had a previous history of psychopathy. The authors also suggest that optimum period of treatment needed to obtain sustainable improvements was 15 to 18 months.

Johnston, Burgess, McMillan and Greenwood (1991) describe successful use of behavioural management techniques to teach self regulation on fluid intake to a woman who had developed diabetes insipidus and memory impairment following removal of a craniopharyngioma.

Alderman and Ward (1991) describe a case in which response cost i.e. removal of valued item when the behaviour is performed was combined with cognitive overlearning. The patient in question had been diagnosed as having Dysexecutive Syndrome (DES) following herpes encephalitis. The authors note that behaviour modification methods using positive reinforcement and extinction are often ineffective with patients who show severe deficits in memory functioning combined with severe deficits on frontal tasks. The authors report that many of the patient’s behavioural problems had been ameliorated using a token economy approach but that she continued to manifest treatment resistant patterns of repetitive speech. A multiple baseline design was used and treatment was completed in 51 days. The results suggested a decline in repetitive speech within treatment sessions, which generalised to other situations and was maintained at three months follow up. Alderman and Ward argue that such an approach may be helpful for use with DES patients because immediate feedback is needed for patients with such severe memory impairments rather than the delayed feedback often used in token economies. Whilst this is an approach which has potential benefits the ethical issues associated with use of punishment based approaches need to be carefully balanced against gains associated with treatment.

Drawing on the skills training approach, Von Cramon and Matthes-Von Cramon (1992) discuss the use of problem solving training with brain injured patients. Their approach draws on behavioural techniques such as saturated cueing, fading and shaping to teach these skills. In an earlier study patients with problem solving deficits were divided into two
groups: half received memory training and half received problem solving training of equal duration and intensity (25-30 sessions). Outcome was evaluated using neuropsychological tests sensitive to problem solving skills and with behavioural observations of every day situations. For the problem solving group, significant improvements were noted on test results and everyday observations. However, this was only noted for approximately one third of the group. Those in the memory group showed no such improvements in their problem solving skills. It was noted that those who benefited most from the intervention used tricks learned in sessions in their everyday life.

Summary
There is some indication that behavioural management approaches can be used to effectively reduce difficult behaviour in head injured patients. However, in selecting an appropriate intervention the severity of the patient’s deficits needs to be taken into consideration (McGlynn, 1990). McGlynn argues that there is scope for more research to delineate more clearly what levels of cognitive ability are required to benefit from different techniques. There is evidence that some patients can benefit from training in problem solving strategies and this is worthy of further exploration.

Evaluation of treatment packages
Whilst the studies discussed so far have attempted to evaluate the impact of training in specific areas, other studies have attempted to evaluate the overall effectiveness of different treatment programmes.

Prigatano, Fordyce, Zeiner, Roueche, Pepping and Wood (1984) compared an intensive experimental programme with traditional rehabilitation. The two groups were matched as closely as possible for age, sex, education level, injury severity and time since injury. Attempts were made in the statistical analyses to minimise the impact of confounding variables where this was not achieved. It should be noted that those in the control condition were described as “for one reason or another...unable to undergo intensive cognitive and psychotherapeutic rehabilitation”. As the reasons behind this are not fully described, the possibility of selection bias cannot be ignored. The experimental programme focused on increasing awareness and acceptance of injury and its associated deficits, intensive cognitive re-training for specific deficits and development of compensatory skills. Staff met regularly with relatives in an attempt to promote generalisation of skills to the home environment. Outcome was evaluated using a battery of neuropsychological tests, a standardised measure of personality adjustment and work status. The results suggested a trend for better post-
treatment neuropsychological functioning for the experimental group as compared with the control group. These improvements were obtained after adjusting for the effects of initial level of performance, and where appropriate, age, education, chronicity and test interval. The experimental group performed significantly better than the controls on WAIS Performance IQ and Wechsler Memory Quotient. Non-significant trends for superior performance for the experimental group were noted on other measures. It was also found that the experimental group showed more improvement on the adjustment measures than the control group. With regard to vocational outcome at follow up, 50% of the experimental group were classified as being “productive” where as 36% of the control group were productive. However, three people in this group were lost to follow-up and consequently their status was unclear. Analysis of the variables associated with successful employment outcome suggested that emotional stability and improvement on the tests of neuropsychological functioning were most important. The authors conclude that this study revealed evidence of modest but statistically significant improvements on standardised neuropsychological tests and some improvement in vocational outcome. They also suggest that further improvements in vocational outcome could be obtained if work related skills had been addressed more directly within the programme. This assertion clearly requires empirical validation. In summary, whilst this study reported some positive result following an intensive programme, it is not clear whether these improvements were maintained in the long term or whether they made a significant impact on patients every day functioning. In addition, given that the control subjects did not receive the same level of input as the experimental group it is not clear whether the improvements obtained represent genuine treatment effects or merely a response to increased attention and stimulation.

Ruff, Baser, Johnson, Marshall, Klauber, Klauber and Minter (1989) describe a well controlled group study which incorporated quasi-random group allocation which balanced groups for sex, age, and level of impairment and equated groups on level of professional attention. A multiple baseline design was also used to control for the effects of spontaneous recovery. All participants underwent extensive neuropsychological testing at the start of the baseline period, at the end of the eight-week baseline period (i.e. immediately before the start of treatment) and at the end of the eight-week treatment period. Wherever possible, parallel forms of the tests were used to avoid practice effects. The control group programme consisted of group psychotherapy and six other activities which emphasised psychosocial adjustment, leisure and activities of daily living. The experimental group programme consisted of group psychotherapy and treatment modules focusing on attention, spatial integration, memory and problem solving. The results suggested that both groups showed
improvements, thus suggesting that an enriched environment even in the absence of formal cognitive remediation can have a beneficial effect. However, the experimental group showed significantly greater improvements in certain areas namely verbal learning and visuo-spatial recall and a trend towards greater improvement on selective attention. They note that the treatment effects noted in this study were comparable with those reported by Prigatano et al (1984) for their six-month programme and they highlight the need for further research exploring optimum treatment durations for different types of patients. Unfortunately, little attention was paid in this study to whether treatment gains generalised to everyday functioning. In addition, longer term follow-up would be helpful in establishing the durability of treatment gains.

Three other studies of treatment packages have attempted to assess the impact of rehabilitation on everyday functioning. Ben-Yishay, Silver, Piasetsky and Rattok (1987) specifically looked at the impact of rehabilitation on vocational outcome. A heterogeneous group of 94 patients, all of whom had failed to return to productive employment despite previous rehabilitation attempts, participated in a three phase programme. Initially, patients completed the package, which included cognitive remediation and small group programmes to develop interpersonal skills. In the second phase, participants completed individualised work placements. Performance was assessed by comparison with paid colleagues. The third phase consisted of making the transition to paid work and long term follow up. Estimates of employment capacity at the end of work placements, suggested that 84% were deemed to have attained the ability to engage in productive endeavours, 63% at a competitive level and 21% at a subsidised level. Follow up data up to 3 years was available for 36 of the participants. These figures highlighted a decline in numbers in competitive employment and an increase in those who were unemployed and who were deemed unemployable. At three-year follow-up, 50% people were employed competitively, 22% achieved non-competitive levels of employment and 28% were unemployed. An analysis of factors related to successful and unsuccessful outcome highlighted some interesting points. Decrements in employability were related to social isolation and lack of adequate support, forgetting to apply strategies learned in rehabilitation and financial disincentives to work. Factors deemed to be associated with successful outcome were improvements in self awareness and emotional regulation; increase in the functional application of residual abilities and improvements in acceptance of the consequences of injury. Given the variable results of other studies of vocational outcome and in the absence of a control group, assessment of the success of this programme in increasing rates of return to work is difficult. However, the rates certainly compare favourably with those reported in other studies. It is interesting to
speculate whether rates of sustained employment may have been increased further by longer term support and therapeutic follow up.

Rattok, Ben-Yishay, Ezrachi, Lakin, Piasetsky, Ross, Silver, Vakil, Zide and Diller (1992) compared outcome for three treatment mixes with groups matched for levels of input and key indices of severity. Package one included cognitive remediation, small group interpersonal communication training, therapeutic community activities and personal counselling. Package two resembled package one but emphasised small group interpersonal exercises and eliminated cognitive remediation. Mix 3 emphasised cognitive remediation and eliminated small group interpersonal exercises. Before and after intervention patients were assessed using a battery of psychometric tests, a measure of competence and independence in everyday life (the Behavioural Competence Index, BCI), measures of inter- and intra-personal functioning and vocational outcome. With regard to the psychometric measures, it was found that all three treatment mixes resulted in transfer to similar and less similar cognitive tasks but systematic cognitive remedial training was observed to yield additional, specific carry over effects. The authors suggested that these improvements were not sufficiently large to indicate enhancement in underlying abilities but rather were evidence of improved general alertness, greater ability to focus attention and greater efficiency in applying residual abilities. On the BCI, all the packages were equally effective but there was some evidence that package one resulted in significantly greater improvements on affect regulation. All packages produced similar improvements on the intra/interpersonal measures but packages 1 and 2 were superior to package 3 on some measures. The three treatment packages were equally effective in terms of vocational outcome. Thus there would appear to be advantages to more comprehensive programmes incorporating both cognitive remediation and interpersonal training. This study represents an invaluable attempt to compare the efficacy of different treatment packages in an attempt to delineate which treatment mixes are most effective. In addition, this study’s use of outcome measures in multiple domains is to be commended. Longer term follow-up data would be useful in evaluating whether these gains are maintained.

Christiansen, Pinner, Moller Pedersen, Teasdale and Trexler (1991) evaluated the outcome of their rehabilitation programme consisting of 4 months intensive intervention including groups to promote social interaction, cognitive re-training, group psychotherapy, lectures and input from a multi-disciplinary team. After the initial intervention period, the group met monthly for six months. The main focus of the current study was on psycho-social outcome. Staff conducted semi-structured interviews with patients and carers, obtaining data on the
patients functioning at four intervals: pre-injury, pre-treatment, post-treatment and follow-up (this ranged between one year and two and a half years). The interview covered independent living, amount of help received at home, use of health services and work and leisure activities. The authors report a number of positive outcomes and maintenance of gains at follow-up, which they attribute to participation in the programme and ongoing therapeutic contact. These positive outcomes included increases in the number of people and hours in work, increased social activity and increased levels of co-habitation. Whilst this study represents an admirable attempt to evaluate the impact of neuropsychological rehabilitation on variables which relate more directly to quality of life, the authors assertion that the improvements can be attributed to the programme are not justified given the limitations in baseline data and the lack of control group. Their assertion that ongoing intermittent contact helps to facilitate maintenance of treatment gains is worthy of further empirical investigation.

Summary
Recent studies of treatment programme outcome have largely reported positive findings using a neuropsychological, psycho-social and vocational measures of outcome. However, the studies are of variable quality and many questions remain unanswered. For example, further research into the optimum duration of treatment programmes and whether ongoing contact with staff after termination promotes maintenance and generalisation of improvements. There is also some indication of superiority of comprehensive programmes that incorporate interventions for inter-personal skills as well as cognitive remediation.

Conclusions and implications for service provision
There is evidence from studies looking at efficacy of specific techniques, intervention programmes targeting particular deficits and evaluation of comprehensive programmes that neuropsychological rehabilitation can be effective. Studies focusing on the efficacy of specific techniques or remediation of particular deficits have often demonstrated post-treatment improvements on neuropsychological measures of functioning. However, evidence regarding maintenance of these improvements is often poor. In addition, reports of generalisation to everyday life are often lacking or rely solely on anecdote. There is a need for future studies to pay particular attention to issues of generalisation and to employ objective measures. Recent studies evaluating effectiveness of programme have begun to incorporate multiple measures of outcome, including evaluation of emotional and vocational issues, and to address issues of maintenance and generalisation more systematically and this is to be commended.
The difficulties in maintenance and generalisation of treatment effects noted in many studies are instructive for clinicians. Studies vary considerably in the duration of treatment programmes but what is less clear is whether duration of intervention is related to durability of improvement. Further research specifically addressing this issue would be helpful to clinicians seeking to plan intervention programmes. Given Milders et al's (1995) findings of poor maintenance of improvement four years after follow-up, strategies for promoting maintenance also need to be explored. Christiansen et al (1991) suggest that ongoing intermittent therapeutic contact, after the cessation of intensive treatment, can help to facilitate maintenance. This assertion is also worthy of further investigation. As Wilson (1991) emphasises, clinicians cannot assume that generalisation will occur but rather interventions need to be structured in order to facilitate generalisation. This could include ensuring that skills training occurs in a variety of contexts and maximising liaison with carers and people from work settings.

For clinicians seeking to plan intervention programmes which are as effective as possible a number of factors may need to be taken into consideration. Firstly, the severity of the patient's deficits influences the type of intervention that is appropriate. For example, Wilson (1987) has shown that the type of memory strategy which patients can use effectively depends on the severity of their memory impairment. Alderman & Ward (1991) have shown that where standard behaviour modification techniques may be ineffective with Dysexecutive Syndrome, other techniques such as response cost may be effective. Further research is needed to delineate the relationship between severity of deficit and effectiveness of intervention approach.

Secondly, clinicians need to consider the combination of treatment components to be used. Attempts have been made recently (e.g. Rattok et al., 1992) to evaluate the relative efficacy of different treatment mixes. The evidence to date suggests that optimal effectiveness, across multiple measures of outcome, requires comprehensive programmes which address inter-personal issues as well as cognitive remediation. Again there is scope for further research to explore the relative efficacy of different treatment combinations.
REFERENCES:


“THERE IS SOME EVIDENCE THAT CHILDREN WITH CHRONIC PHYSICAL HEALTH PROBLEMS ARE AT INCREASED RISK OF PSYCHOLOGICAL DIFFICULTIES. HOWEVER, THE MAJORITY DO NOT SHOW PSYCHOLOGICAL PROBLEMS.” DISCUSS WITH REFERENCE TO AT LEAST TWO CHRONIC CONDITIONS.

INTRODUCTION
Approximately 10-12% of children experience some sort of chronic disease (Eiser, 1990) of varying degrees of severity. Such conditions are typically associated with pain or discomfort, frequent medical interventions, hospital admissions, disruptions to schooling and every day functioning and in some cases with the possibility of permanent disability or death. Given the stresses associated with having a chronic disease, it might be hypothesised that such children would be at increased risk of psychological difficulties. Research aimed at delineating the prevalence and nature of such difficulties has often resulted in conflicting findings. However, the consensus which seems to be emerging is that whilst children with chronic illnesses at increased risk of psychological difficulties, the vast majority of these children do not show such problems. This has led to a consideration of factors which may be associated with vulnerability and resistance.

The first part of this essay will review the research outlining the prevalence and nature of psychological difficulties amongst children with chronic diseases. Rather than attempting to review studies covering all conditions, attention will be focused on two conditions, Sickle Cell Disease and Cancer. These were chosen because of the writer’s interest and experience in these fields but also because they illustrate issues which occur in other diseases. The next section will introduce one of the theoretical models of adjustment to chronic disease. Next, the effectiveness of the model in accounting for the available data will be considered. Finally, implications for clinical practice will be discussed.

THE PREVALENCE AND NATURE OF PSYCHOLOGICAL DIFFICULTIES AMONGST CHILDREN WITH CHRONIC PHYSICAL HEALTH PROBLEMS

Sickle Cell Disease
Sickle Cell Disease (SCD) is an inherited group of blood disorders predominantly affecting people of Afro-Caribbean origin. In Britain, it is estimated that over 5 000 people have SCD and at least 150 babies with SCD are born every year. There are three main types: sickle cell anaemia (SS), SC disease (SC) and sickle B thalassemia (SBThal). SCD is associated with a
variety of medical complications including strokes, leg ulcers, renal complications and seizures. The most commonly reported problem is painful episodes due to vaso-occlusion arising from sickling of red blood cells. Pain in SCD can be extremely variable and unpredictable in terms of timing, location and intensity (Shapiro, 1993). There is currently no cure and treatment consists largely in alleviating the underlying factors associated with sickling and in controlling pain, primarily with analgesic medication.

Many of the studies of psychological functioning in children with SCD have been conducted in the United States, although there has been increased interest in Britain over the last few years. The studies have produced mixed findings.

Hurtig and colleagues have conducted a number of studies exploring the adjustment of children and adolescents with SCD. Hurtig and White (1986) studied 50 SCD children aged 8-16 using measures of personality, behaviour, locus of control and self-concept. As compared with test norms, increasing problems in adjustment were noted with increasing age, particularly for boys, on both measures of personality and behaviour.

Hurtig and Park (1989) assessed behavioural problems, family environment and life events amongst a group of 33 SCD adolescents. Using the cut off for Achenbach’s Child Behaviour Checklist, adolescent boys with SCD were found to have significantly higher levels of behaviour problems in every domain, with scores in the clinical range in three domains. For girls, scores were significantly higher than the normative group in eight domains and approached the clinical range on one domain. In the area of social competence scores for both boys and girls were within the normal range but were significantly lower than the normative group.

These studies highlight some of the problems in conducting research with the SCD population. These studies used comparison with national norms for standardised tests to assess adjustment. However, these tests were standardised on the American general population not on a black American population. Thus interpretation of results becomes complicated by the fact that it is not possible to determine whether noted discrepancies are attributable to SCD or to other factors such as SES and experiences associated with coming from a particular racial group.

Lemanek, Moore, Gresham, Williamson and Kelley (1986) compared 30 SCD children with 30 controls matched for SES. They found no differences between the groups on a variety of
measures and suggested that the psychosocial problems found in other cross-sectional studies of children with SCD may have been attributable to low SES rather than SCD.

However, Morgan and Jackson (1986) compared levels of body satisfaction, depression and social competence amongst 24 SCA adolescents and 24 controls, matched on sex, race, age and SES. The SCA group showed greater dissatisfaction with their bodies, spent less time in social and non-social activities and were more depressed. This later finding remained even after the removal of somatic items from the analysis. It is not clear whether the reductions in activity are related to levels of depression or to disease related factors such as painful crises or visits to healthcare professionals.

Brown, Kaslow, Doepke, Buchanan, Eckman Baldwin and Goonan (1993) compared 61 children with SCD with a group of 15 non-diseased siblings using various measures completed by multiple informants. The results suggested that the SCD children manifested more depression and internalising behaviour as rated by their mothers. These differences were not attributable to increased somatic complaints amongst the SCD group. SCD children also showed a more depressive attributional style and were rated as showing more externalising behaviours by their teachers. Whilst there were no overall differences between the groups on measures of self perception, the SCD groups scored lower on peer acceptance and scholastic competence. The findings suggested that adaptive behavioural skills deficits, internalising symptoms and depressive attributional style increased with age. SES was related to few of the variables. Whilst this study is superior to some earlier studies in using multiple informants and measures of adjustment, the control group was small which limits the statistical power of the findings. It is also to be noted that the most severe cases of SCD would have been excluded by the eligibility criteria & recruitment via a clinic may have excluded those who were coping most successfully.

In a well designed British study, Midence, McManus, Fuggle and Davies (1996) compared a group of 39 SCD children with a group of 24 control children on a range of measures from multiple informants. They found no significant differences between the groups on intellectual ability, parental report of behavioural problems, depression and self esteem. Analysis of teachers' reports of behavioural problems suggested that the SC group showed significantly more behavioural problems than controls. The authors suggested that this could be due to subtle neurological problems. They also point to other research which has highlighted particular problems amongst those with milder physical health problems, suggesting this may be due to ambiguity as to whether the individual belongs to a “healthy”
or "ill" group and to the perception that families with children with less severe problems require less support. Thus on the whole it did not appear that the SCD groups showed increased risk of psychological difficulties. However, given the small sample sizes it is difficult to draw firm conclusions.

The literature reviewed so far has presented mixed results as to whether children with SCD are at increased risk of psychological difficulties. Midence, Fuggle and Davies (1993) in their review of the studies in this field, concluded: "There is some evidence for an increased risk of psychological and social problems in children and adolescents with SCD compared with non-affected peers. However, the large majority of patients do not show any psychological disorder". Particular difficulties have been noted around depression, cognitive style, body dissatisfaction and behavioural difficulties. Their conclusions would appear to be justified on the evidence so far. However, there is certainly a need for further well controlled research, particularly in Britain, to explore the prevalence and nature of psychological difficulties amongst this group. Such research needs to take account of the confounding variables of race and SES and the impact of these on presentation. There is also a need to not just recruit samples from specialist centres whose patients may not be representative of the population as a whole. In addition, the suggestion that children with SC disease may be at particular risk needs to be explored in greater detail.

**Cancer**

Cancer in childhood is a rare condition, with leukaemia one of the most common forms, affecting only 0.03 per 1000 live births (Eiser, 1990). Formerly cancer was viewed as a fatal condition and much of the early research in the field focused on adjustment to death in the child and their family. Recent medical advances have dramatically increased survival rates such that for some types of cancer 80-90% of children now survive. Consequently, many authors have argued that many types of childhood cancer are best viewed as life threatening chronic conditions. Several studies have noted similarities between oncology patients and those with other chronic conditions on a range of psychological measures (Kellerman, Zeltzer, Ellenberg, Dash & Rigler, 1980; Zeltzer, Kellerman, Ellenberg, Dash & Rigler, 1980). Interest has shifted to looking at adjustment to treatment, living with an ongoing illness and quality of life issues. Many of the treatments used are very aggressive and aversive with long term effects such as disturbances in growth hormone production, sterility and cognitive impairments. This has led to increased interest in how people cope with the impact of treatment as well as the impact of disease per se.
Research into the psychological adjustment of children with cancer has produced contradictory findings.

Koocher, O’Malley, Gogan and Foster (1980) used a variety of self and clinician rated assessments with a representative sample of 115 paediatric cancer survivors, all of whom had ended treatment at least 1 year previously. They rated 59% as having adjustment problems with 23% falling in the moderate to severe category. Whilst this study is frequently cited, it is not without difficulties. The criteria used to allocate someone to the adjustment problem category were very liberal and consequently may have included a number of people with only mild problems. The lack of a normal control group is also problematic.

Kupst and colleagues (1984; 1988) carried out a longitudinal study of adjustment in paediatric leukaemia patients up to 6 years after diagnosis. Kupst, Schulman, Maurer, Honig, Morgan and Fochtman (1984) noted that for the 60 families in their sample, most were judged to be coping well by staff and by themselves. Scores on a range of standardised measures were within normal range. The predominance of successful coping was noted in a 6-year follow-up by Kupst and Schulman (1988). Again this study did not include a control group.

Greenberg, Kazak and Meadows (1989) compared 138 8-16 year old cancer survivors who had been off treatment for at least 2 years with a matched control group of 92 physically healthy controls, pre-screened for psychological problems. Participants completed measures of self concept, locus of control, depression and family environment. The survivor groups scored significantly lower than controls on self concept and showed a more external locus of control, although both groups scored within normal limits. No differences were noted for depression. This comparison may have been biased by the exclusion from the control group of any child with psychological problems.

Using the Child Behaviour Checklist, Mulhem, Wasserman, Friedman and Fairclough (1989) looked at adjustment in 183 children who had completed treatment. They found a significantly higher rate of difficulties (3-4 times higher) than would have been predicted from the standardised norms and more than half the children had scores suggestive of excessive behavioural problems and nearly as many had deficits in the area of social competence. Problems were particularly noted in poor school performance, somatic complaints and social competence. Sanger, Copeland and Davidson (1991) assessed 48
children, aged 4-17, who were at varying stages in their disease. Using the Personality Inventory for Children, they found that 52% of the children had profiles with two or more clinically significant problem areas, significantly higher than the rates found amongst the standardisation sample. Both of these studies can be criticised for adopting quite a narrow definition of adjustment and for relying solely on a single informant. In addition, neither included a control group.

Sawyer, Toogood, Rice, Haskell and Baghurst (1989) carried out a well controlled study of 42 children with leukaemia. Their scores on ratings of psychological adjustment obtained from themselves, their parents and teachers were compared with ratings for their siblings and for a matched control group from the same school and their siblings. Compared with controls, as rated by the children, their parents and teachers, the cancer group showed poorer scores on school competence and performance. However, on the teacher version of the Rutter behaviour scales, no differences were observed. In other areas of adjustment, no significant differences were found. It was also noted those who received radiation treatment at a younger age were less competent at school but showed fewer behavioural problems. The difficulties noted at school could be due to a number of factors. Firstly, the neuropsychological effects of CNS irradiation which often accompanies treatment for leukaemia. Secondly, the impact of missing significant portions of school and the associated skill development due to repeated hospitalisation. Thirdly, emotional and behavioural difficulties. Other studies have also noted difficulties related to school performance amongst long term survivors of leukaemia (Peckham, Meadows, Bartel & Marrero, 1988).

Sawyer, Antoniou, Nguyen, Toogood, Rice and Baghurst (1995) conducted a prospective study of children’s adjustment, assessing 45 children with cancer immediately after diagnosis and one year later. Maternal and child assessments of adjustment were compared with scores obtained by a group of matched controls. For the 4-10 year olds, the cancer group were found to be more withdrawn and less competent than their peers at initial assessment. However, this difference disappeared at follow-up due to a significant change in the scores of the cancer group. For the 11-16 year olds no significant differences between groups were found. Thus both age and time after diagnosis appeared to be important in assessing the extent of adjustment problems. It should be noted that only a limited number of assessment measures were included in the assessment and the definition of adjustment was fairly narrow.
As with children with SCD, the research with children with cancer has produced mixed results, with some studies noting that children are well adjusted and others noting difficulties as compared with controls, particularly in the areas of locus of control, school competence and social relationships. Vami, Katz, Colegrove and Dolgin (1995), commenting on the inconsistencies in research in this field, propose the following explanation: firstly, a lack of statistical power may explain some null findings; secondly, samples are often heterogeneous for time since diagnosis and time since end of treatment; and thirdly, informant variability in detection and reporting of difficulties. Use of multiple informants would seem vital in gaining a full picture of the child's functioning, yet many of the studies cited above rely solely on one informant or on one assessment tool. It is also important to ensure that measures are selected and interpreted appropriately. Worchel, Nolan, Willson, Purser, Copeland and Pf efferbaum (1988), using the Children's Depression Index, have highlighted the extensive use of denial used by cancer patients which may lead to the under reporting of psychological distress. They also showed that somatic and self concept items on this measure were not good discriminators between depressed and non-depressed children with cancer. This highlights the need to look at how paediatric cancer patients manifest distress and to ensure that tools are used which adequately reflect this.

SUMMARY OF KEY ISSUES
Research across these two groups suggests that having a chronic physical health problem may increase the risk of having psychological difficulties but should not be viewed as automatically resulting in psychological problems. Many of these children cope well despite the stresses associated with having a chronic illness. Many of the difficulties that have been observed are not necessarily manifested as overt pathology but as more subtle difficulties, for example in socialising, body image etc.

Given these findings, many authors (e.g. Eiser, 1990) have highlighted the need to move away from pathology based models to models based around coping which identify both risk and resilience factors. One of the difficulties which has emerged is around definition of key terms such as coping and adjustment. Some authors have drawn on ideas from Lazarus and Folkman (1984) and have defined coping as any strategy used to manage either a stressful situation or the emotional responses associated with that situation. Strategies are viewed as not being inherently good or bad but are evaluated on the basis of success in dealing with the situation and the impact on adjustment. Adjustment in turn has been defined variously. Some authors seem to view adjustment purely in terms of the presence or absence of psychological distress, where as others use more broad based definitions including
functioning in key areas, reliance on health care services etc. Other authors have used the term coping synonymously with adjustment. Thus those who are coping well are those who are well adjusted. Across studies considerable variation is noted in these areas and there appears to be conceptual and practical confusion. Measures used in one study as an outcome measure are used in other studies as measures of mediating variables or coping (e.g. measures of cognitive style). This confusion highlights the need for a move towards the development of clearer models and more research based on evaluation of the explicit hypotheses derived from these models. The next two sections will describe one of the theoretical models in the field and will consider its success in accounting for the empirical data.

THEORETICAL MODEL
One of the most commonly cited and researched models in this field is the Risk - Resistance - Adaptation model (Wallander & Vami, 1989). They suggest that adjustment to chronic physical health problems arises from the interaction between risk and resistance factors. Risk factors include disease parameters, functional independence and psychosocial stress. Resistance factors include intrapersonal factors such as personality, stress processing and coping strategies and socio-ecological factors such as parental mental health and family functioning. They suggest that the reason why families with chronically sick children are at increased risk of adjustment problems relates to the increased number of stressful situations to which they are exposed i.e. problematic situations requiring a solution or decision making process for appropriate action. The precise nature of these stressful situations will depend on the exact condition. The adjustment of a particular individual is determined by their competence in dealing with these stressful situations. This is in turn influenced by the complex interaction between the different factors identified above. Essentially, difficulties are predicted to occur where risk factors are excessive and resistance factors too few. The model distinguishes between sources of stress, coping and resistance factors and adaptation. Interestingly, adaptation is defined broadly in terms of mental health, social functioning and physical health. Disease per se therefore does not result in psychological difficulties. In addition, the model stresses the interaction between risk and resilience factors, emphasising the dynamic nature of adjustment to having a chronic physical health problem.

HOW WELL DOES THE MODEL ACCOUNT FOR THE DATA?
The model has never been tested explicitly, in its entirety with either children with SCD or children with cancer. However, application of the model to SCD (Brown, Doepke & Kaslow, 1993) and cancer (Vami, Katz, Colegrove & Dolgin, 1994) has been advocated and
parts of the model have been tested. For ease of discussion, studies will first be discussed relating to risk factors and then to resistance factors.

**SCD**

**Risk factors:**

**Disease related variables**
Attention has focused on the following parameters: genotype, painful crises and physical complications associated with SCD.

Hurtig, Koepke and Park (1989) explored the relationship between illness severity (measured by genotype, frequency of contacts with health services, frequency and intensity of pain and duration of illness) and adjustment amongst 70 children aged 8-16. Adjustment was assessed using a broad range of measures completed by the children, parents and teachers. They found that severity of disease was not a significant predictor of outcome and that sex and age were more important. Only two severity factors were found to impact on adjustment, independent of age and sex. Pain frequency was a significant predictor of school performance and having an SS genotype was associated with reduced intellectual capacity. Some of the criteria used for disease severity in this study do not seem to be particularly meaningful, in that duration of illness is likely to be confounded with age and use of health care services can be highly dependent on the success of using other coping strategies to manage painful crises at home.

Thompson, Gil, Burbach, Keith and Kinney (1993) in their study of adjustment to SCD found that illness severity variables and demographic variables accounted for only 3-17% and 6-8% of the variance in child adjustment, respectively. Other factors, to be discussed later, made a significant additional contribution in addition to the variance explained by these variables.

As predicted by the model, disease severity per se does not seem to determine adjustment. Rather interaction with other variables is important.

**Other psychosocial stressors**
Hurtig and Park (1989) assessed the impact of family environment and life events as reported by the adolescents and by their parents on behavioural problems amongst a group of 12-17 year olds with SCD. They confirmed earlier findings suggesting that adolescent boys
were particularly prone to behavioural problems. Life stressors, particularly in the area of sexuality, had a negative impact on the adjustment of girls but showed less impact on boys.

**Resistance factors:**

**Intrapersonal factors**

A number of studies have highlighted the impact of age and gender on adjustment, with adolescent boys being at particularly high risk (Hurtig & Park, 1989; Hurtig et al, 1989). Other studies have started to focus on other factors particularly coping strategies and cognitive style.

There is now good evidence to suggest that the coping strategies employed by children and adolescents, particularly in dealing with their pain, plays an important role in influencing their overall adjustment.

Thompson, Gil, Burbach, Keith and Kinney (1993) in their study found that after controlling for illness severity and demographic variables, children's pain coping style, characterised by negative thinking, accounted for a 21% increment in the variance of child reported distress. When the children were followed up 10 months later, after controlling for adjustment at time 1 and the contribution of illness, demographic parameters and length of follow up, child pain coping strategy was still found to have a significant effect (Thompson, Gil, Keith, Gustafson, George and Kinney, 1994). Negative thinking strategies at follow up accounted for a 19% increment in child-reported symptoms. Low levels of coping attempts at follow up accounted for an 8% increment in the variance in maternal-reported internalising behaviour problems.

Gil, Williams, Thompson and Kinney (1991) found that amongst children and adolescents, those high on coping attempts were more active and required less frequent health services. However, those high on negative thinking and passive adherence showed lower levels of activity, higher levels of depression, anxiety and behavioural problems and had more frequent contact with health services than those with lower scores on these factors. Coping strategy was not associated with pain frequency, duration or intensity. It was also found that pain coping strategies were significant predictors of adjustment after controlling for pain and demographic variables. These findings were confirmed at 9 months follow up by Gil, Thompson, Keith, Tota-Faucette, Noll and Kinney (1993). Although children showed stability in their coping strategies, there was some suggestion that adolescents show
increased reliance on negative thinking and passive adherence, strategies associated with poorer outcome.

There is some evidence to suggest that the social environment may influence children’s coping strategies. Gil et al (1991) have explored the relationship between child coping strategies and parental coping strategies. They found that increased tendency to use passive adherence amongst parents was associated with high levels of passive adherence amongst children/adolescents. Increased use of coping attempts by parents was associated with reduced levels of negative thinking amongst children/adolescents. It was suggested that the first of these findings could be explained within a social learning model. It was also suggested that a pro-active coping style amongst parents might serve to engender a sense of hope in the child and thus reduce reliance on negative thinking.

Some evidence to support this hypothesis was presented by Kliewer and Lewis (1995). They found that after controlling for age, gender, family structure and disease type, parents’ active coping suggestions were positively associated with children’s levels of hope. General family environment also seemed to exert an influence in that, after taking account of the previously mentioned variables, family cohesion was positively related to active coping.

Less attention has been paid to the influence of cognitive appraisal factors on coping and this is an area worthy of further research.

**Interpersonal and social-ecological factors**

As has already been highlighted there is some evidence to suggest that coping styles adopted by mothers can impact on the coping styles and adjustment of children (Gil et al, 1991; Kliewer & Lewis, 1995). A number of studies have also looked at the inter-relationship between maternal coping and anxiety and child adjustment.

Thompson, Gil, Burbach, Keith and Kinney (1993) proposed a transactional stress and coping model. They highlight a number of factors, which they suggest influence the adjustment process, including: the characteristics of the illness, demographic factors, maternal mediational processes (cognitive processes, coping strategies and family functioning) and child mediational processes (cognitive processes and pain coping strategies). In their study of 50 mother-child dyads, they found the model accounted for 30-49% of the variance in child adjustment. Child adjustment was rather narrowly defined as maternally reported behavioural problems on the Missouri Children’s Behaviour Checklist.
and child reported difficulties on the Child Assessment Schedule. As part of the study, Thompson et al compared those who were classified as well adjusted with those who were classified as poorly adjusted. No differences were found on the measures of illness, demographic variables, cognitive processes or coping strategies. However, children with a maternally reported behaviour problem had mothers who reported significantly higher levels of anxiety and depression than those with mothers who did not report behavioural problems in their children. In a hierarchical multiple regression analysis, after controlling for illness and demographic variables, maternal anxiety added a 16% increment in internalising and a 33% increment in externalising behaviour problems. Given the correlational nature of this study, it was not possible to draw any conclusions about the direction of causality of this relationship. It could be that mothers with more difficult children become more depressed and anxious or vice versa. It is also possible that there could be any interactive effect between maternal mental health and children’s’ adjustment.

Thompson et al’s (1994) follow-up study did not find any significant impact of maternal anxiety on maternally reported behavioural problems after controlling for baseline levels of adjustment and illness and demographic variables.

Midence, McManus, Fuggle and Davies (1996) in their study of psychological adjustment and family functioning amongst children with SCD found that whilst mothers with SCD children did not show significantly higher GHQ scores than the control group, maternal mental health was related to children’s adjustment. Maternally reported behavioural problems were predicted by maternal mental health and mother’s marital status and teacher reported behavioural problems were predicted by poor maternal mental health. With regard to family functioning, the SCD groups were found to show significantly higher levels of cohesion and lower levels of conflict than the control group. This confirmed earlier findings by Anderson, Weitzman and McMahon (1986) that families of SCD children scored higher on family integration, co-operation, optimism and psychological stability within the family.

Other studies (e.g. Moise, 1986; Hurtig & Park, 1989) have reported a positive association between family cohesion and children’s adjustment.
Cancer
Risk factors:
Disease related variables
Koocher et al (80) found that whilst duration of treatment did not impact on adjustment, age at diagnosis and time off treatment were important factors. Being younger at the time of diagnosis and being off treatment for longer were both associated with better adjustment. There is also some evidence that certain types of cancer, specifically ALL and Hodgkin’s disease, are associated with better adjustment. This may be related to the fact that these conditions have a relatively good prognosis as compared with some other types of cancer.

Greenberg et al (89) found that in their group those with more severe medical late effects showed poorer self concept, more depressive symptoms and more external locus of control than those with less pronounced late effects. Mulhem, Wasserman, Friedman and Fairclough (1989) found that factors associated with increased risk of school problems were: functional impairment, physical disability, cranial irradiation, being over 12 at the time of evaluation and coming from a single parent household. However, O’Malley, Foster, Koocher and Slavin (1980) in their group, found that there was no relationship between degree or visibility of physical impairment and current level of adjustment.

Slavin, O’Malley, Koocher and Foster (1982) explored the relationship between adjustment and the way in which children were informed about their diagnosis. They found that regardless of age, those who were informed about their diagnosis in the early stages showed better adjustment that those who were informed later or discovered the diagnosis for themselves. Whilst this finding provides some support for those who advocate openness of communication about diagnosis, there are some difficulties in interpreting these findings. Firstly, no baseline adjustment data were obtained and secondly, it is not clear whether communication about diagnosis per se is helpful or whether this merely represents a more general reflection of communication style and/or emotional support within the family. It could be that ongoing openness and willingness to talk about issues is highly correlated with communication of diagnosis and is in fact the more important factor in influencing adjustment.

Other psychosocial stressors:
Vami, Katz, Colegrove and Dolgin (1994) explored the impact of variables such as age, gender, SES, cancer diagnosis & life events on psychological adjustment (measured by SCL90-R and Self Perception Profile for Adolescents) in a group of 39 adolescents aged 13-
23, all of whom were diagnosed at least five years previously. Age was associated with higher levels of psychological distress but gender and SES had no impact. Greater number of stressful life events was associated with greater psychological distress and lower self esteem. Perceived level of stress accounted for significant increments in the variance on psychological adjustment measures after controlling for age and diagnosis. Specifically, higher perceived stress predicted 24% of the variance on the GSI of the SCL90-R and between 13 and 32% variance on individual scales.

**Resistance factors:**

**Intrapersonal factors**

Sanger, Copeland and Davidson (1991) explored the impact of a number of demographic, social and psychological variables on adjustment. They found that more boys tended to have adjustment problems. Those who were rated as better adjusted by their parents were also more likely to be rated as more socially competent by their teachers. The authors interpreted this as indicating that social competence could act as a protective factor for adjustment difficulties because such children are better able to elicit social support from others. Whilst this is an interesting explanation of the data, as no measure of social support was included it cannot be explicitly tested and there are other possible explanations. For example, both measures may reflect different aspects of good adjustment. Children who were better adjusted also tended to have parents who attempted to maintain family integration and retain an optimistic stance.

**Interpersonal and social-ecological factors**

Kupst and Schulman (1988) in their review of the literature highlight a number of characteristics that are associated with successful coping and adjustment. Family variables associated with good adjustment were: openness in family communication (Koocher & O’Malley, 1981; Spinetta & Deasy-Spinetta, 1981); emotional support (Koocher & O’Malley, 1981); family income & SES (Koocher & O’Malley, 1981); positive outlook (Koocher & O’Malley) and satisfaction with type of medical care provided (Koocher & O’Malley, 1981). At two years after diagnosis, Kupst et al (1984) found that coping was related to quality of marital/family relationships, previous coping with illness, coping of other family members, adequacy of support system, lack of additional stresses, open communication within the family and an attitude of living in the present. At 6 year follow up, they found that those who were coping best had better family support, better marital relationships, fewer concurrent stresses and more open communication.
Blatky, Raczyński, Gurwitch and Smith (1985) explored factors contributing to hopelessness in a group of children three months after diagnosis. Two patterns of coping behaviour by fathers & mothers - fostering the family's integration and maintaining "self stability" - proved to be major independent contributors to the variance in children's hopelessness scores. High scores on subjective distress by parents were correlated with children's hopelessness. Thus it would appear that parental reactions can have an important impact on children's responses to their diagnosis.

Spinetta, Murphy, Vik, Day and Mott (1988) conducted a five-year longitudinal study of the adjustment of children with cancer and their families. They found that coping and ability to maintain day-to-day functioning during treatment were predictive of adjustment at the five-year follow-up. They identified three areas that characterised well adjusted families. Firstly, the families were able to place the cancer experience in perspective and make plans for the future. Secondly, they were able to seek professional help when necessary and recognised the importance of social support. Thirdly, they viewed coping as an ongoing process, saw crises as an opportunity to learn additional coping skills and accepted that some questions would remain unanswered.

EVALUATION OF MODEL:
The model has a number of advantages. Firstly, its emphasis on coping and resistance rather than psychopathology is to be commended. Secondly, the model highlights the dynamic nature of adaptation to a chronic illness and the interaction between different factors. Thirdly, the model provides a useful guide to factors that may be important in adjustment and a means of drawing together literature from diverse fields. It is also flexible enough to accommodate the incorporation of additional factors, which may be highlighted by the research. In addition, the model highlights areas for possible psychological intervention. Whilst the model has not been tested in its entirety with either children with SCD or cancer, the evidence so far supports some of the model's predictions. Specifically, disease related variables clearly do not solely determine adjustment but rather a range of other mediating factors are important. These include intrapersonal factors such as age, gender and coping style and interpersonal factors such as maternal mental health and family coping and communication style.

However, the model is not without its problems. Firstly, because of the complexity of the proposed interactions and the lack of explicit predictions it is very difficult to test. Much of the research conducted so far in the field has only used limited samples. These conditions
are relatively rare and even specialist centres are unlikely to have access to large samples. However, this makes it more difficult to conduct the sort of large scale, longitudinal research projects that would be needed to test the model effectively. It would seem that there needs to be a move towards larger scale, multi-centre studies to increase sample sizes and statistical power as occurs in many medical treatment trials.

Whilst the model is fairly comprehensive, certain important areas seem to have received limited attention. Firstly, whilst much research has looked at family environment, less attention has been paid to other sources of social support. As children become older, it is likely that friends play an increasingly important role in their lives. Anecdotal reports from adolescents with cancer, as well as the findings of Glasson (1995), have highlighted the value of supportive friends. Likewise, the role of teachers and other professionals has received little attention. Children with chronic illnesses can often spend considerable periods of time in hospital and develop close relationships with hospital staff. Yet this has received little attention in the literature. In addition, whilst maternal mental health is often assessed, the role of fathers is often neglected despite evidence suggesting the importance of fathers in influencing children’s adjustment (Blotcky et al, 1985). Secondly, the model highlights disease severity but has paid less attention to the impact of hospitalisations and aversive treatments. Particularly in the field of oncology, increasing attention is being paid to the long-term psychological impact of chemotherapy and radiotherapy. The model also does not seem to take account of the cognitive deficits which have been shown in both SCD (Midence, McManus, Fuggle & Davies, 1996) and following certain types of treatment for cancer (Cousens, Waters, Said & Stevens, 1988).

Further areas worthy of further attention are around cognitive style and coping strategies, particularly as these would be potentially important areas for psychological intervention. Some attention has been paid to these issues particularly in SCD with regard to pain coping strategies and this has highlighted the importance of this factor in influencing outcome. Less attention has been paid to these issues in oncology. Whilst research using standardised measures of coping is helpful, this needs to be carried out in parallel with studies using more qualitative methodologies. The strategies used by children to cope with chronic health problems can be quite creative and idiosyncratic and this may not be captured by standardised measures. In addition, the same strategy may serve a number of different functions for different individuals. For example, one of the items on the Coping Strategies Questionnaire (Rosentiel & Keefe, 1983) is Praying and Hoping, which covers a heterogeneous collection of strategies. Endorsement of a particular item would not,
however, indicate whether prayer constituted distraction, relaxation, a type of cognitive reframing, emotional ventilation or a passive giving in to a higher power. Thus the same strategy could be serving quite different functions and be related with quite different outcomes for different people.

**IMPLICATIONS FOR CLINICAL PRACTICE**

The literature reviewed above suggests that adjustment to chronic illness is not just determined by disease severity, but is influenced by a range of intrapersonal and interpersonal variables. Many of these areas are potentially amenable to psychological interventions. The model outlined by Wallander suggests both areas which should usefully be covered in assessment and the identification of individuals who may be at risk of developing psychological difficulties but also points to a number of potential areas for intervention. For example, it highlights the importance of considering parental coping and distress and the communication style of the family as potential risk factors.

The research also highlights quite specific risk factors. For example, the research in SCD clearly suggests that adolescent boys are at particular risk. There is some suggestion that SS individuals may be at risk for school related problems thus highlighting the importance of ensuring that those with milder versions of SCD are not neglected in service provision. The work on children with cancer has also highlighted a number of risk factors. School appears to be an area of particular difficulty thus highlighting the importance of adequate liaison with schools to ensure that they receive appropriate information about the type of support which the child may need and to ensure that this is implemented. There is also evidence to suggest the importance of communication of the diagnosis to the child and this is another area which psychologists may be able to offer advice and support.

Two further important areas for psychological involvement are more generally around ensuring open communication within families and facilitating use of adaptive coping strategies generally and specifically pain coping strategies in SCD.

**CONCLUSION**

The research reviewed so far has supported the assertion that whilst children with cancer and SCD are at increased risk of psychological difficulties, the majority of children do not show psychological problems. Whilst Wallander and Varni's model has much to commend it, there are gaps and weaknesses and as yet no study has adequately evaluated the applicability
of the model to either population. However, the existing research does highlight a number of areas in which psychologists could become involved.
REFERENCES


Clinical Chapter
SUMMARY

This chapter of the Portfolio consists of a brief summary of experience gained on each of the six clinical placements.

This is followed by abstracts of five clinical case reports, previously submitted for examination. Four of the case reports were written on core placements, including one which consists of a neuropsychological assessment; the fifth is from one of two specialist placements. The case reports draw on a variety of therapeutic models including Cognitive-Behavioural, Behavioural and Systemic. Client confidentiality has been maintained throughout by referring to clients by their initials and by removing references to any identifying features.

Finally, copies of contracts from each of the placements are included. As these are photocopies of the originals they are not in the same format as the rest of the text.

The reader is reminded that the five clinical case reports and all placement logbooks and evaluations forms are contained in the Clinical Appendix.
SUMMARY OF PLACEMENT EXPERIENCE

Adult Mental Health
Mrs Elspeth Bawtree at Bournewood NHS Trust.
Working primarily using a Cognitive-Behavioural approach with clients with a wide range of presenting problems including anxiety, depression, complex bereavement and eating problems. Work was undertaken mainly in an out-patient setting but included some work in a Day Hospital and Rehabilitation Unit. I also acted as co-facilitator for a Cognitive Therapy group for people with depression.

Learning Disabilities
Dr. Nan Holmes at Kingston and District Community NHS Trust.
Part of a multi-disciplinary team, working with clients in residential and day care settings. Clinical work included functional analyses and behavioural interventions with clients with challenging behaviour, Cognitive Therapy with a client with mild learning disabilities and a variety of cognitive assessments. A Training session was undertaken with staff on teaching relaxation exercises. I also conducted an evaluation of clients and carer satisfaction with a specialist day care facility.

Child and Family
Mr Bruce Holroyd at St. Peter’s Hospital, Chertsey.
Working as part of a multi-disciplinary team with children with a wide range of problems, including feeding difficulties, toileting problems, developmental delay and school refusal. Whilst the main approaches used were Behavioural and Cognitive, ideas and techniques from White and Epston’s Systemic approaches were also employed. A talk on sleep in the first year of life was given to a post-natal group.

Older Adults
Dr. Ajay Kapoor at Heathlands Mental Health NHS Trust.
Working as part of a multi-disciplinary team in community, day hospital and in-patients settings. Clinical work included a neuropsychological assessment with someone who was believed to be dementing, Cognitive Therapy with someone with depression and couple work. Group experience was gained in co-facilitating a Reminiscence group for people with Alzheimer’s Disease.
Specialist placement 1: Post-traumatic Stress reactions in children and adults
Dr. Peter Scragg and Mrs Joanne Morris-Smith at the Traumatic Stress Clinic, Camden and Islington Community NHS Trust.
Child: Involved in multi-disciplinary team assessment and treatment of children involved in wide variety of traumatic events, especially parental homicide. Extensive observations of medico-legal assessments and consultations around issues such as contact with perpetrator parents. Involved in training programme for Cruse counsellors.
Adult: Focus on the assessment and treatment of clients exposed to a wide variety of traumatic events. Cognitive and Behavioural approaches used in the treatment of simple and more complex traumatic reactions.

Specialist placement 2: Paediatric Psycho-Oncology
Ms. Lesley Edwards at The Royal Marsden HNS Trust, Sutton.
Working with children and their families both in in-patient and out-patient settings. Clinical work included cognitive assessment with children experiencing late effects of treatment, Behavioural approaches in management of eating problems, anxiety management for a mother of a child on treatment and work around improving communication within families.
ABSTRACTS OF CASE REPORTS

Adult Mental Health
B.S. was a 42-year old man referred for low mood and marital difficulties following the sudden death of his son five years previously. During the assessment, it emerged that B.S. had never come to terms with losing his son and that he had never been able to express his feelings about his son's death. His difficulties with his wife centred largely around his conviction that she was going to leave him and the associated arguments. It also emerged that B.S. had experienced an unhappy childhood during which he received little affection.

The case formulation focused on issues around attachment and loss, drawing connections between B.S.' childhood experience, his reactions to his son's death and his beliefs that his wife would leave him. The formulation drew on ideas from Bowlby and Erickson and also on Murray-Parkes' work on bereavement. A second theme was around the constructive expression of anger.

Therapy concentrated on two main areas. Firstly, providing B.S. with an opportunity to work through his feelings around the loss of his son. Secondly, the use of anger management and assertiveness skills to improve communication with his wife.

During the final session of therapy B.S. reported subjective improvements in his mood and his relationship with his wife. There was also evidence that B.S. had been able to accept the reality of the loss of his son and was showing a greater focus on the present and future rather than ruminating on the past.

Learning Disabilities
S.P. was a 27-year old Asian man, referred by the manager of the Social Services residential home where he was living, because of his behavioural problems. This consisted of destructive behaviour and verbal and physical aggression towards staff.

Information for the assessment was collected from a variety of sources including medical records, ABC charts, interviews with staff and observations.

A Behavioural formulation was adopted in this case. Following identification of vulnerability factors, antecedents and consequences of the behaviour, hypothesised functions
for the behaviours were proposed. Specifically, it was hypothesised that S.P.'s behaviour was a means of obtaining social interaction, represented an expression of boredom and frustration and was a way for S.P. to occupy himself.

The intervention consisted primarily of indirect work with residential and day care staff to look at ways of increasing S.P.'s level of activity and to identify more constructive ways in which he could occupy himself. A number of calming strategies were also recommended. Referrals to the Speech and Language Therapist, for work on communication skills, and to the Psychiatrist, for assessment of mental state, were initiated. Management guidelines were developed with staff to ensure that a consistent approach was adopted.

These strategies were in the process of being implemented at the time when the author left the placement, which limited evaluation of the effectiveness of the intervention. However, there were some initial indications that S.P. was responding positively to a greater level of activity and a more consistent response to his behaviour.

*Child and Family*

O.S. was a 7-year old boy referred for difficulties around enuresis. Although O.S. had briefly achieved bladder control as a younger child, this had been lost following a period away from home. Since then O.S. had shown periods where he had been able to control his bladder interspersed with periods during which his enuresis became a more severe problem. The family had previously tried a variety of rewards based approaches which seem to have resulted in temporary improvements followed by deterioration. The family expressed feelings of hopelessness about the problem.

The case was formulated drawing on ideas from Michael White’s Systemic approach to encopresis. This involved externalising the problem so that it was not located within the child but was rather viewed as something against which the family needed to unite and work together.

The family and O.S. were encouraged to identify allies and strategies to use against the problem. This was combined with rewards for success and a problem solving approach to the times when the problem still caught them off guard.

Although O.S. showed an objective decrease in incidents of enuresis, as shown by records kept by the family, his parents remained negative and convinced that the problem would
return. The case was taken on by another psychologist following the departure of the author from the placement.

**Older Adults**

E.C. was an 80-year old woman who was referred for assessment with a view to cognitive therapy for depression. The referral noted that E.C. had “cognitive impairment” but gave no further details.

Clinical interview and assessment using a self-report scale revealed no evidence of depression. The picture regarding E.C.’s cognitive functioning remained confused and so it was felt that a full cognitive assessment would be valuable to clarify her current level of functioning.

The assessment covered current intellectual functioning, pre-morbid functioning, memory, verbal fluency and naming, perceptual and spatial abilities and practic functioning. There was some evidence of concrete thinking and poor planning and some suggestion of memory difficulties in the medium and longer term. The picture regarding deterioration in functioning was mixed.

The case highlighted the complexities around assessing cognitive functioning in the older adult population.

**Specialist**

J.H. was a 30-year old woman referred for sleep disturbance and nightmares following involvement in a bomb blast four years previously.

Assessment comprised a clinical interview, completion of a diagnostic interview schedule and various self-report measures. This suggested that J.H. showed evidence of Post-Traumatic Stress Disorder (PTSD), clinical depression and panic disorder.

The case was formulated within a Cognitive-Behavioural framework, drawing on the model of PTSD proposed by Foa and her colleagues and the cognitive model of panic delineated by Clark. It was also apparent that J.H. showed an exaggerated perception of risk, which served to maintain her hypervigilance and ongoing high level of arousal.
Intervention included Cognitive therapy and controlled breathing for managing panic, imaginal desensitisation to trauma related cues combined with in vivo graded exposure and cognitive techniques to challenge self critical thoughts and exaggerated perception of risk.

At the end of therapy, J.H. reported a subjective improvement in her mood. Her scores on the self-report questionnaires were largely within the normal range and her residual arousal and intrusion symptoms no longer interfered with her everyday functioning.
PLACEMENT CONTRACT

Placement: Adult Mental Health  
First year (core) placement

Duration: 15 October 1994 - 1 May 1995 inclusive

Trainee: Imogen Collins

Supervisor: Elspeth Bawtree

Aims of the placement:
To provide a range of experience of services to adults with psychological problems sufficient to allow the trainee to develop competencies for dealing with this group.

Objectives -

Assessment:

Trainee -

1. To be able to conduct an assessment interview, selecting appropriate measures, and to produce a formulation based on this.

2. To be able to conduct formal psychometric assessments, using a range of agreed tests, and to score and interpret these.

3. To be able to write up an assessment in the appropriate form depending on the purpose of it and the person to whom the results are being communicated.

Supervisor -

1. To ensure that the trainee is provided with a suitable number and range of individuals to achieve 1 - 3 above.

Contd/-.
Therapy -

Trainee -

1. To be able to establish rapport and use appropriate skills, both verbal and non-verbal, to facilitate the therapeutic relationship.
2. To be able to formulate the individual’s problems in psychological terms and select the appropriate intervention.
3. To be able to explain the proposed intervention in easily understood terms and obtain the individual’s active participation in the therapeutic process.
4. To be able to monitor and evaluate the progress of the individual in therapy.
5. To be familiar with cognitive-behavioural approaches to problems.

Supervisor -

1. To ensure that the trainee is provided with a suitable range and number of individuals to meet the University’s requirements and achieve the above.
2. To provide a grounding in a cognitive-behavioural approach.

Teaching/Training:

Trainee -

1. To be able to present a case or paper at a Departmental meeting.
2. To be able to explain a therapeutic approach to a member of another profession/provide basic training in a behavioural approach.

Supervisor

1. To ensure that the trainee is provided with the opportunity to achieve the above.
2. To provide regular supervision or ensure such supervision in speciality areas to meet the requirements of the University.
3. To ensure that the trainee has study time allocated.
Research -

Trainee -
1. To undertake any research projects required by the University.

Supervisor -
1. To facilitate the achievement of the above.

Professional -

Trainee -
1. To read and adhere to the B.P.S. guidelines for professional practice; Departmental policies and procedures; and Trust policies and procedures.
2. To attend Departmental meetings and Trust-wide psychology meetings.
3. To attend relevant other meetings or special interest group meetings.

Supervisor -
1. To ensure easy access to policies and procedures.
2. To inform the trainee of relevant meetings.

Administrative:

Trainee -
1. To carry out routine administrative duties connected with the provision of a clinical psychology service in line with Departmental and Trust policies and procedures - for example, note-keeping, completing Korner returns, writing up diaries, etc.

Supervisor -
1. To provide appropriate facilities e.g. secretarial assistance to achieve the above.

Signed: ____________________________  ____________________________

Imogen Callous  November, 1994
PLACEMENT CONTRACT FOR IMOGEN COLLINS

IN LEARNING DISABILITIES

Supervisor: Nan Holmes

Placement Dates: 18 May 1995 to November 1995

Base: Elmbridge Lodge, Weston Green Road, Thames Ditton and Guildhall 1, Kingston upon Thames

Aims of Placement

To acquire knowledge and skills in the assessment and treatment of Adults with Learning Disabilities and to gain understanding of the needs of these adults, their carers and the services they use.

Objectives

NB Imogen already has experience of people with learning disabilities from her work as an assistant psychologist.

At the end of the placement Imogen should have:

an understanding of the network of services surrounding people with learning disabilities and be able to describe the range of services available.

an understanding of the roles of the various professionals working with this client group.

an understanding of the role of the Kingston Community Learning Disability Team in providing services to adults with learning disabilities and also have contributed to its work.

an understanding of the needs of people with learning disabilities and should know something of their typical life experiences and have become more familiar in ways of relating to people with disabilities.

an understanding of the effects of disability on families.

become familiar with the workings of the speciality and its inter-relationship with the whole Psychology Department.

become aware of the impact of recent legislation on services to people with learning disabilities.

an insight into the organisation of Kingston & District Community NHS Trust.
learned how to administer and interpret a variety of psychometric tests to adults with learning disabilities, eg WAIS-R, Leiter, BPVS, (Neale) etc.

gained an understanding and experience of the range of skill's assessments used with people with learning disabilities and have made an evaluation of their strengths and weaknesses etc. Paths to Independence, STAR, ABS, Halo, Whelan and Speake's Coping Schedule etc.

become familiar with and have experience of using observation techniques with this client group eg direct observations, ABC charts, frequency measures etc.

been involved with working with clients with a range of degrees of intellectual impairment.

undertaken work with a client to assess and reduce problem behaviours.

undertaken counselling with a client with mild learning disabilities.

undertaken work with a client to promote the development of skills.

experience of training staff.

understood and experienced working as a direct carer.

have some experience of sexuality issues, bereavement and loss issues and interpersonal problems such as in managing anger and being assertive.

These objectives will be achieved by:

visiting residential establishments in health, Social Services and the voluntary sector, eg Elmbridge Lodge, Woodbury, Maple Lodge, Penrith Road.

visiting day services run by health, education and Social Services eg Weston Green Day Unit, Causeway, Springboard, Stairway, Dysart School.

by attending CLDT meetings

by meeting with individual CLDT members to hear about their work.

eg community nurse, psychiatrist, speech and language therapist, resettlement officer, care manager.

by joint work with team members.

by working a shift in a residential establishment.

by working sessions in a Day Unit.
by two hours of supervision a week.

by reading appropriate literature.

by observing supervisor.

by attending relevant meetings and case conferences and reviews.

by working directly with clients.

by working with clients' carers.

by visiting a long-stay hospital (unless Imogen has already done this in her previous job).

Specifically

to undertake a HALO with a client and staff at a residential establishment

to use a WAIS-R with a client

to use a Leiter

  to work with a client from an ethnic minority
  to work on a challenging behaviour
  to undertake counselling with a client with a mild learning disability

  to work with a family
  to work on skills building with a client

  to have some experience of sexuality issues, bereavement and loss, and interpersonal
  skills such as assertiveness and anger management.

  to try to teach a client with challenging behaviour relaxation skills

* (need to contact Sheila Hollins)
CONTRACT

IMOGEN COLLINS - Child and Adolescent Placement, St Peters Hospital

Supervisor - Bruce Holroyd

CLIENTS

Approximately 10 clients across the age span covering pre-school, middle childhood and adolescence. This will include direct or indirect experience and work with a child/family from a different ethnic group.

ASSESSMENTS

3 assessments will be conducted using intelligence tests and tests of development. Knowledge and practice with tests not used for formal assessments with clients will be gained via test seminars and observation.

Other assessment procedures will include:
- using a structured developmental schedule to take a history.
- observational assessment using a structured format and record forms in order to do a behavioural analysis and drawing up a genogram.

TREATMENT

Direct client work will include behavioural treatments, cognitive behavioural interventions and work with families.

Either direct/indirect work will involve family therapy and work with children with long-term difficulties.

SERVICE/ORGANISATIONAL USES

Familiarity with local services and procedures will be gained through visits, interviews with other professionals and participation in team, speciality, departmental and SIG meetings.

MODELS

Development of a working knowledge of psychodynamic, cognitive and systemic models within a child/family context.
PARTICULAR INTERESTS

To give one departmental presentation

Opportunities to be involved with teaching/training other professionals

To observe family therapy sessions

To spend time in supervision considering system aspects of particular cases

Experience of working with children exposed to trauma and children with special needs

28 February 1996
IC94.Feb/mg
Trainee: Imogen Collins
Supervisor: Dr Ajay Kapoor

Placement Aims:-

(i) To develop knowledge of role of different professionals within CMHTE and of the range of services available to clients. This is to be achieved through attending team meetings, shadowing members of staff and visiting services.

(ii) To develop skills in formulation drawing on range of models including cognitive, behavioural, systemic and psychodynamic models.

(iii) To develop knowledge of assessment tools used with this client group including tools specifically designed for older adults and modification of generic tools.

(iv) To see at least 10 clients for independent treatment, covering a range of ages and, if possible, including someone from a different ethnic background. Specific issues to include:-

   a) working with carers,
   b) depression,
   c) cognitive change with age,
   d) dementia,
   e) adjustment and adaptation difficulties,
   f) mortality,
   g) strokes,
   h) challenging behaviour,
   i) OCD.

(v) To have exposure to at least one intervention specifically designed for older adults.

(vi) To have the opportunity to be involved in planning and running a group.

Signature of Trainee Imogen Collins

Signature of Supervisor Ajay Kapoor

13.06.96
IC/mc/icplcon
PLACEMENT CONTRACT AT THE TRAUMATIC STRESS CLINIC

TRAINEE: IMOGEN COLLINS
SUPERVISOR: DR PETER SCragg

Aims

1. To gain experience of a range of client/patients who have experienced major traumatic events.
2. To become independent and confident in the assessment of traumatic sequelae.
3. To become independent and confident in treatment planning for patients who have experienced major trauma.
4. To develop and broaden cognitive behavioural therapy skills.
5. To learn particular cognitive behavioural skills appropriate for Post Traumatic Stress Disorder.
6. To gain some understanding and appreciation of the legal and compensation issues that arise from working with patients who have been traumatised.
7. To develop greater skill in concise report writing.

Objectives

To gain experience of critical incident debriefing.

To gain experience in administering a semi-structured interview for Post Traumatic Stress Disorder.

To develop an understanding of the reliability and validity of questionnaire measures of PTSD.

To develop advanced skills in cognitive behavioural case formulations.

To develop advanced skills in imaginal exposure therapy techniques.

To develop skills in cognitive restructuring via imaginal techniques.

To gain observational experience of the preparation of legal reports.

To assess and treat at least one refugee.
Parameters of Placement

The placement will include observation of supervisor assessing and treating patients. The supervisor will expect to sit in on some initial assessment interviews.

Supervision will provide a forum for developing specific and advanced cognitive behavioural skills, advanced formulations skills and an opportunity to debrief following difficult sessions with patients.

Trainee will be expected to attend 50% of the Adult Team meetings. The trainee will be expected to attend Academic meetings held at lunch time here at the Traumatic Stress Clinic.
PLACEMENT CONTRACT WITH CHILD TEAM AT THE TRAUMATIC STRESS CLINIC

TRAINEE: IMOGEN COLLINS
SUPERVISOR: JOANNE MORRIS-SMITH

Aims

1. To gain direct and indirect experience of the assessment of the psychological consequences of traumatic events for children and their families.

2. To develop skills in formulation and treatment planning for children exposed to traumatic events.

3. To develop and refine therapeutic skills in working with children.

4. To gain understanding and indirect experience of legal issues pertaining to client group.

5. To develop presentation and teaching skills.

6. To gain experience of working within a multi-disciplinary team.

Objectives

1. To be involved in a minimum of three assessments and three treatment cases.

2. To observe and participate in multi-disciplinary team assessments of families.

3. To become familiar with the administration and scoring of the Pynoos PTSD Reaction Index.

4. To give one presentation as part of child team seminar programme.

5. To participate in CRUSE training programme for bereavement counsellors by observing sessions and by active participation in teaching at one session.

6. To observe Dr Dora Black giving evidence in court and if possible to observe at least one assessment in a prison context.

7. To observe at least one multi-agency meeting.

Supervision arrangements: 1 hour every two weeks.
IMOGEN COLLINS APRIL-SEPTEMBER 1997
PAEDIATRIC PSYCHO-ONCOLOGY SPECIALIST PLACEMENT

CONTRACT

AIMS:

1. Gain understanding and experience of impact of physical illness on individual and family functioning, both current and long lasting.

2. Gain experience of multi-disciplinary team working.

3. Gain experience of networking and consulting with external agencies.

4. Experience of wide range of therapy types and different psychological models.

5. Undertake psychometric testing relevant to psycho-oncology population and contribution to statement of special educational needs.

6. Gain experience of different roles of paediatric psychologist in a medical setting.

7. Participate in ongoing research.

8. Do background research for proposed new groups.

OBJECTIVES:

1. See minimum of 10 children and/or their families.

2. Gain specialist experience in cognitive-behavioural, systemic and visual imagery therapies in a medical setting.

3. Active participation in multi-disciplinary meetings.

4. Presentation in Department of Psychological Medicine meeting.

5. Active participation in preparation for Bone Marrow Transplant with child and sibling donors.

6. Contribution to development of "when a child dies" booklet.

7. Devise questionnaire, do background interviewing and planning for parent support group.
Research Chapter
SUMMARY

This chapter consists of three distinct pieces of research conducted during the three years of Clinical training.

Year 1
*Methodological and theoretical issues in investigating traumatic stress in children.*

This is a critical review of the published empirical and theoretical literature which highlights the methodological issues around investigating traumatic stress reactions in children. Following a brief review of the main models of traumatic stress reactions in the adult literature, the application of these models to children is discussed.

Year 2
*An investigation of user satisfaction with a specialist facility for people with learning disabilities.*

This consisted of a small scale piece of research conducted whilst on placement in keeping with the British Psychological Society (BPS) guidelines for research on placement. A key aim was to develop a measure which could be used to assess user satisfaction in this group, with reference to the literature in the field and in consultation with the multi-disciplinary team. Preliminary data on reliability and the impact of verbal ability are reported.

Year 3
*Cognitive style, pain and depression in Sickle Cell Disease.*

This piece of research was intended as an empirical exploration of specific research hypotheses. The relevant literature was reviewed, research hypotheses generated, a research protocol designed and implemented and the data collected and analysed.
LITERATURE REVIEW

YEAR 1

PSYCH.D.
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METHODOLOGICAL AND THEORETICAL ISSUES IN INVESTIGATING
TRAUMATIC STRESS IN CHILDREN

Section 1: INTRODUCTION
The last two decades have produced an explosion of research into reactions to traumatic events. It has been noted (e.g. Yule & Williams, 1990) that work with children has lagged behind developments in the adult field. However, recent work has begun to examine the patterns of reactions observed in children after traumatic events, comparing these reactions with those of adults and exploring the impact of factors such as age and gender. A number of reviews have been published which have summarised findings regarding the phenomenology of traumatic stress in children (e.g. Lyons, 1987; Armsworth & Holaday, 1993). These reviews often adopt broad criteria for defining traumatic events, including prolonged physical and sexual abuse and having a severe illness as well as more discrete natural or manmade disasters. It often seems to be assumed that all these events produce similar effects, although this has not been empirically confirmed. Although methodological and theoretical issues are usually considered in these reviews, they are rarely discussed in detail.

In contrast to earlier reviews, this review aims to have a narrower scope in terms of the types of traumatic events included and to focus on methodological and theoretical issues rather than phenomenology. Rather than attempting to review literature on all types of traumatic events, attention will be focused on reactions to single, fairly discrete traumatic events. This decision was taken partly for practical reasons, to reduce the size of the literature to be covered to more manageable proportions, and partly for theoretical reasons. Terr (1991) has argued that traumatic experiences in childhood should be sub-divided into two main categories. Type I traumas follow from "unanticipated single events" where as Type II traumas result from "repeated or long-standing ordeals". Terr argues that in the latter there is a sense of living in a "prolonged and sickening anticipation", awaiting the next trauma/abuse. Although Terr argues that reactions to these two types of trauma share common features, she also argues that each type has unique characteristics. For example she argues that Type I reactions are largely characterised by full detailed memories for the event; Type II reactions are characterised by denial, psychic numbing and dissociation.

Criteria for inclusion of empirical studies were as follows. Firstly, subjects had to have been under 19 at the time of the traumatic event. Secondly, the traumatic event itself had to be
fairly discrete and met the DSMIIIR (APA, 1987) criteria for a “traumatic event” included under the diagnosis of Post-Traumatic Stress Disorder (PTSD) (see Appendix 1). This definition was interpreted in an over- rather than under-inclusive manner and was taken to include severe natural disasters (e.g. hurricanes, earthquakes), other types of disasters (e.g. the sinking of a ship, the collapse of a dam) and man-made traumatic events (e.g. being kidnapped, witnessing parental homicide).

The first part of this review explores the main methodological issues and difficulties pertinent to conducting research into traumatic stress in children. An evaluation of the methodological rigour of research in any field is clearly important before the results and conclusions of particular studies can be interpreted. The methodological flaws of research in this field have been highlighted by several authors (e.g. McFarlane, 1985). Aptekar and Boore (1990) in their review of the long term impact of disasters on children’s mental health noted three main positions:

1) Disasters have a significant impact on children’s mental health, with the effects lasting for several years (e.g. Terr, 1979, 1981, 1983a; Newman, 1976; Green, Korol, Grace, Vary, Leonard, Gleser & Smithson-Cohen, 1991);

2) Disasters do not produce psychopathology in the majority of individuals (e.g. Breslau & Davis, 1987);

3) Children’s reactions to disaster can vary from “the mild and transient to an acute evolving psychopathology” (Anthony, 1986).

Aptekar and Boore argue that these contradictions can be attributed probably to “certain basic methodological difficulties that make acceptable conclusions problematic”. It would therefore seem beneficial to specifically explore these methodological difficulties and to identify examples of good practice.

The second part of this review will focus on theoretical issues. Scant attention has been paid in the literature on child traumatic stress to building models on the basis of the phenomenological findings and testing specific hypotheses. This section will focus on Post-Traumatic Stress Disorder (PTSD), although this is not to suggest that this is the only psychological outcome of exposure to a traumatic event. Examples of models from the adult PTSD literature will be described and the application of these models to children will then be discussed.
Section 2: METHODOLOGICAL ISSUES
The following section aims to review the main methodological difficulties and issues pertaining to studies of traumatic stress in children. Whilst some of the issues are pertinent also to studies with adults, others are more specific to research with children. It should also be noted that these issues are complex and inter-related, for example defining the research question has an impact on the choice of measurement tools.

Section 2:1 IDENTIFICATION OF A “TRAUMATIC EVENT” TO INVESTIGATE AND DEFINING TERMS
One of the first methodological issues confronting researchers in this field is identifying what constitutes a “traumatic event”. Whilst clarity of definition of terms such as “traumatic event”, “disaster” and “trauma” would appear to be a fundamental starting point, such definitions are frequently absent from the research (Lyons, 1987). This is probably due to the fact that developing clear and operationalised definitions is exceedingly difficult.

Terr (1985b) has highlighted the importance of distinguishing between the “traumatic event” i.e. “the externally generated blow” which happens to the person and the “trauma” which is the “emotional condition” following the occurrence of an event which overwhelms the individual’s coping mechanisms. In addition Terr suggests that traumatic experience must be “real...surprising, unanticipated, and piercingly intense”.

So how do you define what constitutes a “traumatic event”? What types of events must “traumatic events” be distinguished from? Much of the empirical literature is fairly ad hoc in this respect. Researchers seem to find a fairly serious, distressing event, investigate it, refer to the PTSD literature in their introduction and implicitly assume that the event investigated is “traumatic” often without offering any definitions or theoretical justifications. Where a definition is offered, the most commonly used is that included under the diagnosis of PTSD as defined by the American Psychiatric Association (see Appendix 1). However, this definition is not without faults. Breslau and Davis (1987) point out that whilst this definition offers examples of events which are considered to be “traumatic” and contrasts them with examples of events which whilst distressing are within the range of normal human experience (and therefore not considered to be traumatic), clear operational criteria are not included. The implicit assumption seems to be that these “traumatic events” are somehow categorically different from distressing life events and are easily identifiable as such. However, an
alternative way of viewing "traumatic events" is to postulate that they lie at the extreme end of a continuum including more commonly occurring distressing or stressful life events.

Breslau and Davis (1987), who favour a continuum approach, draw on the stress literature to highlight two approaches to a related issue, evaluating how stressful or traumatic any given event is. They suggest that there are two main paradigms:

- **The Classic Stress Paradigm:** This approach is derived from the work of Selye (1976). He characterised stress as a stereotypical biological response to increased demand of any kind, pleasant or unpleasant. The emphasis is on measuring the objective magnitude of the external event, for example in terms of standard Life Change Units, with less emphasis on the meaning of the event for the individual. However, later work within this framework has acknowledged the interaction between stressful events and individual vulnerabilities in the aetiology of psychological difficulties. Applying this paradigm to "traumatic events" it should therefore be possible to develop Traumatic Events ratings scales, resembling Life Events scales (e.g. Holmes & Rahe, 1967), which assign relative values to how traumatic different events are.

Breslau and Davis argue that the DSMIII (APA, 1980) (see appendix 1) criteria implicitly adopts the Classic Stress paradigm. They criticise the way in which DSMIII attributes aetiological specificity to an extreme stressor, assuming that such stressors are distinct from ordinary stressors. They suggest:

"The distinction in DSMIII between ordinary and extraordinary stressors tacitly assumes that the importance of individual characteristics as factors in the stressor-disease connection is inversely related to the magnitude of the stressors."

However, a review of the empirical literature suggests that the role of individual differences in determining whether someone develops PTSD following a "traumatic event" cannot be ignored. While exposure to an extremely traumatic event clearly places someone at risk of developing PTSD or at least manifesting some PTSD symptoms not everyone exposed to such an event will develop the full blown disorder.

- **Psychological - Clinical Paradigms:** In contrast this approach emphasises that the impact of an event on an individual is determined by the subjective meaning of the event for that individual. Thus the same event may be perceived differently by different individuals and they may be affected in different ways. The importance of cognitive mediation has been emphasised for example by Janoff-Bulman (1984) and Horowitz (1983). This would imply
that predicting the impact of any given event on a particular individual would be extremely complex.

The importance of the interaction between individual and event is stressed in other commonly cited definitions of trauma. Eth and Pynoos (1985) argued that psychological trauma:

"occurs when an individual is exposed to an overwhelming event that renders him or her helpless in the face of intolerable danger, anxiety and instinctual arousal".

Given that individuals exhibit varying coping mechanisms, it could be argued that they will exhibit variable vulnerabilities to being “overwhelmed” by particular events.

Thus there would appear to be two main approaches to determining how traumatic a given event is. One minimises the role of individual differences in perception and emphasises objective measurement; the other would appear to emphasise the importance of individual factors in determining how an event is perceived and the impact which the event has on the person. However, the two are not necessarily mutually exclusive. On average a particular sample may find one event more “traumatic” than another whilst at the same time individual differences could exist within the sample regarding ratings. It should be noted that the definition in DSMIV (APA, 1994) (see appendix 1) includes both objective and subjective elements.

Practically, it would appear that the distinction between “traumatic” and “distressing” or “stressful” events is not as clear-cut as the DSMIIIR definition would seem to imply. Yule and Williams (1990) argue that confusing “stressful” and “traumatic” events has contributed to the contradictions which exist in the literature regarding the prevalence of psychological disturbance following such events. For example, they suggest that Garmezy and Rutter’s (1985) conclusion that children do not show long term effects of acute severe stressors and do not experience PTSD, is largely based on investigations of events which would not qualify as major life threatening disasters or traumatic events. In their discussion of some of the research in this field they argue, for example, that Handförd, Mayes, Mattison, Humphrey, Bagnato, Bixler and Kales’ (1986) study of reactions to the leak of radiation on Three Mile Island and McFarlane’s (1987) study of reactions to a bushfire in Australia, are not studies of “traumatic events”. However, not everyone would necessarily agree with Yule and Williams’ conclusions. Others might argue that the threat of being exposed to toxic levels of radiation is “traumatic” thus illustrating the influence of implicit beliefs regarding the dividing line.
between trauma and distress. It could also be argued that those who have experienced an event at first hand may differ as to how they would describe an event from a supposedly dispassionate and objective researcher.

Thus it would seem that adult researchers can not agree whether some events are traumatic or not. Can we assume that children will perceive the same events as "traumatic" as adults? Yamamoto (1979) asked a group of children to rate how upsetting they would find twenty unpleasant life events. The ratings of the children differed from the professionals' ratings on a number of items. Although the events in this study were "stressful" rather than "traumatic", the findings do highlight the fact that it cannot be assumed that children perceive upsetting events in the same way as adults do.

What conclusions can we draw from all this? This discussion has served to highlight the difficulty of achieving adequate definitions of key terms such as "traumatic event" and of distinguishing between "traumatic" and "distressing" or "stressful" events. There is certainly more scope for work to explore whether "traumatic events" lie on a continuum with or are categorically distinct from more ordinary stressful life events and for elucidating which are the critical characteristics in determining these distinctions. There is also scope for identifying what types of events children of different ages would regard as traumatic and how their perceptions compare with those of adults. Practically, researchers cannot assume that because they regard an event as "traumatic" their child subjects will. Thus it would seem advisable to try to elicit children's perceptions of an event routinely as part of any study. The issue of measuring severity of exposure to trauma will be discussed in more detail under section 2:4:2(c).

Section 2:2 PRACTICAL DIFFICULTIES AROUND TRAUMA RESEARCH WITH CHILDREN
A review of the literature rapidly highlights a number of difficulties which impinge on the types of methodology which can be adopted in traumatic stress research with children.

- Several authors have noted the difficulties of arranging a comprehensive research programme in the aftermath of a major disaster, particularly those which cause major disruption to communities. Given the unpredictable nature of traumatic events and disasters in particular, research programmes often need to be developed in haste which can lead to less
than rigorous design (McFarlane, 1985). Alternatively, there may be a long delay before the start of the research whilst assessment tools and personnel are gathered together and permission is gained from relevant authorities (e.g. Galante & Foa, 1986). This mitigates against investigation of acute responses to traumatic stress and can exacerbate retrospective biases.

- McFarlane (1985) has highlighted the difficulties associated with recruiting subjects and obtaining representative samples in the aftermath of a disaster. In particular, access to lists of victims may be restricted by the authorities. Consequently, alternative methods of recruitment may be required, for example through hospitals or outreach centres. However, this can introduce biases into the sample, for example over-representing those who have been severely impacted. In general both individual victims and relief workers can be reluctant to become involved for fear of retraumatisation. Logue, Melick and Hansen (1981) have noted lower rates of return in disaster research compared with other community populations.

Such difficulties encountered in work with adults are often magnified to an even greater extent with children. Pynoos, Frederick, Nader, Arroyo, Steinberg, Eth, Nunez and Fairbanks (1987) in their study of the impact of a sniper attack on a school commented that four teachers refused access to children in their classes, including one class which was the most directly exposed to the traumatic incident. Yule and Williams (1990) note that parents are often reluctant to allow their children to participate in research projects desiring to protect them from further traumatisation. This may result from a belief that getting on with life and forgetting that the traumatic event ever happened will be more beneficial to the child.

- It has been noted repeatedly that parents and other adults tend to underestimate the impact of traumatic events on children. Burke, Borus, Burns, Hannigan Millstein and Beasley (1982) studied the psychological after effects of a disastrous flood and blizzard. Comparing parental ratings of specific behaviours prior to and after the disaster, they concluded that parents identified more problem behaviours after the event. However, when parents were asked their subjective impressions of the impact of the disaster on the children, all parents denied that their child’s behaviour had been affected. Similarly, Handford et al (1986) found parental underestimation of the extent and severity of children’s reactions in that self report measures revealed residual anxieties amongst children of which parents seemed unaware. Yule and
Williams (1990) noted that there was a striking increase in the levels of distress reported when children were interviewed away from their parents.

In traumatic events affecting communities or which have devastated the family e.g. parental homicide, adult relatives may be having to deal with their own distress and may feel unable to deal with the child’s distress even if they detect it (Black, Harris Hendricks & Kaplan, 1992; Harris Hendricks, Black & Kaplan, 1993).

This denial of the impact of traumatic events on children appears not to be limited to parents. Benedek (1985) argues that this denial is also prevalent among professionals. She cites as an example the exceedingly hostile reaction to a presentation of Lenore Terr’s work with the victims of the Chowchilla kidnapping. She concludes that “this distinctly unusual response with characteristics of hostility and rage and incredulity appeared to be a massive form of denial”.

Difficulties in recruitment of subjects extends beyond the immediate aftermath. Long term follow-up studies often encounter problems of high attrition rates. Jesse, Strickland and Ladewig (1992) used questionnaires to investigate reactions to a hostage situation at 1 week, 4- and 12-months after the event. The parental response rate was highly variable. Of 99 families sent questionnaires the following returns were obtained: 48 families responded at time 1; 27 parents responded at time 2 (it is not clear how many families this included) and 25 mothers responded at time 3. Terr (1983a) reports a 4-5 year follow-up study of 26 of the victims of the Chowchilla kidnapping in which she successfully contacted all but one of the kidnap victims’ families. She notes that half the group volunteered to join the follow-up and the remaining children agreed after payment was offered. So it would appear that even with the Chowchilla group who had had a high degree of involvement with the researcher, obtaining agreement to co-operate was difficult. This reluctance seemed to come partly from parents and partly from the children themselves.

The role of researcher is complex, particularly if research is conducted by a trained clinician. It has been noted that the victim’s distress can lead to the avoidance of more difficult questions and a tendency towards brevity rather than comprehensive questioning (McFarlane, 1985). There can also be a confound between the role of researcher and counsellor/clinician (Garmezy, 1986) with individuals feeling pulled in two directions, namely
wanting to assist the victims therapeutically and wanting to investigate their experiences from an objective standpoint. It was noted that in a number of studies researchers also offered therapeutic input to varying extents (e.g. Terr’s work in Chowchilla; Galante & Foa, 1986; Yule & Williams, 1990). Benedek (1985) has commented on the complexity of counter-transference reactions to victims of traumatic events, particularly children. This can result, for example, in over-identification with the victim, rage against the victim’s circumstances, a desire to nurture or protect the victim or in some cases a denial or disbelief of their account because it is too distressing to contemplate.

- Garmezy (1986) has noted that most traumatic stress research has to rely on retrospective reconstruction of pre-traumatic event functioning with all the attendant difficulties of questionable reliability. Where possible archival records may be used but it is pointed out that these are often not available or may have been destroyed if a major disaster is being investigated. Aptekar and Boore (1990) suggest that researchers often neglect to explore how children have dealt with stressful situations prior to the event. They recommend collecting baseline information for example in disaster prone areas, although acknowledging that first time disasters may have a different impact from repeated disasters.

- Garmezy (1986) and others have noted the problems of controlling for the effects of a multiplicity of influencing variables in determining the impact of a trauma. For example, in cases where a child has witnessed parental homicide by the other parent, it is difficult to separate out the effects of witnessing the event from the effects of possible exposure to prior conflict or violence, bereavement reactions to the loss of the murdered parent, reactions to separation from the incarcerated parent and the dislocation of having to move in with relatives or possible into residential care (Harris Hendricks et al, 1993).

Section 2:3 TYPES OF METHODOLOGY USED IN EXPLORING TRAUMATIC STRESS IN CHILDREN: STRENGTHS AND WEAKNESSES

The practical difficulties noted above clearly influence the type of methodologies which can be employed in exploring traumatic stress amongst children and these constraints need to be considered when interpreting results from published studies. In addition it should be noted that ethically it is not feasible to carry out experimental, controlled studies with traumatised children and therefore researchers have to rely on other methods and be particularly inventive in developing programmes. In this section the main types of methodology will be reviewed,
evaluating the strengths and weaknesses of each approach. In addition the impact of methodology on results will be considered.

For the sake of clarity Garmezy's (1986) classification of research methodology has been employed in this discussion. However in practice many of the studies reviewed did not fit clearly into one or other of these categories but rather lay between two different categories.

Section 2:3:1 Clinical descriptive:
This approach relies on the detailed description of single case histories. A single case study approach enables the in depth description of the reactions of an individual to a particular trauma and may be useful in exploring which aspects of a traumatic event are critical to the development of distress (Armsworth & Holaday, 1993). It is possible to observe fine details which may be lost in larger scale studies. Given the smaller sample size, follow up over a longer period of time is facilitated enabling the exploration of the way in which coping/defense mechanisms develop over several years (see Pruett, 1984). This idea of process would appear to be critical given Horowitz's (Horowitz & Reidbord, 1992) theoretical model of PTSD. Horowitz suggests that classification of a particular response pattern as dysfunctional is dependent in part on how long after the traumatic event the response occurs. Thus a response occurring immediately after a traumatic event may be considered perfectly normal. However, if the same response is observed to persist several months later, because the process of working through the event has somehow become stuck, then the response would then be considered dysfunctional and abnormal. Given this perspective adopting a longitudinal approach rather then merely a cross sectional design would appear critical.

However, studies relying on single cases are not without problems. These studies seem to rely mainly on clinical interview as the main method of data collection with little reference to standardisation or the psychometric properties of such an approach (see Pynoos & Eth, 1986 and Garmezy's, 1986, critique). Lack of a control group and the small number of subjects do make it difficult to determine whether the reactions observed are due to the trauma or to other factors such as the personality of the child, prior vulnerability factors etc. It is therefore difficult to make generalisations on the basis of these studies. Given that such studies are likely to be based on cases referred to therapeutic agencies they may over-represent cases where the reaction has been particularly adverse or severe.
Within this review few studies were found which focused solely on one single case. However, several authors drew on small numbers of cases (less than 5) of similar trauma with the aim of identifying similar features (e.g. Gislason & Call, 1982; Terr, 1985a). This approach would appear to an intermediary between the single case study approach and a pure epidemiological approach using a larger sample.

Section 2:3:2 Epidemiological:
This approach collates several case histories with the aim of identifying similar patterns of response and identifying prevalence rates of particular response types. Studies using this approach are useful in that they allow for the collection of data regarding the prevalence of particular response patterns in a population following a traumatic event. If based on a community sample they can allow for the exploration of a spectrum of reactions from mild to severe. However, this may be constrained by sampling biases arising from the practical constraints noted earlier. Given that such studies tend to have larger sample sizes it may be more feasible to generalise on the basis of these findings.

However, this approach does provide a more static and cross sectional picture rather than a longitudinal and dynamic picture. Obtaining follow up data may prove difficult given all the difficulties of poor return rates noted earlier. In addition these studies often rely on questionnaires sent to parents and teachers ignoring the child’s perspective (e.g. McFarlane, 1987). Thus they may tend to underestimate the extent of the child’s distress.

Most studies appear to fall into this framework, using a survey approach either collating data from several individuals who have experienced the same traumatic event (e.g. Galante & Foa, 1986; Green, Korol, Grace, Vary, Leonard, Glesen & Smithson-Cohen, 1991; Shannon, Lonigan, Finch & Taylor, 1994) or extracting patterns from observations of children exposed to similar traumatic events (e.g. Malmquist, 1986; Black et al, 1992).

Section 2:3:3 Quasi experimental:
Given the ethical difficulties of adopting a pure experimental methodology, this approach attempts to explore the influence of key variables on response patterns, for example comparing subjects with different levels of exposure to the traumatic event. This approach has the advantage of enabling the testing of specific predictions derived from particular models, a characteristic often absent from research in this field. The inclusion of control
groups within the design, where this is actually achieved, means that it is more feasible to control for the effects of variables apart from the traumatic event and makes the attribution of observed effects to the traumatic event more reliable. However, as with the epidemiological approach the elements of individual difference and process can be lost.

There would appear to be few studies which fall into this category (e.g. Joseph, Brewin, Yule & Williams, 1993; Dollinger, 1984,1986b). However, the boundary between epidemiological studies and quasi-experimental studies may not be as clear cut as Garmezy suggests. Many studies, which superficially could be classified as epidemiological, consider variables such as age and gender and the impact which these may have on reactions to trauma. It could also be argued that some types of traumatic event lend themselves more naturally to this approach than others.

Section 2:3:4 The influence of methodology on results:
It has been suggested by several authors that the type of methodology employed may influence the levels of distress and dysfunction which are found. Perry (1979) and McFarlane (1985) suggest that sociological or survey based studies often report small correlations between mental health problems and disasters where as psychodynamically oriented or clinically based studies report evidence of significant emotional impairment after disasters. However, a review of the literature suggests that this is not necessarily the case. There have been studies using single case methodology in a clinical setting which report minimal impact following severe trauma (e.g. Lebovici, 1974) whilst some larger scale epidemiological/quasi experimental studies have found considerable evidence of emotional disturbance (e.g. Galante & Foa, 1986; Pynoos et al, 1987; Shannon et al, 1994). One important factor in survey techniques is whether appropriate questionnaires and assessment tools are utilised, an issue which will be discussed in more detail in section 2:4:2(a).

Section 2: 4 OTHER ISSUES PERTINENT TO RESEARCH DESIGN:
There are two further areas which are related and would appear to be pertinent to all of the above approaches, but particularly the epidemiological and quasi-experimental. Firstly, clearly establishing the research question and secondly, choosing appropriate assessment tools to measure severity of reaction and long term outcome, level of function prior to the traumatic event and level of exposure to the traumatic event. These issues are critical to the design and interpretation of studies in this field.
Section 2:4:1 Clarifying the research question:
Many studies in this field would appear to lack clarity in describing the question they are aiming to answer. There would appear to be a number of key issues which need to be considered.

- McFarlane (1985) stresses the importance of clarifying whether a study is aiming to measure distress or disorder, specifically disorders which can be diagnosed using classificatory systems such as DSMIIIR (APA, 1987). Related to this is the issue of "caseness", in other words what features of a presentation would lead to it being labelled as divergent from the norm.

- Garmezy (1986) emphasises that focusing on distress and disorder can lead the researcher to ignore those who are coping successfully and competently which may be a critical source of information regarding protective factors.

- If the aim of the study is to measure the prevalence of disorder in the aftermath of a traumatic event, the question then arises as to which disorders? Attention is typically focused on PTSD but as Terr (1991) notes this is by no means the only difficulty which results from exposure to traumatic events in childhood. If the focus is on PTSD then a distinction may need to be drawn between measuring symptom prevalence and the prevalence of disorder. These measures need to take into account how much time has elapsed since the event, given that in the immediate aftermath of a severe traumatic event PTSD type symptoms would appear relatively common whilst fewer people go on to develop a diagnosable disorder.

Section 2:4:2 Choice of measurement tools:
This section aims to cover the main measurement tools found in the literature reviewed and the difficulties associated with finding appropriate measures. It is does not aim to be comprehensive in its coverage of the measures available.

(a) Measuring outcome:
The choice of measurement tool clearly should be guided by the research question. However this does not always appear to be the case.

Problem Behaviour Checklists completed by adults:
Many of the studies reviewed used problem behaviour checklists (e.g. Saylor, Swenson & Powell, 1992; McFarlane, 1987; Yule & Williams, 1990; Jessee, Stricklend & Ladewig,
1992) as a measure of outcome. Some studies explicitly stated that the focus of interest was
behaviour change (e.g. Burke et al, 1982; Jessee et al, 1992). However other studies claimed
to be exploring PTSD or did not make their aims clear but referred to the PTSD literature
(e.g. Galante & Foa, 1986; McFarlane, 1987). Yule & Williams (1990) have queried the
pertinence of these research tools to investigations of PTSD, targeting the Rutter scales
(Rutter & Graham, 1967; Rutter, Tizard & Whitemore, 1970) in particular. Firstly, these
questionnaires were developed as a screening instrument for general population studies rather
than to pick up rare conditions such as PTSD. Thus whilst it could be argued that it may be
valid to use these scales to look at general behavioural disturbance after trauma, they are not
useful in identifying PTSD. Secondly, these scales are completed by third parties rather than
by the children themselves. As already noted there is a tendency for adults to under-report the
impact of a trauma compared to the child’s self report. Thus using the Rutter scales apart
from instruments relying on the child’s self report, either a detailed history or questionnaire,
may result in a distorted picture. However, some studies (e.g. McFarlane, 1987) have relied
solely on these scales and have not attempted to assess the children directly.

Self report measures
Yule and his colleagues in their work with the child survivors of shipping disasters are
developing a battery of self report measures designed to screen survivors for future
psychological difficulties including PTSD. Yule & Williams (1990) in their initial
assessments combined detailed histories from the child and parents separately, with
completion of the Rutter parent and teacher scales. At one-year follow-up the children (aged 8
to 16) completed the Impact of Events Scale (IES: Horowitz, Wilner & Alvarez, 1979) and
the Birleson Depression Inventory (BiDI: Birleson, 1981). They concluded that children of
this age found “the questions meaningful in relation to their private experiences of trauma and
that the data have face validity”. Yule and Udwin (1991) screening child survivors of the
Jupiter, aged 14 to 16, utilised the IES and BiDI in combination with the Revised Children’s
Manifest Anxiety Scale (R-CMAS: Reynolds & Richmond, 1978) and the Fear Survey
Schedule for Children (FSSC: Ollendick, 1983). As Yule and Udwin point out ideally any
screening battery, “would be validated against agreed criteria of a disorder and the number of
false positive and false negative identifications as well as the number of true positives
reported.” As this is not yet possible yet given the state of knowledge about PTSD in children
they suggest the following useful comparisons:
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- comparison of traumatised children's scores with normative data;
- comparison data immediately post trauma and at 5 months follow up;
- relationship between scores and help seeking behaviour.

Malmquist (1986) also used the IES with children aged 5 to 10 years. He states that the questions were asked to the children and about them and then a clinical judgement was then made as to how to rate them on each item of the scale. The means from this study were slightly higher than those obtained by Yule and Williams (1990) although it is not clear whether this is due to:

- difference in presentation of questionnaire
- the younger age of Malmquist's group
- differences in the severity of the traumatic events explored.

Shannon et al (1994) successfully utilised a self-report battery including the Revised Manifest Anxiety Scale and the Frederick Reaction Index for Children (Frederick, 1985) which is designed to assess PTSD symptoms as defined in DSMIII. Questions were read aloud by teachers and explained if necessary. The children were aged 9-19. Shannon et al highlight the need for caution in relying solely on self-report measures pointing out that children may exaggerate their responses or operationalise the severity dimensions differently than would adults or a trained professional conducting a standardised interview. In addition it should be noted that in this study no attempt was made to standardise explanations provided by the teachers.

Semi-structured interviews
A number of other studies (Bradburn, 1991; Pynoos et al, 1987; Nader, Pynoos, Fairbanks & Frederick, 1990) have employed semi-structured questionnaires specifically the PTSD Reaction Index for Children (Frederick & Pynoos, 1988) to explore the prevalence of PTSD symptoms and disorder with success, either as the sole measure or in combination with other measures. Earls, Smith, Reich and Jung (1988) used The Diagnostic Interview for Children and Adolescents (DICA) in combination with other measures to screen children aged 6 to 17 years for PTSD following severe flooding.

(b) Measuring pre-morbid levels of functioning:

Assessing level of function prior to the traumatic event is clearly necessary before behaviours observed after the traumatic event can be argued to have resulted from the exposure to
trauma. It may also be critical in establishing factors which may result in increased vulnerability to develop severe reactions to traumatic events. The difficulties pertaining to collecting this information have already been noted. It was also noted that many studies found within this review paid scant attention to this issue. Terr (1979; 1981; 1983a) asked general questions regarding problems prior to the Chowchilla kidnapping and attempted to relate this information to reactions observed after that event. Similarly, Gislason and Call (1982) commented on personality change following severe dog bite in infancy based on retrospective parental reports in a clinical interview. Burke et al (1982) used behavioural assessments conducted for a Head Start programme prior to severe storms as a baseline to assess changes in behaviour after the storms. However, this may have introduced biases into the sample as the children were not selected randomly. Jessee et al (1992) asked for reports regarding behaviour change and Saylor et al (1984) asked that behaviour questionnaires be completed for behaviours both before and after a hurricane. However, it is not clear how effectively participants were able to comply with these instructions. Finally, other studies have asked about prior exposure to stressful life events (e.g. Bradburn, 1991) but do not assess how the child dealt with these or evaluate whether this prior exposure was likely to have sensitised the child to subsequent trauma or whether it had the effect of "inoculating" the child.

(c)Measuring the severity of trauma:

Whilst most studies attempted to find some objective measure of level of exposure to trauma, the way in which this was done varied considerably. Measures also tended to focus on how severely exposed the individual was compared with other people within the study. Many of the indices used were quite gross, for example Galante and Foa (1986) compared six villages affected by an earthquake according to percentages of homes damaged or destroyed or percentage of people killed within the village. Jessee et al (1992) assessed length of time held hostage and Bradburn (1991) grouped people according to the area in which they lived. McFarlane (1987) and Burke et al (1982) employed questionnaires assessing level of destruction and disruption in the immediate aftermath and also in the longer term, an important dimension which often seems to be neglected. However, both relied on parental report and therefore did not directly access the child’s experience of the event.

In contrast Shannon et al (1994) used a self-report multiple choice questionnaire covering a number of aspects of the traumatic event. Pynoos et al (1987) also assessed children’s experience directly asking them their whereabouts during a shooting, concerns regarding
siblings, degree of acquaintance with the deceased child and the occurrence of additional traumas in the previous year.

Whilst obtaining gross objective measures such as how many homes were destroyed in a particular area may have some value it would seem to also be important to ask the child about their own experience to determine their understanding and perception of the event. Pynoos and Eth (1986) also advocate asking about a child's worst moment as they argue that this can be very idiosyncratic.

(d) Conclusions:
Given that all measures of outcome have their limitations, Lyons (1987) and Garmezy (1986) have advocated using multiple methods of assessment incorporating self report measures, semi-structured interviews and reports from significant others. This method was utilised very successfully by Kinzie, Sack, Angell, Manson and Rath (1986) and Sack, Angell, Kinzie and Rath (1986) in their study of the impact of multiple traumatic events on Cambodian children. However, such an approach does have practical difficulties given the time required to collect and analyse all the data. It is difficult to avoid the problems of relying on retrospective data to assess pre-morbid function unless by some fortuitous circumstance more reliable records exist. However, it would appear important that this aspect of the assessment is also structured with specific questions about previous levels of functioning, exposure and reactions to previous stressful and traumatic events etc. In addition assessment of exposure to the current traumatic event should include not only objective measures but also subjective measures exploring the child's perceptions of the event.

Section 3: THEORETICAL ISSUES
For the most part discussion so far has been focused around methodological issues pertinent to investigating reactions to trauma in children. The latter part of this review will focus on theoretical issues particularly whether models developed to explain phenomena observed in adults are applicable to children. This part of the review will focus on models of PTSD.

Section 3:1 MAIN MODELS IN ADULT PTSD LITERATURE

Section 3:1:1 Conditioning models:
Some researchers have adopted Mowrer's (1960) two factor learning theory in explaining the clinical symptoms of PTSD. For example, Keane, Albano & Blake (1992) suggest that
extraneous stimuli (e.g. odours, sounds, etc.) which co-occur with the traumatic event become associated with the trauma and through a process of classical conditioning acquire anxiety provoking properties. Through processes of higher order conditioning and stimulus generalisation, a wide variety of stimuli, including words related to the trauma, also become triggers for anxiety and fear. Keane et al suggest that anxiety does not decline following repeated re-experience phenomena, as might be predicted on the basis of the model, because these spontaneous exposures are not of sufficient duration for anxiety levels to peak and for habituation to occur.

Avoidance phenomena are interpreted within an instrumental/operant framework. In the case of PTSD it is argued that the desired consequence is to control levels of anxiety. The individual learns that avoidance of or escape from trauma related cues is effective in minimising the aversive consequences of exposure to anxiety provoking stimuli. Thus avoidance and escape are negatively reinforced.

Thus, within this model, some symptoms (e.g. exacerbated startle response, sleep disturbance etc.) are viewed as involuntary anxiety responses associated with the UCS/CS where as other symptoms (e.g. behavioural avoidance) are viewed as instrumentally conditioned responses.

A number of criticisms of conditioning models have been put forward. In particular it has been argued that conditioning models do not provide an adequate explanation of the cognitive re-experiencing phenomena which are so distinctive of PTSD and which do not appear to occur in other anxiety disorders (Foa & Rothbaum, 1992). Keane et al argue that these phenomena are the result of the high degree of generalisation in PTSD which therefore renders avoidance of all triggers of traumatic memories impossible. However, it has been suggested that this is not really an adequate explanation and in particular that it does not account for the occurrence of nightmares within PTSD (Foa & Rothbaum, 1992).

**Section 3:1:2 Information processing models:**

Information processing models argue that re-experiencing phenomena occur as a result of inadequate processing of the traumatic event such that the representation of the traumatic event has not been properly incorporated into pre-existing knowledge structures. A number of authors have proposed models within this framework. For example, Foa, Steketee & Rothbaum (1989) outline a model around the idea of fear structures, networks in memory
which contain information about feared stimuli, response to these stimuli and information about threat or danger. The fear structures in PTSD are large, easily activated and associated with an intense response. Exposure to stimuli associated with events triggers intense physiological responses and re-experiencing phenomena. Foa et al (1989) argue that this will continue until the fear structure is activated and new incompatible information is incorporated into the structure. They suggest that certain factors facilitate emotional processing of an event, such as good social support, whereas other factors, such as avoidance of reminders, inhibits this process.

Horowitz’s model of PTSD assumes that one basic aspect of human information processing is the so-called “completion tendency”. It is argued that important information which does not accord with existing models or beliefs is re-processed until either the situation or the models change and hence there is concordance between reality and the mental model (Horowitz & Reidbord, 1992). Until the traumatic memory is assimilated into existing schemata, it will at times intrude into consciousness as emotionally upsetting, intrusive and uncontrolled memories of the event. As these memories are so distressing there is a tendency to defend against the memory, its meaning and emotional associations, through numbing and avoidance. These processes serve to protect the person against feelings of overwhelming distress and anxiety, but also block further processing of the memory. This cycle occurs both in “normal” reactions to trauma and in PTSD. In normal reactions to trauma, assimilation and accommodation gradually occur so that there is a reduction over time in the intensity, pre-emptoriness and frequency of these intrusions as the traumatic experience is integrated into the way in which the individual views the world and themselves. However, in some people this process becomes stuck and consequently the intrusion-numbing/avoidance cycle is repeated over and over again but without integration occurring. It is these individuals who would be diagnosed as having PTSD (Horowitz & Reidbord, 1992).

Given the above observation that in the immediate aftermath of a trauma most people manifest PTSD type symptoms, are there factors which influence who is likely to go on to develop PTSD? Green, Wilson and Lindy (1985) have identified three main areas which appear to be important for adults:

- **Nature of the traumatic experience**: Key areas related to long-term outcome appear to be level of exposure, degrees of bereavement, life threat, warning, displacement and exposure to grotesque sights. Anecdotal evidence suggests that the person’s role in
the event e.g. whether they respond in an active or passive way, is also important. It has also been suggested that reactions to man-made disasters may be more severe than to natural disasters;

-Individual characteristics: Although the influence of personality is still being debated, Green et al suggest that outcome is likely to be influenced by the interaction between the nature of a particular event and personal characteristics. Prior experience and pre-existing beliefs are likely to influence a person’s appraisal of an event. In particular prior exposure to traumatic or negative events may make someone more vulnerable to PTSD following subsequent exposure to trauma. It is also likely that a person’s habitual coping styles and beliefs about seeking help and support will also influence their response.

-Recovery environment: Environments which provide good social support and an opportunity to talk about the traumatic experience seem to be related to better outcome (Jones & Barlow, 1990). One proviso with this data is the problem that social withdrawal and emotional numbing are often observed in the aftermath of trauma. Thus it is important to establish whether poor social support is a reaction to social withdrawal on the part of the traumatised person, an independent factor or whether there is a reaction between level of withdrawal and level of social support. It has been suggested that social support may promote emotional processing of traumatic events (Foà et al, 1989). Also important are the interaction between the event and the recovery environment. For example, societal attitudes to victims of trauma are likely to vary according to the nature of the trauma, whether the person is perceived as being responsible etc. As many large scale disasters have profound effects on whole communities, as others are also coming to terms with their own trauma they may be less willing to respond sympathetically to the needs of others. (See Harber & Pennebaker, 1992). Finally cultural norms may influence whether individuals feel able to talk openly about their experiences.

Section 3:2 APPLICATION OF ADULT MODELS TO CHILDREN’S REACTIONS
Before discussing how well the adult PTSD models fit children’s reactions to traumatic events, two issues will be briefly addressed. Firstly, whether children do in fact seem to develop PTSD and secondly, whether their symptoms mirror those seen in adults.
Section 3:2:1 Can children develop PTSD?
As noted earlier there has been considerable debate regarding this question. However a number of recent reviews have suggested that children do show PTSD (Lyons, 1987; Armsworth & Holaday, 1993; Yule & Williams, 1990; Terr, 1991). A full discussion of the evidence pertaining to this question is beyond the scope of this review.

Section 3:2:2 Nature of PTSD symptomatology in children:
Terr (1985a) has argued on the basis of her work with traumatised children that children exposed to single traumatic events differ from adults in their reactions in the following respects:
1. Children over the age of 3 or 4 do not seem to show post-traumatic amnesia. Children under this age may forget their traumas possibly due to massive denial or an inability to represent or express the event. However she claims there are exceptions to this (Gislason & Call, 1982). She suggests any errors in report are due to misperceptions, distortions or time skew, whereby an event or symptom which occurred after the traumatic event is misplaced to a time before the event (see Terr, 1983b for a fuller discussion).
2. Terr argues that children exposed to single traumatic events do not show psychic numbing although children exposed to prolonged (type 2) trauma may do so.
3. Terr suggests that children do not experience sudden, intrusive visual flashbacks but rather tend to reflect on their traumatic experiences in a more controlled way e.g. during times when bored in class, just prior to falling asleep etc. Terr argues that the reason children do not show intrusive flashbacks is that they do not tend to use denial in the same way as adults and therefore do not become locked into the intrusion-avoidance cycle outlined by Horowitz.
4. The performance of children at school does not appear to suffer for longer than a few months after the trauma possibly due to their lack of intrusive flashbacks and numbing.

Terr has also argued that the following features are more prevalent amongst children than adults following trauma:
5. Post traumatic play and re-enactment occur more frequently in childhood;
6. Children have a greater tendency to show time skew and omen formation than adults (Terr, 1983b)
7. Childhood victims of trauma often manifest a foreshortened sense of future (Terr, 1983b)
There has been some debate regarding Terr's conclusions, particularly her argument that children do not show intrusive flashbacks. For example, Yule & Williams (1990) found that children reported intrusive thoughts on the IES and talked about flashback experiences in interview. They concluded most show intrusive thoughts and some experience full-blown flashbacks. They also found evidence of amnesia and problems concentrating at school. However, they concluded that there was little evidence of "psychic numbing" (see also Frederick 1985). One of the problems in resolving this question is that the phenomena under question are not clearly defined in the literature. It is therefore difficult to establish whether different authors mean the same thing when they refer to "intrusive thoughts". Breslau & Davis (1987) argue that re-experiencing phenomena are highly heterogeneous, ranging along a continuum from common phenomena such as intrusive thoughts to a more extreme feeling and acting as if the traumatic event were re-occurring. They suggest that the more benign forms of re-experiencing also occur following ordinary life stresses.

Pynoos et al (1987) suggest that patterns of symptoms vary depending on the severity of disorder. Re-experiencing and avoidance phenomena were found to be most prevalent in children manifesting severe and moderate PTSD. Unwelcome and disturbing visual images were more common amongst highly exposed individuals. In contrast increased fear and anxiety were prevalent across the severity spectrum.

There is also evidence that age may influence a child's presentation. Scheeringa, Zeanah, Drell and Lameu (1995) found that although pre-school children showed some of the symptoms seen in older children and adults, the diagnostic criteria for PTSD needed to be modified for children in this age group. The new criteria, which emphasised trauma related play, behavioural re-enactment and regressive behaviours, were found to be more reliable and valid than the original criteria.

Thus it would seem that children can develop PTSD and that children manifest many of the same symptoms as adult victims. Whilst there is some debate regarding the prevalence and nature of re-experiencing phenomena amongst children, some reports suggest that children can also show these symptoms. Assessing the applicability of adult models to children's reactions would therefore seem to be a valid endeavour.
Section 3:3 HOW WELL DO ADULT MODELS FIT CHILDREN’ S REACTIONS?
Most of the studies reviewed adopted a descriptive, phenomenological approach with few studies providing a theoretical framework and testing specific hypotheses. However, two studies were found which explored one aspect of the conditioning model and two studies looked at the impact of cognitive processing on severity of distress. Finally, evidence pertaining to the factors identified by Green, Korol, Grace, Vary, Leonard, Gleser and Smithson-Cohen (1991) as being important in influencing who develops PTSD will be reviewed.

Section 3:3:1 Conditioning models:
Two studies were found which explicitly used a conditioning model, specifically looking at the development of fears following traumatic events. Both studies utilised the idea of a generalisation gradient, that is that exposure to a high intensity stimulus can result in conditioned fear which can subsequently generalise to other related stimuli.

Dollinger (1984; 1985; 1986a) explored the reactions of a group of 10-13 year olds to a lightning strike disaster during which one person was killed and several others injured. As part of a broader assessment mothers were asked to complete a questionnaire about the children’s sleep problems and somatic complaints (Dollinger,, 1986a) and both mothers and children completed the Louisville Fear Survey for Children (LFSC; Miller, Hampe, Barrett & Noble, 1972). Scores on the LFSC were compared with controls matched for age, gender, and social-economic status. It was found that both mother and child reports suggested that the lightning strike (LS) group showed significantly more storm related fears than controls. There was some evidence of elevated scores on fears of related stimuli e.g. death, dying & disasters in the LS group. However, on fears not related to the traumatic incident e.g. school, people, embarrassment, levels in the two groups were comparable. There was also a good correlation between LFSC scores and ratings of the degree of emotional upset and sleep problems / somatic complaints. Thus results were in accordance with the predictions of the conditioning model. As with many other studies it was assumed that controls were not traumatised but it appears that no attempts was made to test this assumption.

Yule, Udwin and Murdoch (1990) compared fears, anxiety and depression in the aftermath of a shipping disaster amongst four groups of girls:

- Survivors from the cruise;
- Girls who wished to go on the cruise but did not get places (Near miss group);
- Girls in the same school year as the survivors but who did not want to go on the cruise;
- Girls in the same school year at a different school in a similar area.

This design allowed for comparisons of fears at different levels of exposure although the groupings are quite crude. Yule et al found no differences between the groups on overall means on the fear measure. However, survivors showed significantly higher scores on fears related to the cruise (as judged by experienced clinicians). There was some evidence of fear generalisation to rats and other forms of transport amongst survivors. The increase in fear scores occurred only amongst the directly exposed group. However, on the anxiety and depression measures, evidence of a dose related response was observed, with increased exposure correlated with greater levels of anxiety and depression. The authors report that they are attempting to develop more sophisticated indices of exposure to explore this relationship further.

Thus, the evidence from these studies supports the predictions made on the basis of the fear generalisation gradient. However, this is only one part of the conditioning model and other predictions of the model have not been rigorously tested within the child population. Therefore no firm conclusions about the applicability of this model to children’s reactions can be drawn.

Section 3:3:2 Information processing models:
Two studies were found which explored one aspect of the information processing approach, specifically the role of attributional processes amongst teenagers in the development of post traumatic distress and disorder.

As part of his assessment, Dollinger (1986b) asked lightning strike victims about their explanations for the event. The presence or absence of attributional statements and the type of attribution made was compared with measures of emotional distress. The results suggested that children providing any answer to the attribution question tended to be more upset than those who made no attribution. The direction of causality or the role of other variables was not clear. Whilst this study is based on a very crude attributional measure which may not be accessing children’s causal explanations very reliably, it does provide some interesting
preliminary results regarding the possible role of cognitive mediation in the development of post-traumatic distress in children.

Joseph, Brewin, Yule & Williams (1993) also explored the role of attributional processes amongst adolescents. Joseph, Brewin, Yule and Williams (1991) had previously found that amongst adult survivors of a shipping disaster, more internal and personally controllable attributions were associated with greater psychiatric symptomatology. An experienced rater, blind to outcome status, coded the adolescent survivors proofs of evidence for causal attributions using the Leeds Attributional Coding System (LACS: Stratton, Heard, Hanks, Munton, Brewin & Davidson, 1986). They found that on the whole attributions for the traumatic event tended to be external. More internal attributions for negative disaster related events were associated with increased post-traumatic symptomatology. Unfortunately this sample is biased in that all subjects were identified as being at high risk and requiring further assessment and the evidence from Dollinger's study suggested that individuals who were most distressed by an event were also more likely to make attributions.

These results suggest that attributional processes amongst adolescents play a role in the development of post-traumatic symptomatology as is also the case amongst adults. There is scope for using similar techniques with younger children, coding attributional material gathered in interviews or play sessions. It may also be productive to explore the interaction between developmental stage, type of traumatic event and attributional processes in influencing symptomatology. Once again, however, these studies have addressed only one peripheral aspect of the information processing model and consequently no conclusions can be drawn as to how well this model fits the reactions observed in children.

Section 3:3:3 Factors influencing the development of PTSD:
Green et al (1991) argue that many of the factors which determine vulnerability to developing PTSD in adults (see discussion under Section 3:1:2) are also important for children. However, additional factors are also seen as important, specifically parental reaction and the child's developmental stage at the time of the traumatic event.
(A) Nature of the traumatic experience

- Impact of the level of exposure:

A number of studies have found evidence that those who are most exposed to traumatic experiences, for example those who are exposed for longest or who experience more loss, are most at risk of subsequently developing difficulties (Newman, 1976; Jessee et al, 1992). However, these results need to be interpreted in the light of the difficulties in measuring level of exposure highlighted earlier. Pynoos and his colleagues investigating the impact of a sniper attack (Pynoos et al, 1987; Nader et al, 1990) on school children (aged 5 to 13) found evidence that symptom severity was related to levels of exposure with those in the most exposed group i.e. those who were in the playground in positions near to the child who was killed, were at the highest risk of developing PTSD and at most risk of showing severe symptoms. In the lower exposure groups, only those with particular vulnerabilities such as knowing the victim well, tended to develop more severe symptomatology. Green et al (1991) found that life threat to self was significantly associated with number of PTSD symptoms two years after the Buffalo Creek disaster, particularly amongst children in the 8-15 age range.

- Type of event:

Less attention seems to have been paid to comparing the impact of different types of single traumatic events on children, although Frederick (1985) has compared the impact of disasters, physical and sexual abuse. Studies tend to adopt exposure indices to compare children within the same study rather than across different disasters. Comparisons across studies would be valuable in determining whether the pattern of vulnerability is similar amongst adults and children.

(b) Individual characteristics:

- Age:

Lyons (1987) outlines two main hypotheses regarding the impact of age on vulnerability to PTSD:

- The younger the child is the less likely they are to be able to understand the threat associated with a traumatic event. Therefore they are less likely to be distressed by it and develop subsequent symptomatology.

- Younger children may be vulnerable to developing problems because they have a less sophisticated range of coping mechanisms.
These two are not necessarily incompatible as it could be argued that the appreciation of threat by a young child is dependent on factors such as the nature of the event and the reaction of significant adults. However if the young child does appreciate the significance of an event under those circumstances they may be more at risk of developing problems because of the poverty of their coping mechanisms.

A number of authors have commented in detail on the impact of age on reactions to trauma (e.g. Pynoos & Eth, 1984; Lyons, 1987; Green et al, 1991; Shannon et al, 1994) and a full review of the evidence is beyond the scope of this review. Once again it would appear important to clarify what question is being asked e.g. the impact of age on vulnerability to a specific disorder or the impact of age on patterns of symptomatology. In addition the nature of the event and the child’s understanding of the event also need to be considered (Lyons, 1987). In general developmental stage does seem to influence the pattern of responses observed at different ages with younger children (pre-school) manifesting chaotic responses and behavioural difficulties and older children (adolescents) manifesting responses which more closely resemble those seen in adults (see for example Scheeringa, Zeanah, Drell & Lameu, 1995).

-Coping style:

Although some studies have explored the defense mechanisms employed by children following traumatic events (e.g. Pynoos & Eth, 1984; Terr, 1990) less attention has been paid to the impact which various defense and coping strategies have on short and long term outcome. Dollinger & Cramer (1990) used the Thematic Apperception Test (TAT: Cramer, 1987) to assess the use of denial, projection and identification amongst 10-13 year olds following a lightning strike disaster. They found that boys who had the highest total defense scores were rated as less upset at two months after the traumatic event. The use of the more mature defences of projection and identification was an even better predictor of reduced emotional upset. It was also noted that whilst there was consistency between self-reports of fears and parental report of upset amongst low-defensive boys, highly defensive boys’ reports were not consistently related to parental reports. Thus consideration of use of defense mechanisms may be a further factor to assess in determining the reliability of self and third party report. Finally, Pynoos and Nader (1988) have explored the interaction between exposure to a traumatic event and memory for that event six and sixteen weeks after a sniper attack on their school. They found that children in different exposure groups showed very different patterns.
of recall. Highly exposed children tended to minimise their exposure to threat, for example maximising their distance from the sniper and focus on actions perceived as emphasising self efficacy. In contrast children in the low exposure group tended to bring the threat closer and were more influenced by rumour in their description of events. The medium exposure group showed variable recall depending on their particular experiences. The impact of these strategies on outcome was not explicitly addressed.

There would appear to be scope for further exploration of children’s use of coping strategies at different ages and different stages in the recovery process, particularly given Horowitz’s (1979) observations that strategies which are useful at some stages can be detrimental at others.

(c) Recovery environment

Freud & Burlingham (1943) in their early work on childhood trauma emphasised the impact of parental reaction on the child’s adaptation. This has been upheld by subsequent finding. For example, McFarlane (1987) found that mothers’ responses to disaster, specifically the mothers’ experience of intrusive memories and a shift to an over-protective parenting style, were a better predictor of the presence of post-traumatic phenomena than the children’s direct exposure to the disaster. However it should be noted that this study relied solely on parental and teacher report. Green et al (1991) found that parental PTSD symptomatology and an irritable and/or depressed family environment were important factors in predicting PTSD symptomatology in children. This relationship was particularly important for the younger children (aged 2-7 years).

Other studies have noted the impact of the disruption of community life (Galante & Foa, 1986) on children and Yule (1992) found more positive outcome in a school which had held debriefing sessions following a shipping disaster compared to a similar school which had tried to avoid talking about the traumatic event.

Section 4: CONCLUSION

This review has highlighted a number of methodological difficulties associated with conducting research in this field. One complex issue is defining terms such as “traumatic event”. Whilst some events would instinctively be described as “traumatic” and others as “distressing” or “stressful” there would appear to be a considerable grey area between the
two. Perhaps aiming to determine a clear dividing line between the two is an illusory goal and a more profitable approach would be to try to identify what characteristics of events make them more or less traumatic for children in general and for particular individuals.

The issues of measuring severity of trauma, outcome and pre-morbid function are also fraught with difficulties. All assessment tools have their limitations and consequently the best approach would appear to be using multi-method assessment for each aspect. Thus the results obtained on any one measure could be compared with results from other measures.

Moving on to theoretical issues, whilst most researchers would now seem to agree that children can develop PTSD, debate still exists regarding symptom profiles. Whilst there is clear evidence of both avoidance and increased arousal in children following traumatic events, researchers disagree as to whether children show the full range of re-experiencing phenomena observed in adults. One of the difficulties in resolving this issue is again a lack of clarity in the definitions used.

Within the child literature there is a paucity of studies addressing theoretical issues and testing specific hypotheses in a controlled way. The studies which were found tested only limited aspects of the conditioning and information processing models. Whilst these studies showed promising results there is a necessity for far more work before any conclusions can be drawn regarding the applicability of adult models to children's reactions. However, there is evidence to suggest that some of the factors which influence outcome in adults, such as levels of exposure and quality of the recovery environment, are also important for children. There are also additional factors which need to be considered in children such as the child's age.

Thus there would appear to be a number of issues in this field which are worthy of further investigation. There is still a need to clarify symptom profiles seen in children after traumatic events and to explore the impact of age and severity on these. In general there is a need for more studies testing hypotheses derived from theoretical models of PTSD. The work on appraisal and coping styles has produced some interesting result and this is an area which could usefully be explored. Similarly, there is scope for more work in looking at the impact of systemic factors and social support on recovery and vulnerability. Such studies are vital if clinicians are to understand how they can best help children in the aftermath of traumatic events.
REFERENCES


APPENDIX 1: DEFINITIONS OF A TRAUMATIC EVENT

"The essential feature is the development of characteristic symptoms following a psychologically traumatic event that is generally outside the range of normal human experience....................The stressor producing this syndrome would evoke significant symptoms of distress in most people, and is outside the range of such common experiences as simple bereavement, chronic illness, business losses or marital conflict."

Taken from: DSMIII (1980).

"The person has experienced an event that is outside the range of usual human experience and that would be markedly distressing to almost anyone (e.g. serious threat to one’s life or physical integrity, serious threat or harm to one’s children, spouse or other close relatives or friends; sudden destruction of one’s home or community; or seeing another person who has recently been, or is being, seriously injured or killed as a result of an accident or physical violence.”

Taken from: DSMIIIR (1987)

"The person has been exposed to a traumatic event in which both the following were present: the person experienced, witnessed or was confronted with an event or events that involved actual or threatened death or serious injury, or threat to the physical integrity of self or others and the person’s response involved intense fear, helplessness or horror (note in children this may be expressed instead by disorganised behaviour.”

Taken from: DSMIV (1994)
SMALL SCALE RESEARCH
PROJECT CONDUCTED ON
CLINICAL PLACEMENT

YEAR 2

PSYCH.D.
ABSTRACT

The primary aim of this study was to develop a measure for assessing user satisfaction amongst a group of people with learning disabilities attending a specialist day care facility. This process was informed by the existing literature on interviewing people with learning disabilities and by consultation with the multi-disciplinary team at the day care facility. A second aim was to explore the reliability of the information collected and to investigate the impact of verbal ability on reliability. 15 people, with a wide range of degrees of intellectual impairment and communication difficulties, participated in the study. The results suggested that although the views expressed were largely positive, people were able to express a range of opinions. Preliminary data on reliability and the impact of verbal ability are reported and areas for further investigation delineated.
AN INVESTIGATION OF USER SATISFACTION WITH A SPECIALIST DAY CARE FACILITY FOR PEOPLE WITH LEARNING DISABILITIES

1. INTRODUCTION

Over the past few years there has been an increasing emphasis within the National Health Service on user satisfaction with the services they receive, usually as part of a broader evaluation of the quality of service provision. A number of authors have stressed the importance of extending this endeavour to include people with learning disabilities. This is partly in keeping with the philosophy of normalisation/social role valorisation (Wolfensberger, 1983) but also because it is acknowledged that it is only service users who can evaluate some aspects of a service (Crocker, 1990; Dagnan, Dennis & Wood, 1994). The problems associated with conducting user satisfaction surveys with the non-learning disabled population have been explored extensively in the literature (see for example, Lebow, 1982; Larsen, Attkisson, Hargreaves & Nguyen, 1979). However, there are additional factors that need to be considered for the learning disabled population, particularly people with severe learning disabilities, communication problems and/or physical disabilities.

The primary aim of this project was to develop a measure, which could be used to assess user satisfaction amongst a group of people attending a specialist day facility for people with learning disabilities. This sample included people with a wide range of intellectual abilities and communication skills. The measure was developed with reference to the existing literature and in close consultation with the multi-disciplinary team at the day care facility.

The second aim of the project was to assess the reliability of the information obtained using this measure and to explore the impact of verbal ability on reliability. The emphasis of this paper is methodological; the service recommendations made on the basis of this study and a related project with carers are covered in the associated Audit Report.
2. FACTORS WHICH NEED TO BE TAKEN INTO ACCOUNT IN DEVELOPING A MEASURE OF USER SATISFACTION FOR PEOPLE WITH LEARNING DISABILITIES

2.1. The nature of the client group imposes limitations on the type of methodology that can be used

Lebow (1982) has reviewed the main methods of assessing user satisfaction amongst the non-learning disabled population and their associated strengths and weaknesses. However, many of the methods he describes could not be used with people with learning disabilities because of the nature of the client group. For example, measuring rates of service use or attendance is unlikely to provide useful information where clients are heavily dependent upon and influenced by carers in attending services. Whilst the advocacy movement has stressed the importance of encouraging people with learning disabilities to express their opinions, spontaneous expression of complaints or compliments are still likely to be infrequent.

Amongst the non-learning disabled population, surveys using written questionnaires or interviews are commonly used. These have the advantage that the aim of the project is clearly stated and the desired information is directly accessed, thus facilitating interpretation of results. However, amongst people with learning disabilities, using written or postal questionnaires is likely to introduce sample biases given the variable literacy rates for this group.

Some authors have used postal or telephone questionnaires to assess the satisfaction of referrers (Dagnan, Jones & McEvoy, 1993; Jenkins & Grey, 1994) or parents (Justice & McBee, 1978) with the services used. Whilst such surveys provide some useful information on others’ views of the quality of services, they should be regarded as complementary to attempts to directly access the views of people with learning disabilities. These users may have very different views to their carers or families.

Many studies of user satisfaction, including the present study, have used an interview based methodology. As Lebow (1982) noted, even with the non-learning disabled population, obtaining valid and reliable information using interviews can be problematic. Many of the difficulties he cites are even more pronounced for people with learning disabilities. For example, Lebow points out that biases in the sample can arise in terms of those initially approached to participate and / or those who choose to respond. The respondent sample may
not be representative of the broader population and the views they express may not accurately reflect the views of the population. Within the learning disability literature, the difficulties of accessing the views of people with severe learning disabilities or communication difficulties are often side-stepped by interviewing parents or carers instead (Lowe, 1992; Jenkins & Grey, 1994) or by only including people who are judged as having adequate communication skills or an I.Q. above an identified criterion (Ballinger, 1973; O’Donnell, 1976; Heath Jnr, Hultberg, Ramey & Ries, 1984; Flynn & Saleem, 1986; Lowe & De Paiva, 1988; Foote & Rose, 1993). However, there is no evidence to suggest that parents or carers views adequately represent the views of people with learning disabilities or that the views of more able clients are representative of the learning disabled population as a whole.

Lebow (1982) notes that reliability and validity of information can be jeopardised where there is a lack of clarity amongst respondents regarding the meaning of terms used in the project. This is likely to be particularly marked amongst people with learning disabilities given that many have both expressive and receptive communication difficulties. Clearly this can impact upon understanding the purpose of the project and ensuring meaningful consent to participation. Difficulties may also arise around understanding the meaning of particular questions. Expressive difficulties can impact on the person’s capacity to communicate their views and on the interviewer’s ability to understand the information conveyed.

2.2. The literature on interviewing people with learning disabilities suggests that a number of response biases are in operation and are more pronounced amongst people with more severe learning disabilities

Lebow (1982) has noted that a number of processes such as acquiescence and suggestibility can operate within interviews to bias the responses given and reduce the reliability and validity of information obtained. Although these processes occur within the non-learning disabled population, the literature suggests that specific biases are more pronounced amongst people with learning disabilities.

Atkinson (1988) highlights the fact that people with learning disabilities, particularly those from an institutionalised background, are particularly likely to try to please the interviewer through their responses. She also stresses the need to consider the participants’ perceptions of the project. For example, do they view it as some kind of test? Do they fear the consequences
of expressing negative views on a service? Wright and Roy (1991) noted in their study that participants were fearful of service reduction if their views were identified.

Acquiescence has been defined as the tendency to say “Yes” to a question, regardless of its content. Sigelman and colleagues, in a series of studies, have explored this process amongst people with a range of learning disabilities from both community and institutional backgrounds. Sigelman, Schoenrock, Spanhel, Hromas, Winer, Budd and Martin (1980) conducted interviews with three samples of adults and children representing a range of degrees of learning disability from mild to profound. Interviews consisted of 22 questions of different types (16 yes/no; 2 either/or; 1 multiple choice and 3 open ended) which were largely factual in nature. Quality of response was coded using a 9-category system; acquiescence was checked using one reversed question and response validity was measured by checking agreement with a knowledgeable non-disabled informant. Overall, the results suggested that people with higher levels of intellectual functioning were better able to answer questions, were more likely to provide information consistent with the other informant and were less likely to acquiesce. Amongst more severely disabled participants, acquiescence was higher and information was less likely to accord with the other informant. However, this could have been due in part to biases introduced by the high levels of acquiescence. Although asking an informant may be an adequate test of validity when factual questions are being asked, it is less clear that this is the case when the questions require subjective responses.

Sigelman, Budd, Spanhel and Schoenrock (1981) explored acquiescence biases amongst people with learning disabilities in more detail using two reversed pairs of questions embedded within a longer interview. They found that across the three samples 40-50% acquiesced by saying “Yes” to both the original question and the reverse. As in the 1980 study, acquiescence was higher amongst respondents with a more severe degree of learning disability, although this was significant only on the questions pertaining to emotions. The second part of the study included only those who were more difficult to interview. Five pairs of reversed questions were used, including both subjective and factual questions. It was noted that the rate of acquiescence was very variable depending on the question pair (20% - 83.3%). However, this did not appear to be related to whether the question was factual or subjective. Acquiescence was also assessed by asking questions to which the correct response was negative. Again rates of acquiescence were very variable (28% to 73.1%). Acquiescence was lowest where the response relied on information that was immediate and concrete (i.e. an inquiry about the
weather) and highest where questions were difficult to understand or the information required for the response was less accessible.

Although it has been argued that the artificial content and context of these interviews may have led to an overestimation of response bias in people with mild and moderate learning disabilities (Dagnan & Ruddick, 1995), clearly the construction of any interview protocol for use with people with learning disabilities needs to ensure that acquiescence is minimised.

A related phenomenon of "nay-saying", that is responding "No" to negatively worded questions (Budd, Sigelman & Sigelman, 1981) has also been observed in the literature. Shaw and Budd (1982) investigated this process by asking participants to answer two questions ("Is it against the rules to ....?" and "Are you allowed to ....?) about each of a list of behaviours which varied in their desirability. As found in earlier studies, levels of acquiescence and nay-saying increased amongst those with a more severe degree of learning disability. Nay-saying occurred more frequently for prohibited behaviour whereas acquiescence occurred more frequently for desirable behaviour. Thus, they suggested that "intellectual limitations predispose respondents to biased responding," and "social desirability determines the direction of bias".

Gudjonsson (1988; 1990) has also highlighted the prevalence of suggestibility amongst people with learning disabilities. Suggestibility is the modification of a reply in response to cues contained in the question or in the circumstances under which the question was asked. For example, indirect pressure to modify an answer can be applied by repeating a question several times. Using a scale designed to measure two types of suggestibility, namely "yielding" to suggestive questioning and "shifting" answers following negative feedback, Gudjonsson (1988; 1990) found evidence of a negative correlation between I.Q. and suggestibility. This relationship is non-linear in that intelligence appears only to exert a major effect for those whose I.Q. is below average. As this is clearly the case with people with learning disabilities, user satisfaction surveys with this group need to take into account the possibility of suggestibility when devising instructions and interview formats.

Given these findings, any measure designed to assess the opinions of people with learning disabilities must aim to minimise response biases, for example through consideration of how the project is presented to participants, and to ensure that the study includes checks for the
extent of biases. One strategy for minimising the extent of response bias is the selection of suitable question types.

2.3. Choice of question type has been shown to influence both rates of response and response bias

Several studies (e.g. Crocker, 1989; Sigelman, Budd, Winer, Schoenrock & Martin, 1982; Dagnan, Dennis & Wood, 1994) have explored the interaction between question type, responsiveness (i.e. percentage of people able to respond to questions), response bias and reliability. The ideal question type would maximise responsiveness, minimise response bias and maximise reliability and validity.

Sigelman, Budd, Winer, Schoenrock and Martin (1982) evaluated different question types along the following categories:

- responsiveness: coded using a nine category system;
- agreement with non-disabled informants: this provided a measure of response validity and is likely to be accurate given that the questions asked were factual in nature;
- freedom from systematic response bias: assessed by comparing responses to alternative question formats eliciting the same information.

A comparison of open-ended questions with open-ended questions combined with example responses suggested that including examples failed to increase responsiveness and slightly reduced agreement. There was also evidence for the introduction of response bias in that respondents were more likely to refer to the exemplar in their response. Open-ended questions were also compared with open-ended questions combined with probes, specifically asking “What else?” until no more answers were given. Responsiveness was the same for both types of open-ended questions. However, the use of probes led to an increase in inconsistencies and on occasions meaningless and irrelevant answers were given. It would appear that this was an example of suggestibility in operation in that respondents seemed to be “yielding” to suggestive questioning in both cases.

A comparison of open-ended questions with Yes-No checklists suggested that Yes-No checklists produced good levels of responsiveness. However, respondents also tended to acquiesce with the Yes-No format and this produced an associated decline in agreement with informants. Open-ended questions were also compared with verbal and pictorial multiple
choice formats. Responsiveness was excellent for both types of multiple choice format (100% pictorial and 94.5% verbal) and was significantly better than for open-ended questions. There was also good consistency with informants and across question type. There was no evidence of systematic bias.

On the basis of their results the authors recommended the use of multiple choice formats. However, some caution needs to be exercised when interpreting Sigelman et al’s results. Firstly, the questions used were largely factual and it is not clear whether similar results would have been obtained using subjective questions designed to access opinions. No account was taken of the effects of suggestibility. Alternative question formats were evaluated in two sessions one week apart. Participants could have interpreted the need for a second interview as indicative of the fact that their first answers were “wrong” and therefore modified their second responses.

2.4. Use of pictures also reduces verbal demands and minimises response biases

A number of authors have suggested that the use of pictures may reduce the verbal loading of questions, facilitating comprehension of the question being asked and also providing an option for participants to respond using a non-verbal method. Thus, people with a wider range of communication skills may be able to participate. It has also been suggested that use of pictures can minimise response biases thus improving the reliability and validity of information obtained.

Sigelman and Budd (1986) explored the impact of the use of pictures on the ability of adults and children with a range of intellectual impairments to answer factual questions in three different formats (Yes - No; Multiple choice; and Either - Or). They found that using pictures significantly increased responsiveness on multiple choice formats although they also noted a slight decline in levels of agreement with a non-disabled informant. With the Either-Or format, pictures produced a significant improvement in responsiveness, a slight (non-significant) increase in agreement with a non-disabled informant and reduced the tendency to select the last item, which had been noticed in some studies. Thus, for multiple choice and Either-Or formats, use of pictures resulted in improved rates of response without having a marked detrimental effect on validity and reliability.
Wadsworth and Harper (1991) compared test/re-test reliability for verbal and pictorial presentations of Either-Or questions with a group of adults with moderate learning disabilities. The questions used came from the Sheltered Care Environmental Scale (Moos, 1988) which consists of three sub-scales, evaluating different aspects of the social climate of residential facilities from the individual’s perspective. Participants were asked the questions on four occasions, twice for each format. Question presentations were conducted with a one-week gap between each interview. They found that use of pictures produced a significant improvement in re-test reliability for one of the three sub-scales and levels of reliability on all three sub-scales, presented in pictorial form, were adequate. No attempt was made to evaluate the validity of the responses obtained or to control for the effects of suggestibility due to repeated question presentation.

March (1992) explored the use of photographs as an aid for people with severe learning disabilities responding to Either-Or questions regarding choice of activities and factual information. Although they only had a small sample (n=15), their results did suggest that the use of photographs had a beneficial effect. Both responsiveness and intelligibility of responses was improved using photographs. There was some evidence that use of photographs reduced the tendency to select the second response choice. In the factual condition, more questions were answered correctly when photographs were used. However, it was acknowledged that it was difficult to evaluate the validity of the responses on the items looking at preferences for activities. Using photographs did not increase level of agreement with staff in this condition but it was not possible to evaluate whether staff had an accurate appreciation of clients’ preferences. The authors acknowledged that obtaining a clear, intelligible response to a question about activity choice could not be interpreted as evidence that participants had understood and responded to the question they had been asked.

Thus, it would appear that pictorial cues, used with Either-Or formats, can reduce selection bias and increase responsiveness for people with moderate and severe learning disabilities. The impact on validity is not entirely clear from the available results.

2.5. Collection of quantitative / ordinal data is advisable
Many of the studies of user satisfaction amongst people with learning disabilities have collected only nominal data. However, in order to be able to measure change in satisfaction
over time, for example after the implementation of improvements suggested by participants, collection of quantitative, ordinal level data is essential.

Dagnan, Dennis and Wood (1994) and Dagnan and Ruddick (1995) have explored the use of a number of question formats to obtain ordinal data, specifically:

- Either-Or questions presented with pictures: reliability being assessed by repeating questions at the end of the interview with the pictures reversed to control for position effects;
- Visual analogue scales: reliability being assessed by repeating the analogues with the anchors reversed at the end of the interview;
- A three point personal questionnaire developed by Shapiro (1961). (See Section 3.2.3 for full description). This format includes an inherent reliability check. It was not clear whether this format had been combined with pictures.

Dagnan et al (1994) reported on the use of these question formats amongst a small sample (n=11) of people with learning disabilities all of whom had “reasonable verbal skills” (as determined by scores on the British Picture Vocabulary Scale (BPVS), Dunn, Dunn, Whetton & Pintilie, 1982). Reliabilities for the first and last format were presented as percentage of people who responded consistently. This ranged between 73% and 100% according to format and response but was generally nearer 100%. Pearson’s R correlations for the two presentations of the analogue ranged between 0.52 and 0.71. No differences in language ability were found between those who responded consistently and those who did not for any of the formats. However, the sample only showed limited variation in language ability.

Looking at the response patterns on the different formats some interesting points emerge. On Either - Or formats, the majority of people consistently adopted the positive option. It could be argued that people with learning disabilities are influenced by a desire to please and consequently avoid opting for purely negative options. Another explanation is that people were genuinely satisfied with the service they received. On the analogue scales, responses tended to be on the positive side of the mean but a much wider range of responses were given. Thus, analogue scales would appear to be a more effective tool for eliciting a range of opinions. The personal questionnaire format also elicited a range of responses.
Dagnan and Ruddick (1995) reported on an extension of the original project during which they interviewed 29 people with learning disabilities, identified by professionals as being "able to offer their views on services". A more precise definition of inclusion criteria was not included. This group all had mild- moderate learning disabilities. Using the analogue format, 25 people were able to respond. Re-test reliabilities, obtained by repeating the questions at the end of the interview, with the anchors reversed, varied between 0.40 and 0.80 with two of the three coefficients being statistically significant. There was some suggestion of a ceiling effect operating with the analogue responses. No differences were found in BPVS scores for those who were and those who were not able to respond consistently. Using the personal questionnaire 27 people were able to respond. Over 75% of people who responded showed consistent responses on this format. On two of the questions, differences in BPVS scores between those who responded consistently and those who did not, were statistically significant. The difference was not significant on the other question.

It was noted that for the personal questionnaire there was a tendency for people with more developed language skills to be able to use the format more successfully. With the analogue scales, which relied less on language skills, no such pattern was observed.

Thus, there is evidence that both visual analogue and personal questionnaire formats can be used to elicit reasonably reliable, ordinal level data from people with mild to moderate learning disabilities. Although responses do seem to be predominantly positive, there is some evidence that these formats encourage respondents to express a variety of opinions. No information exists as to the use of these formats with people with more severe learning disabilities.

2.6. Summary
The primary aim of the study was to develop and evaluate a tool, which could be used to assess user satisfaction with a specialist day facility for people with learning disabilities. The development of the measure used in the study was guided by the following considerations:

1. The limitations placed upon the methodology used by the nature of the client group. In this case a semi - structured interview seemed most appropriate;
2. Given the prevalence of response biases, particularly amongst people with more severe learning disabilities, care needs to be taken to minimise and control for response biases. This was achieved by consideration of the context of the interview and the question formats used;

3. Use of pictures seems to be beneficial in minimising the verbal skills required to participate, increasing responsiveness and reducing response bias. Therefore pictorial presentation formats were used here;

4. Collection of quantitative, ordinal level data was desirable so that change over time could be evaluated. Therefore, in this study formats providing ordinal level data were used.

Given the above considerations, modified versions of the visual analogue and personal questionnaire formats combined with pictorial cues formed were used. However, this study extended earlier work by Dagnan and Ruddick (1995) with these formats, firstly, by asking questions on a broader range of topics and secondly, by including participants with a broader range of learning disabilities.

Another of the aims of the study was to explore the impact of verbal ability on reliability of responses obtained using the different question formats. It was hypothesised that given Dagnan and Ruddick’s (1994, 1995) findings, verbal ability would be related to ability to respond consistently to the personal questionnaire. It was also hypothesised that such an effect would also emerge for the visual analogue scales if participants with a wider range of abilities were involved as was the case in this study.

3. METHOD

3.1. Participants
All participants attended a small, specialist health service resource, the Day Unit, for adults with learning disabilities and additional problems, including behavioural problems and mental health difficulties. Clients attending the Day Unit required an intensive, specialist service in order to facilitate their integration into mainstream day services. Thus, they were not representative of the broader population of people with learning disabilities.
All the people attending the Day Unit at the time were offered the opportunity to participate in the project. There were no refusals although two participants indicated that they wished to leave before the end of the interview. One person left after two items and the other left halfway through the second presentation of the visual analogue scales. In total 15 adults were interviewed, nine men and six women. The median age of the group was 27, range 20 to 59. BPVS (Short Form) scores were obtained for 11 of the participants; 3 participants were untestable with the BPVS and 1 participant was not available for testing. For those subjects who were testable with the BPVS, the median raw score was 12 and the range 2 to 21. Details of degree of intellectual impairment (where available), additional diagnoses and any other relevant information were obtained from participants’ files. Appendix 1 includes full details of age, level of intellectual impairment, communication skills and additional difficulties for each participant.

3.2. Development of measure used in the project

During the early stages of the project, the multi-disciplinary and staff team at the Day Unit were consulted as to the issues they would like the project to address. Previous surveys have sometimes noted resistance (McAuliffe & MacLachlan, 1992) or mixed feelings (Spencer, 1995) amongst staff towards user satisfaction surveys, and it was hoped to minimise this by involving staff at all stages. In addition, staff and professionals were familiar with the day to day running of the Day Unit and could therefore advise on which aspects should be included in the evaluation.

Many of the topics suggested at this early stage were very general and were subsequently broken down into more precise and concrete questions. The topic areas identified were:

- Activities;
- Environment;
- Timing;
- Staff and professional input;
- Food and drink;
- Overall ratings.

As the literature suggests that use of pictures and symbols is a useful tool to facilitate responsiveness and understanding, photographs and symbols to represent each topic were collected. The symbols were those already in use, for example in daily timetables, in the Day
Unit. Photographs of people and rooms were employed, as there were no symbols in use for these. During the interviews, these pictorial cues were used to introduce each topic and were left on the table and frequently referred back to as an aid to focus attention on the topic being discussed.

Choice of question formats was guided by the considerations delineated earlier. Given that a number of authors have recommended the use of multiple question types, three types of questions were used in each topic area. It was also hoped that asking questions in more than one format would allow for some exploration of response validity. However, asking repeated questions about the same topic risks the introduction of biases due to suggestibility.

The question formats used were:

3.2.1. Open ended questions: These were used only with more verbally able participants. These participants were identified informally during interviews on the basis of verbal response quality and level of co-operation. BPVS score was not employed because some of the participants in the sample whilst showing reasonably high scores on the BPVS (a measure of receptive language skill) were restricted in their use of speech. These questions provided an opportunity for any additional comments to be made and an opportunity for participants to raise issues not covered in the main part of the interview. Whilst only asking these questions to a select group of clients may have introduced bias, practically it was not possible for all participants to be asked these questions as many participants had extremely limited expressive skills. Six of the participants were asked the open ended questions.

3.2.2. Analogue scales with pictorial anchors: Dagnan and Ruddick (1995) used analogue scales successfully with participants with mild to moderate learning disabilities but no studies have evaluated their use with people with severe learning disabilities. Dagnan and Ruddick also only asked questions about a limited number of areas. Here a modified version of the format used by Dagnan and Ruddick was employed and questions were asked about a broader range of topics. Participants were presented with a ten-centimetre line, with a symbol and phrase at each end. The symbols and phrases used were selected in consultation with the Speech and Language Therapist working at the day care unit. The criteria guiding selection were that the phrases and symbols would be in common use in the day care unit and, as such, were already familiar and more likely to be meaningful to
participants; and the anchors allowed for expression of a range of views, both positive and negative.

Each participant was asked to indicate the point on the line which best represented their views about that topic. Responses could be indicated solely by pointing. For scoring purposes, the line was divided into one-centimetre sections, which were numbered one to ten.

As in Dagnan and Ruddick's study, the analogue scales were repeated at the end of the interview as a measure of response reliability. Participants were told that this was "to see if they still thought the same". These instructions attempted to minimise the effects of suggestibility. For this second presentation, the position of the anchors was reversed to control for position bias and scoring was corrected to allow for scale reversal.

3.2.3. Three point personal questionnaire:

This format was originally developed by Shapiro (1961) and was used by Dagnan and Ruddick (1995) with people with mild to moderate learning disabilities. However, they used verbal presentation and response formats and again only a limited number of questions were asked. In the present study, verbal presentation was combined with symbols. Participants could indicate their response solely by pointing if they wished, thereby minimising the verbal skills required to use this format.

Participants were presented with three consecutive pairs of responses to a particular question, e.g. very good / very bad; very bad / O.K.; and O.K. / very good. As with the Visual Analogue Scales, the symbols and phrases used were selected in consultation with the Speech and Language Therapist. Again familiar phrases and symbols were used and the options allowed for expression of a range of positive and negative views.

Pairs of response options were presented simultaneously in verbal and pictorial forms. For each pair the participant indicated which of the options best reflected their views, by pointing to the relevant symbol or by answering verbally.

The format was designed to control for position bias and contained an inherent reliability check. Thus, it did not need to be repeated.
With this format, if participants respond consistently, their responses can be converted into a four-point scale. For example, if the participant selects very good- O.K. - very good from the three response pairs, this is converted into a score of 4, indicating this area of the service is considered to be very good. If the participant selects: very good- O.K. - O.K., this is converted into a score of 3, indicating that this aspect of the service is O.K.. If the participant selects: very bad- O.K. - O.K., this is converted into a score of 2, indicating a more negative view of this aspect of the service. Finally, if the participant selects: very bad- very bad – O.K., this is converted into a score of 1, indicating a negative appraisal of this aspect of the service. Any other combination of responses can be considered inconsistent and is not scored.

A copy of the interview protocol and rating scales used is included in Appendix 2. It should be noted that due to different patterns of days of attendance and professional involvement with participants, the number of questions directed to particular participants varied. Hence the variable numbers of responses to different questions.

3.3. Interview
Interviews were conducted either at the Day Unit (in 13 cases) or at the person’s home (in two cases). The confidential nature of the interview was stressed and it was made clear that participants could end the interview at any time. Full details of instructions and consent procedures are provided in Appendix 3. It was made clear that the interviewer, a trainee Clinical Psychologist, was not attached to the day care unit. In two cases a third person was present for the interview. A member of staff at a residential unit, not associated with the day care unit, was present during one interview for the safety of the interviewer. They made no interventions during the interview. Another participant spoke only limited English having only been resident in this country for about a year. An independent interpreter was present for this interview. The importance of precise translation for the purposes of research was stressed although it is acknowledged that translation may have introduced biases. All interviews were taped and lasted between ten and thirty minutes.

4. RESULTS
The results section will focus on results obtained using the visual analogue and personal questionnaire formats. A fuller discussion of answers to the open ended questions can be found in the Audit Report. Throughout all the tables in this section professionals are identified by the letters A, B and C in order to maintain anonymity.
4.1. Visual analogue scales with pictorial anchors:

All participants responded to at least one of the analogue scale items. However, response rates varied across questions between 78.6% and 100%, with a mean responsiveness rate of 90.1%. In some cases responses were not clear, for example one participant swept their hand over the scale but it was not clear where they were pointing. A summary of response rates for each question including incidents of refusal/no response and cases where the response was not clear is included in Table 1. Table 2 shows a summary of the median and range of responses obtained on each question. The opinions expressed were largely but not exclusively positive suggesting that participants to some extent felt able to express negative views about the service.

Two measures of test-retest reliability were used. Firstly, Kendall’s Tau was calculated between the ratings obtained for the first and second presentations of each question. This non-parametric test was selected because of the small size of the sample and the ordinal nature of the data (McCormack, De L. Home & Sheather, 1988; Breakwell, Hammond, Fife-Schaw, 1995). Statistical analysis was conducted using SPSS for Windows 5.1. A significance level of p<0.05 was used, balancing the considerations of repeated statistical tests with the small sample size. As can be seen from the results in Table 3, only two of the analyses, for the Users’ Group and Quiet Room, reached statistical significance (p<0.05).

A second, less stringent, estimate of reliability was obtained by calculating the amount of agreement/disagreement between responses on the first and second presentations. The results are summarised in Table 3. Consistent responding was defined as a difference of either 0 or 1 point between first and second presentations; inconsistent responding was defined as a difference of 2 points or more between the first and second presentation. Approximately 62% of people, an average across questions, gave responses which met the criteria for consistent responding. Any consideration of the significance of this finding needs to take into account the levels of agreement which would be expected to occur by chance. The probability of chance consistent responding for any one individual was calculated to be 0.28. Thus the probability of a consistent responses in b cases can be calculated using the following formula, derived from the formula for Binomial coefficients (Freund, 1988):

\[ p = \frac{b!}{a! (b-a)!} \alpha^b (1-\alpha)^{(b-a)} \]

\[ \alpha = 0.28 \quad b = 0.72 \]
Using this formula, for each of the questions the probability of the obtained level of consistent responding occurring by chance was calculated. The level of significance was set at $p < 0.05$ balancing the small size of the sample against the fact that a large number of tests were being performed. The results are shown in Table 4. As can be seen from Table 4, the levels of consistency obtained on nine of the questions (Outings, Users' group, Main room, Quiet room, Kitchen, Craft room, Staff, Professional group C and Food and drink) were significantly above what would be predicted by chance ($p < 0.05$).

More detailed inspection of cases of inconsistencies between responses to the first and second presentations suggested that, across all items, 56.6% of cases of inconsistent responding were due to a bias towards selection of the right hand anchor. All other cases of inconsistent responding appeared to be due to chance pointing at the scale.

A further aim of the study was to explore the impact of verbal ability on consistency of response. Descriptive statistics for BPVS scores for items presented to all participants are included in Table 5. While the median BPVS raw scores are higher for consistent responders compared with inconsistent responders, it should be noted there is considerable overlap between consistent and inconsistent responders when the range of BPVS scores is considered. To test the hypothesis that consistent responders would have higher levels of verbal ability than inconsistent responders, a series of Mann Whitney tests were performed on the data for questions in which $n=3$ or greater in both cells (Siegel & Castellan, 1988). Again the significance level was set at $p < 0.05$ balancing sample size with repeated statistical tests. The Mann Whitney tests, corrected for ties, indicated no significant differences in BPVS scores between the two groups for any of the questions (Outings: $U=5$, $n=9$, $p=0.217$, n.s.; Skills building: $U=10$, $n=10$, $p=0.599$, n.s.; Main room: $U=7$, $n=10$, $p=0.422$, n.s.; Kitchen: $U=6$, $n=10$, $p=0.198$, n.s.; Staff: $U=6$, $n=10$, $p=0.302$, n.s.; Overall: $U=6$, $n=10$, $p=0.198$, n.s.).
**TABLE 1**

**RESPONSE RATES ON VISUAL ANALOGUE SCALES FOR EACH QUESTION**

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Topic</th>
<th>Number of people showing any response/Number of people presented with question (response rate)</th>
<th>Number of cases where response not clear</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Outings</td>
<td>12/15 (80%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Skills Building</td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Monday Group</td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Tuesday Group</td>
<td>7/7 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>7/7 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Users' Group</td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Main Room</td>
<td>13/14 (92.9%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Quiet Room</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Kitchen</td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Craft Room</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/13 (92.3%)</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>Staff</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/13 (84.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Profession A</td>
<td>1/2</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>1/2</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Profession B</td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Profession C</td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Food &amp; Drink</td>
<td>12/14 (85.7%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/13 (84.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Overall</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/13 (92.3%)</td>
<td>0</td>
</tr>
</tbody>
</table>

Key to column 1
1 = 1st presentation
2 = 2nd presentation
**TABLE 2**

**MEDIAN AND RANGE OF RESPONSES ON VISUAL ANALOGUE SCALES**

<table>
<thead>
<tr>
<th>Presentation</th>
<th>Topic</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Outings</td>
<td>10</td>
<td>3-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>9</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Skills Building</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Monday Group</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>8</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Tuesday Group</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Users' Group</td>
<td>10</td>
<td>6-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>6-10</td>
</tr>
<tr>
<td>1</td>
<td>Main Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Quiet Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>8</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Kitchen</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Craft Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Staff</td>
<td>10</td>
<td>3-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
</tbody>
</table>
| 1            | Profession A     | 4      | 4}*
| 2            |                  | 4      | 4} small number of responses |
| 1            | Profession B     | 10     | 3-10   |
| 2            |                  | 10     | 10     |
| 1            | Profession C     | 10     | 10     |
| 2            |                  | 10     | 1-10   |
| 1            | Food & Drink     | 10     | 5-10   |
| 2            |                  | 10     | 1-10   |
| 1            | Overall          | 10     | 1-10   |
| 2            |                  | 7      | 1-10   |

Key to column 1

1 = 1st presentation

2 = 2nd presentation

*Based on very small number of responses*
<table>
<thead>
<tr>
<th>Topic</th>
<th>Kendall's Tau</th>
<th>No of cases of identical responses on both trials</th>
<th>No of cases where Responses differed by 1 point</th>
<th>No of cases where Responses differed by 2 points</th>
<th>No of cases where responses differed by 3 points</th>
<th>No. of cases of consistent response / No. of cases where a clear response was obtained on both trials (% consistency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings (n=11)</td>
<td>-0.059</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>6/11 (54.5%)</td>
</tr>
<tr>
<td>Skills Building (n=10)</td>
<td>-0.043</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>5/10 (50%)</td>
</tr>
<tr>
<td>Monday Group (n=6)</td>
<td>Calculation not Possible</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3/6 (50%)</td>
</tr>
<tr>
<td>Tuesday Group (n=7)</td>
<td>Calculation not Possible</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4/7 (57.1%)</td>
</tr>
<tr>
<td>Users' Group (n=6)</td>
<td>1.000</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6/6 (100%)</td>
</tr>
<tr>
<td>Main Room (n=11)</td>
<td>0.528</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>7/11 (63.6%)</td>
</tr>
<tr>
<td>Quiet Room (n=12)</td>
<td>0.556</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>9/12 (75%)</td>
</tr>
<tr>
<td>Kitchen (n=11)</td>
<td>0.374</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6/11 (54.5%)</td>
</tr>
<tr>
<td>Craft Room (n=11)</td>
<td>0.530</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>8/11 (72.7%)</td>
</tr>
<tr>
<td>Staff (n=11)</td>
<td>0.454</td>
<td>7</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>7/11 (63.6%)</td>
</tr>
<tr>
<td>A (n=1)</td>
<td>Calculation not possible</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1/1</td>
</tr>
<tr>
<td>B (n=3)</td>
<td>Calculation not possible</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2/3</td>
</tr>
<tr>
<td>C (n=4)</td>
<td>Calculation not possible</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3/4</td>
</tr>
<tr>
<td>Food &amp; Drink (n=10)</td>
<td>0.375</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>8/10 (80%)</td>
</tr>
<tr>
<td>Overall (n=12)</td>
<td>0.068</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6/12 (50%)</td>
</tr>
<tr>
<td>Topic</td>
<td>No. of consistent responses / No. of clear responses on both trials</td>
<td>Probability of this number of consistent responses or greater occurring by chance</td>
<td>Significant at p &lt;0.05</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------------------------------------------------------</td>
<td>---------------------------------------------------------------------------------</td>
<td>-----------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Outings</td>
<td>6/11</td>
<td>3.6%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skills building</td>
<td>5/10</td>
<td>9.74%</td>
<td>No</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Monday group</td>
<td>3/6</td>
<td>24.5%</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tuesday group</td>
<td>4/7</td>
<td>8.7%</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Users' group</td>
<td>6/6</td>
<td>0.04%</td>
<td>Yes</td>
<td></td>
<td></td>
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<tr>
<td>Main room</td>
<td>7/11</td>
<td>0.6%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quiet room</td>
<td>9/12</td>
<td>0.02%</td>
<td>Yes</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Kitchen</td>
<td>6/11</td>
<td>3.6%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Craft room</td>
<td>8/11</td>
<td>0.07%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff</td>
<td>7/11</td>
<td>0.6%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Profession A</td>
<td>1/1</td>
<td>28.0%</td>
<td>No</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Profession B</td>
<td>2/3</td>
<td>17.6%</td>
<td>No</td>
<td></td>
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</tr>
<tr>
<td>Profession C</td>
<td>3/4</td>
<td>4.7%</td>
<td>Yes</td>
<td></td>
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</tr>
<tr>
<td>Food and drink</td>
<td>8/10</td>
<td>0.02%</td>
<td>Yes</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>6/12</td>
<td>6.1%</td>
<td>No</td>
<td></td>
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</tr>
<tr>
<td>Topic</td>
<td>Consistent Responders</td>
<td>Inconsistent Responders</td>
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</tr>
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<td>-------------</td>
<td>--------------------------------------------------------------------------------------</td>
<td>---------------------------------------------</td>
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</tr>
<tr>
<td>Outings</td>
<td>12; 12; 15; 15; 17; untestable</td>
<td>2; 4; 8; 21</td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Median: 15; Range: 12-17</td>
<td>Median: 6; Range: 2-21</td>
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</tr>
<tr>
<td>Skills Building</td>
<td>12; 12; 14; 15; 15</td>
<td>2; 4; 8; 17; 21</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14; Range: 12-15</td>
<td>Median: 8; Range: 2-21</td>
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<td></td>
</tr>
<tr>
<td>Main Room</td>
<td>8; 12; 12; 14; 15; 15; 17</td>
<td>2; 4; 21</td>
<td></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14; Range: 8-17</td>
<td>Median: 4; Range: 2-21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quiet Room</td>
<td>4; 8; 12; 12; 14; 15; 15; 21; untestable</td>
<td>Median: 9.5; Range: 2-17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 13; Range: 4-21</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Kitchen</td>
<td>12; 12; 14; 15; 15; 17</td>
<td>2; 4; 8; 21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14.5; Range: 8-21</td>
<td>Median: 6; Range: 2-21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Craft Room</td>
<td>8; 12; 12; 14; 15; 15; 17</td>
<td>2; 4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14.5; Range: 8-21</td>
<td>Median: 3; Range: 2-4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff</td>
<td>8; 12; 12; 14; 15; 15; 21</td>
<td>2; 4; 17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14; Range: 8-21</td>
<td>Median: 4; Range: 2-17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Food &amp; drink</td>
<td>2; 4; 12; 12; 14; 15; 15; 21</td>
<td>8; 17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 13; Range: 2-21</td>
<td>Median: 12.5; Range: 8-17</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall</td>
<td>12; 12; 14; 15; 15; 17</td>
<td>2; 4; 8; 21; untestable</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Median: 14.5; Range: 12-17</td>
<td>Median: 6; Range: 2-21</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
4.2. Personal Questionnaire:
A high rate of responsiveness was also obtained with this format, with rates ranging from 85.7% to 100% and a mean responsiveness rate of 96.1%. Table 6 provides a summary of response rates across questions.

It was noted during testing that using this format, no instances of ambiguous responses occurred. Participants either responded or did not. Where they did make a response, it was clear which option they were selecting. This may have been related to the fact that there were only two options to choose between.

Table 6 also provides a summary of the percentages of people responding consistently to each question. Generally, lower rates of consistent responding were observed with this format but the rates did vary between questions. Questions on quantity and duration were particularly difficult as would be predicted given that such concepts are difficult for many people with learning disabilities to grasp. Approximately 44% of people, an average across questions, responded consistently.

Closer examination of cases of inconsistent responding across items suggested that in 83.3% cases there was evidence of bias towards selection of the last option, namely the right hand option, regardless of content. In 11.5% cases, there was evidence of a tendency to point to the first response option. In all other cases, participants appeared to be selecting at random.

In cases where consistent responses were obtained, the opinions expressed were largely but not exclusively positive. Thus, it did appear that participants were able to express a variety of views using this format. A summary of this data is included in Table 7.

Tables 8 and 9 provide a summary of descriptive statistics of BPVS scores for consistent and inconsistent responders. Data are only included for questions presented to everyone. Once again although the median for consistent responders is higher than for inconsistent responders, in many cases this difference is small and there is considerable overlap on the BPVS scores obtained in the two groups. A series of Mann Whitney tests was performed on the data for questions in which n=3 or greater for both cells (Siegel & Castellan, 1988). The significance level was once again set at p <0.05 balancing the constraints of sample size and the effect of repeated statistical tests. (Continued on page 180)
TABLE 6
RESPONSE RATES ON PERSONAL QUESTIONNAIRE FOR EACH QUESTION

<table>
<thead>
<tr>
<th>Topic</th>
<th>No. giving any response/No presented with question</th>
<th>No. giving consistent response/No. giving any response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings</td>
<td>14/15 (93.3%)</td>
<td>6/14 (42.9%)</td>
</tr>
<tr>
<td>Skills Building</td>
<td>13/14 (92.9%)</td>
<td>5/13 (38.5%)</td>
</tr>
<tr>
<td>Monday Group</td>
<td>6/6 (100%)</td>
<td>4/6 (66.7%)</td>
</tr>
<tr>
<td>Tuesday Group</td>
<td>7/7 (100%)</td>
<td>4/7 (57.1%)</td>
</tr>
<tr>
<td>Users' Group</td>
<td>6/6 (100%)</td>
<td>4/6 (66.7%)</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>6/6 (100%)</td>
<td>3/6 (50%)</td>
</tr>
<tr>
<td>Rooms</td>
<td>14/14 (100%)</td>
<td>6/14 (42.9%)</td>
</tr>
<tr>
<td>How much time would like to spend at DU?</td>
<td>14/14 (100%)</td>
<td>4/14 (28.6%)</td>
</tr>
<tr>
<td>How friendly staff are?</td>
<td>14/14 (100%)</td>
<td>7/14 (50%)</td>
</tr>
<tr>
<td>Do staff listen?</td>
<td>12/14 (85.7%)</td>
<td>5/12 (41.7%)</td>
</tr>
<tr>
<td>Do they act on what told?</td>
<td>12/14 (85.7%)</td>
<td>4/12 (33.3%)</td>
</tr>
<tr>
<td>A</td>
<td>1/2</td>
<td>0/1</td>
</tr>
<tr>
<td>B</td>
<td>3/3</td>
<td>3/3</td>
</tr>
<tr>
<td>C</td>
<td>4/4</td>
<td>2/4</td>
</tr>
<tr>
<td>Food &amp; Drink</td>
<td>13/14 (92.9%)</td>
<td>7/13 (53.8%)</td>
</tr>
<tr>
<td>Overall Rating</td>
<td>14/14 (100%)</td>
<td>6/14 (42.9%)</td>
</tr>
</tbody>
</table>
TABLE 7

OPINIONS EXPRESSED BY THOSE RESPONDING CONSISTENTLY ON PERSONAL QUESTIONNAIRE

<table>
<thead>
<tr>
<th>Topic</th>
<th>1 (Very Bad)</th>
<th>2</th>
<th>3</th>
<th>4 (Very Good)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Skills Building</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Monday Group</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Tuesday Group</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Users’ Group</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(never)</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(very bad)</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(very good)</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rooms</td>
<td>(very bad)</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Time spent at DU</td>
<td>(less time)</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>How friendly are staff?</td>
<td>(unfriendly)</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>How friendly are staff?</td>
<td>(very friendly)</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(never)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(a lot)</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do they act on what told?</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Profession A</td>
<td>(very bad)</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Profession B</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Profession C</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Food &amp; Drink</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Overall</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>
TABLE 8

RAW SCORES FOR BPVS (SHORT FORM) FOR CONSISTENT AND INCONSISTENT RESPONDERS ON PERSONAL QUESTIONNAIRE QUESTIONS

<table>
<thead>
<tr>
<th>Topic</th>
<th>Consistent Responders</th>
<th>Inconsistent Responders</th>
<th>Non-responders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings 12; 12; 15; 17</td>
<td>2; 4; 5; 8; 21;</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Skills Building 12; 12; 14; 21</td>
<td>2; 4; 5; 8; 15; 15; 17;</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>Rooms 12; 12; 14; 17;</td>
<td>2; 4; 5; 8; 15; 15; 21;</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>How much time would you like to spend at DU? 12; 14; 15; 17</td>
<td>2; 4; 5; 8; 12; 15; 21;</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>How friendly are staff? 12; 12; 14; 15; 17</td>
<td>2; 4; 5; 8; 15; 17; 21</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>How much do staff listen? 12; 12; 14; 15; 21</td>
<td>2; 4; 5; 8; 15; 17; 21</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>Do they act on what told? 12; 14; 15; 17</td>
<td>2; 4; 8; 12; 15; 21;</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>Food &amp; Drink 12; 12; 14; 15; 17; 21</td>
<td>2; 4; 5; 8; 15; 21;</td>
<td>Untestable</td>
<td></td>
</tr>
<tr>
<td>Overall 12; 12; 14; 15; 17; 21</td>
<td>2; 4; 5; 8; 15; 21;</td>
<td>Untestable</td>
<td></td>
</tr>
</tbody>
</table>
### TABLE 9
MEDIANS AND RANGES FOR RAW SCORES ON BPVS (SHORT FORM) FOR CONSISTENT AND INCONSISTENT RESPONDERS ON PERSONAL QUESTIONNAIRES

<table>
<thead>
<tr>
<th>Topic</th>
<th>Consistent Responders</th>
<th>Inconsistent Responders</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>Range</td>
</tr>
<tr>
<td>Outings</td>
<td>15</td>
<td>12-17</td>
</tr>
<tr>
<td>Skills Building</td>
<td>13</td>
<td>12-21</td>
</tr>
<tr>
<td>Rooms</td>
<td>13</td>
<td>12-17</td>
</tr>
<tr>
<td>How much time would you like to spend at DU?</td>
<td>14.5</td>
<td>12-17</td>
</tr>
<tr>
<td>How friendly are staff?</td>
<td>14.5</td>
<td>12-21</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>14</td>
<td>12-21</td>
</tr>
<tr>
<td>Do they act on what told ?</td>
<td>14.5</td>
<td>12-17</td>
</tr>
<tr>
<td>Food &amp; Drink</td>
<td>14.5</td>
<td>12-21</td>
</tr>
<tr>
<td>Overall</td>
<td>14.5</td>
<td>12-21</td>
</tr>
</tbody>
</table>
The Mann Whitney tests, corrected for ties, failed to reveal any significant differences between the groups on most questions (Outings: U=5, n=10, p=0.115, n.s.; Skills building: U=9, n=11, p=0.343, n.s.; Rooms: U= 10, n=11, p=0.448, n.s.; Time: U=7, n=11, p=0.184, n.s.; Staff listening: U=7.5, n=10, p=0.293, n.s.; Staff action: U=7, n=10, p=0.284, n.s.). However, the analyses revealed significant differences on three items (Staff friendliness: U=3.5, n=11, p<0.05; Food and drink: U=3.5, n=11, p<0.05; Overall: U=3.5, n=11, p<0.05), with consistent responders showing significantly higher BPVS scores than inconsistent responders.

4.3. Comparison of responses to Visual Analogue Scales and Personal Questionnaire formats

In order to explore the validity of the data obtained during the study, responses to the Visual Analogue Scale in a particular topic area were compared with responses to parallel Personal Questionnaire items. During all of these comparisons, only cases where the participant responded consistently to both formats were included. Throughout, consistent responding on the Visual Analogue Scale was defined as the same response on both the first and second presentations of a particular item.

The original intention was to use Kendall’s Tau as a measure of the association between the responses obtained using the two question formats for each topic area. Unfortunately, for many topic areas the numbers of people who responded consistently to both formats were such that SPSS was unable to calculate Kendall’s Tau (Skills building: n=3; Monday group: n=2; Tuesday group: n=3; Users’ group: n=3; Staff: n=5; Psychiatrist: n=2; Psychologist: n=2; Food and drink: n=4). Kendall’s Tau was, however, calculated for the following items: Outings: r=0.612, n=5, p=0.221, n.s.; Rooms: r=1.00, n=4, p=0.083, n.s.; Overall: r=1.00, n=5, p<0.05).

As an alternative way of exploring validity, the percentage agreement between consistent responses on both Visual Analogue and Personal Questionnaire formats, across topic areas, was calculated. Overall, there were 38 cases where participants had responded consistently to both formats of question in a particular topic area. There was no discrepancy between responses using the two formats in 92% of cases. In most cases where no discrepancy was found, participants had rated an area as 4 on the Personal Questionnaire and 10 on the Visual Analogue Scale. In one case, a participant rated an area as 1 on both formats and in one case
a participant rated an area as 3 on the Personal Questionnaire and 7 on the Visual Analogue Scale. There were only 3 cases where there was any discrepancy between responses to the two formats and in all cases participants rated an area 3 on the Personal Questionnaire and 10 on the Visual Analogue Scale. Thus, where participants had responded consistently using both question formats in a particular area, there was evidence of a high level of concordance between the views expressed.

5. DISCUSSION

This project was not primarily intended to be a piece of empirical, hypothesis testing research. Rather, it represents an attempt to draw on the relevant literature in order to find a means of addressing a specific Clinical Audit issue. Specifically, the aim was to develop a measure which could be used to assess user satisfaction amongst a group of people attending a specialist facility for people with learning disabilities, a group which included people with a range of complex communication and other health care needs. The intention was to ensure that as many people as possible were able to take part in the project and have an opportunity to express their views. A second aim of the project was to evaluate the quality of the information obtained along a number of dimensions, namely reliability and validity. Finally, preliminary analyses of the impact of BPVS score on reliability were also conducted.

5.1. How successful was the project in involving a wide range of participants?

The levels of involvement and responsiveness obtained in this study were impressive, particularly considering the levels of disability amongst the people who were interviewed. All of the people attending the day care unit made some attempt to participate and in only two cases did participants indicate that they wished their interviews to terminate prior to completion of the schedule. The responsiveness rates reported in Tables 1 and 6 suggest that the question formats used, which were designed with the aim of maximising the numbers of people who could participate and respond, were largely successful. Thus, the use of formats which limit the range of responses, the use of formats which allow for pointing responses and the use of pictures seem to have successfully maximised the number of people able to take part and make some response to the questions. This is in keeping with the findings of previous studies (Sigelman & Budd, 1986; Wadsworth & Harper, 1991; March, 1992; Dagnan & Ruddick, 1995). Thus, it would be recommended that future projects with similar groups of participants use similar question formats in order to maximise involvement and responsiveness.
It should, however, be noted that the responsiveness rates were slightly lower than those reported by Dagnan and Ruddick (1995). This is to be expected given that their sample consisted solely of people with mild to moderate learning disabilities. The participants in the current project had a wider range of learning disabilities and many also had additional communication and health problems.

5.2. Did participants feel able to express a full range of views, reporting dissatisfaction as well as satisfaction?

As Tables 2 and 7 illustrate, the opinions expressed by participants were very largely positive. This tendency to find high levels of reported satisfaction has been noted widely in the user satisfaction literature, both with people with learning disabilities (Dagnan, Dennis & Wood, 1994) and amongst people without learning disabilities (Larsen, Attkisson, Hargreaves & Nguyen, 1979; Damkot, Pandiani & Gordon, 1983; Stallard & Chadwick, 1991). Whilst such findings may be gratifying for staff and management, they do not necessarily facilitate the improvement of services. However, it should also be noted that in the present study a few participants did express negative views and made suggestions for improvements both using the structured question formats and in response to open ended questions. More details are included in the Audit report, which can be found in Appendix 4. This report also outlines a number of recommendations for service improvements. Thus, at least some clients were able to use the interviews as a forum to air criticisms.

Expression of negative comments is likely to have been facilitated by the fact that the interviewer was not a member of staff at the day care unit and was not directly involved in the care of any of the people currently attending that unit. The opening instructions used as part of the interview also stressed confidentiality and the fact that participants' care would not be influenced by any comments they made. The neutrality of the interviewer was felt to be particularly important given that the literature highlights the potential for people with learning disabilities to feel that their care could be jeopardised if they express any negative comments (Atkinson, 1988; Wright & Roy, 1991).

5.3. How reliable was the information obtained during the study?

As is clear from Tables 3 and 6, the reliability of the responses obtained was variable. For the Visual Analogue Scales, using Kendall's Tau, most of the correlation coefficients failed to reach significance. Statistically significant results were obtained on two items: Users' Group
and Quiet Room. It should be noted that those attending the Users’ group represented the most able people attending the day care unit.

The levels of reliability obtained in this study were lower than those reported by Dagnan, Dennis & Wood (1994) and Dagnan and Ruddick (1995). This can partly be attributed to the fact that the participants in the current project had more severe learning disabilities and more complex communication problems than the participants in the earlier studies. In addition, the failure to find statistically significant results may also be due in part to the small sample size.

A second measure of consistent responding was also employed, namely looking at the percentages of people whose responses were the same or differed by only one point between presentations. The percentages of people who gave consistent responses varied across questions. On nine of the questions administered, the level of consistent responding was significantly higher than would be expected by chance. Although in some cases these percentages suggested reasonable levels of reliability, they must be interpreted with some caution. These figures may in some cases have been elevated by the fact that less able clients were more likely to show erratic patterns of response, for example responding to the first presentation but not the second presentation. In such cases it was not possible to calculate consistency. However, it could be hypothesised that had these clients responded to both presentations it is possible that their responses would not have been consistent. Further explorations of reliability of response incorporating larger samples of clients with a range of abilities are needed to clarify such issues.

In 55.6% of cases where inconsistent responses were obtained on the Visual Analogue scales, this was due to a specific response bias, namely pointing to the right hand anchor. The inclusion of pictorial anchors was designed to minimise this response bias as previous studies have suggested that inclusion of pictures with Either-Or formats may reduce response bias (Sigelman & Budd, 1986; March, 1992) and increase response reliability (Wadsworth & Harper, 1991). On the basis of these data it was not possible to estimate whether the use of pictorial anchors had reduced the prevalence of this bias, given that no data were available on the prevalence of this bias without the use of pictures. However, it is clear that the use of pictorial anchors was not successful in eliminating the tendency to select the last option offered.
Similarly, for the Personal Questionnaire, there was evidence of a pronounced tendency to consistently select the last response option, which had a detrimental effect on reliability. 83.3% of cases of inconsistent responding showed evidence of this response bias. Again it is not possible to comment on whether the use of pictures reduced the prevalence of this bias, as was the case in earlier studies (Sigelman & Budd, 1986; Wadsworth & Harper, 1991; March, 1992) but it is evident that the use of pictures did not eliminate this bias entirely. It was also noted that in 11.5% of cases people adopted an alternative strategy, consistently selecting the first option offered.

Whilst the use of pictures and symbols may not have been successful in eliminating response biases, the use of pictorial aids in presentation of questions and as part of response formats would still be recommended. In this project, using pictures to introduce topics was a useful way of engaging participants and keeping their attention focused on the topic being discussed. Use of formats where participants could indicate their responses solely by pointing to an appropriate symbol was beneficial in enabling people with limited expressive skills to participate. Earlier studies such as March (1992) have also commented on the fact that use of pictures can be useful in this way.

5.4. How valid was the data obtained in the project?
Attempts to use Kendall’s Tau analyses to explore the association between responses to different question formats in particular areas were hampered by the small numbers involved. However, looking at responses across all items, it was found that where people had responded consistently to both question formats in a particular area, then there was a high level of concordance between the opinions expressed using the different formats. This suggests high levels of response validity for this group of participants. Most of the opinions expressed were very positive which may have resulted in a ceiling effect. However, there was evidence that people were also expressing negative views. For example, one person made a negative comment about the staff group and gave low ratings on both the Visual Analogue Scales and Personal Questionnaire. This was in contrast to generally positive ratings in other areas.

5.5. Were the hypotheses concerning the relationship between verbal ability and response reliability confirmed?
The results suggested that for the Visual Analogue Scales there were no significant differences in BPVS score between consistent and inconsistent responders. This is contrary to what was
predicted at the start of the project. However, this finding is in keeping with the results found by Dagnan et al (1994) and Dagnan and Ruddick (1995). However, this failure to find any significant differences needs to be interpreted with some caution given the small size of the sample.

For the Personal Questionnaire, significant differences were found on three questions with the results suggesting that consistent responders showed higher BPVS score than inconsistent responders. This was in keeping with the predictions made at the start of the project and with the findings of Dagnan and Ruddick (1995). These differences may represent genuine differences, which have been obscured on other items by the small size of the sample. However, it is also possible that given the number of tests conducted these findings represent chance occurrences rather than genuine differences. Further research with larger sample sizes is needed to explore the influence of BPVS score on the ability to respond consistently using both the Visual Analogue Scale and Personal Questionnaire formats.

5.6. Limitations of the project and areas for further research

The project had a number of limitations. The project was geared towards exploring the views of people attending a specific specialist day care unit. Consequently, the numbers involved were small and this had implications for interpreting the statistical analyses pertaining to reliability, validity and the impact of verbal ability on ability to use different question formats.

In keeping with the literature in the field, the reliability of the responses to the Visual Analogue scales was assessed by re-administering them at the end of the interview with the anchors reversed. However, re-administering the scales so soon after the first administration may run the risk of suggesting to participants that their first response was somehow incorrect. Assessment of reliability could be improved by re-administering the scales at a second later interview. This was not possible for this project due to time constraints.

Whilst some consideration was given in this study to response validity, this is an area which could be improved upon. Validity can be explored by comparison of responses across different formats as was the case in this project. However, any evaluation of response validity where responses to a variety of questions on the same topic are compared also needs to take into account the effects of suggestibility making any estimate of the validity of opinions expressed extremely difficult. Exploration of the validity of responses obtained in the
interview could be further improved through interviews with staff regarding participants' preferences (March, 1992) or by observing participants in different activities and observing their levels of engagement and enjoyment.

As has already been noted, any conclusions regarding the relationship between verbal ability and consistency of response on Visual Analogue Scales and Personal Questionnaires was limited because of the small size of the sample in this project. In addition, it is acknowledged that the participants in the current study are not representative of the broader population of people with learning disabilities. Rather this group represented those with the most complex needs and difficulties. Thus, there is a need for further research into the use of these question formats with larger, more representative samples, which should serve to elucidate the factors influencing response consistency.
REFERENCES


APPENDIX 1

CHARACTERISTICS OF PARTICIPANTS

Notes:
1. Information on intellectual ability was taken from participants’ files, hence inconsistency in format of reporting. Details of diagnosis and other additional information were also obtained from participants files.

2. WAIS-R: Wechsler Adult Intelligence Scale - Revised Version (Wechsler, 1981)
   LIPS: Leiter International Picture Scale (Leiter, 1969)
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<tr>
<th>Sex</th>
<th>Age at Interview</th>
<th>BPVS (Short form) Raw Score</th>
<th>Level of Intellectual Ability</th>
<th>Diagnosis</th>
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<td>Tested 1995&lt;br&gt;WAIS-R: Full Scale IQ: 48&lt;br&gt;LIPS: Adjusted IQ 36</td>
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<td>Long history institutionalisation</td>
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<td>15</td>
<td>Tested 1989&lt;br&gt;WAIS-R: Full Scale IQ: 55-60 range&lt;br&gt;LIPS: Reported IQ 61</td>
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<td>4</td>
<td>Tested 1994&lt;br&gt;LIPS: Mental Age 2 years 11 months</td>
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<tr>
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<td>25</td>
<td>Untestable with BPVS</td>
<td>Tested 1989&lt;br&gt;&quot;severely intellectually impaired&quot;</td>
<td>Cerebral palsy&lt;br&gt;Bipolar affective disorder</td>
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<td>Tested 1992&lt;br&gt;LIPS: IQ 63</td>
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<td></td>
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<td>F</td>
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<td>15</td>
<td>Tested 1992&lt;br&gt;LIPS: IQ 30</td>
<td>Seizures&lt;br&gt;Gilles de Tourettes Syndrome</td>
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<tr>
<td>F</td>
<td>49</td>
<td>8</td>
<td>Tested 1991&lt;br&gt;LIPS: &quot;severely intellectually impaired&quot;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>F</td>
<td>44</td>
<td>14</td>
<td>Tested 1995&lt;br&gt;LIPS: &quot;moderately intellectually impaired&quot;</td>
<td>Bipolar affective disorder</td>
<td>English - second language&lt;br&gt;BPVS carried out with interpreter which may have introduced bias</td>
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<td>M</td>
<td>27</td>
<td>17</td>
<td>Tested 1994&lt;br&gt;WAIS-R: Full Scale IQ: 66</td>
<td>Schizo-affective illness</td>
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<tr>
<td>M</td>
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<td>Reported IQ: &lt;30</td>
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<td>Tested 1994&lt;br&gt;LIPS: &quot;lower end of the mildly intellectually impaired range.&quot;</td>
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<tr>
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<tr>
<td>F</td>
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<td>5</td>
<td>Tested 1994&lt;br&gt;Could not pass basal level tests&lt;br&gt;&quot;profoundly intellectually impaired&quot;</td>
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<td>21</td>
<td>Tested 1996&lt;br&gt;WAIS-R: &quot;borderline&quot;</td>
<td>Depressive Mood Disorder</td>
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APPENDIX 2:

INTERVIEW PROTOCOL AND VISUAL ANALOGUE

RATINGS SCALES
INTERVIEW PROTOCOL FOR ASSESSING CLIENT SATISFACTION WITH
WESTON GREEN DAY UNIT

IMOGEN'S GUIDELINES FOR ADMINISTRATION

1. Explain purpose of questionnaire: find out what like or dislike about the Day Unit.
2. Ensure know is confidential: will not tell anyone else what they tell me.
3. Check agree to participate and that don't mind being taped. Sign consent form and given spoken consent on tape. Explain can refuse to answer any specific questions and to tell me if cannot follow what I am saying.
4. Explain can take a break if need to go to toilet, have a drink etc.
5. Explain that can ask to stop the interview if they change their mind.
6. Explain will be asking lots of questions about different aspects of Day Unit.

For each interview need:

i Interview protocol
ii Score Sheet
iii Rating scales
iv Topic symbols
v Cards 1-12
vi Consent form
vii Tape recorder
viii Blank cassette tape

ENDING (What to do)  

** Ask only more able clients
SCORE SHEET

SECTION 1:

Activities

(1) OUTINGS - PRESENT "OUTINGS" SYMBOL.

QUESTIONS

i) Are the trips from the Day Unit:
   
   very good / very bad (Cards 1 and 2)
   very bad / OK (Cards 2 and 3)
   OK / very good? (Cards 3 and 1)

ii) Are there other places that you would like to go? **

   ______________________________________________________

   ______________________________________________________

   ______________________________________________________

iv) How good are the trips you go on?
   Mark on rating scale (1) iv

(2) SKILLS BUILDING - PRESENT "SKILLS BUILDING SYMBOL"

i) Are the things you learn at the Day Unit:

   very good / very bad (Cards 1 and 2)
   very bad / OK (Cards 2 and 3)
   OK / very good? (Cards 3 and 1)

ii) What new things have you learned at the Day Unit? **

   ______________________________________________________

   ______________________________________________________

   ______________________________________________________

iii) Can you use the things you learn at home? **

   ______________________________________________________

   ______________________________________________________

iv) Are there other things you want to learn? **

   ______________________________________________________

   ______________________________________________________

   ______________________________________________________

v) How good are the things you learn at the Day Unit? Mark on rating scale (2) v.

   ** Ask only more able clients
(3) **GROUPS** - PRESENT SYMBOL FOR EACH ACTIVITY

ONLY CLIENTS WHO ATTEND ON MONDAY/TUESDAY

**QUESTIONS**

i) Is the Monday group:
   - very good / very bad  (Cards 1 and 2)
   - very bad / OK  (Cards 2 and 3)
   - OK / very good?  (Cards 3 and 1)

ii) Is the Tuesday group:
   - very good / very bad  (Cards 1 and 2)
   - very bad / OK  (Cards 2 and 3)
   - OK / very good?  (Cards 3 and 1)

iii) Is the User group:
   - very good / very bad  (Cards 1 and 2)
   - very bad / OK  (Cards 2 and 3)
   - OK / very good?  (Cards 3 and 1)

iv) PRESENT "EAR" SYMBOL

   Do the staff listen to your ideas:
   - a lot / never  (Cards 4 and 5)
   - never / a little  (Cards 5 and 6)
   - a little / a lot  (Cards 6 and 4)

v) How good is the Monday group:  Mark on ratings scale (3)

vi) How good is the Tuesday group:  Mark on ratings scale (3)

vii) How good is the Users' group:  Mark on ratings scale (3)

iv) What other activities would you like to do?

** Ask only more able clients
SECTION 2

Environment

(2) ROOMS

i) Are the rooms at the Day Unit?:
   very good / very bad
   (Cards 1 and 2)
   very bad / OK
   (Cards 2 and 3)
   OK / very good?
   (Cards 3 and 1)

ii) What do you think of each of the rooms at the Day Unit?

PRESENT PICTURE OF EACH ROOM AND MARK ON RATINGS SCALES UNDER (2) (i)

   a) Main Room
   b) Quiet Room
   c) Kitchen
   d) Craft Room

SECTION 3:

Timing

ii) Would you like to come to the Day Unit more? Yes / No

iii) Would you like to come to the Day Unit less? Yes / No

iv) Would you like to spend

   more / less
   (Cards 7 and 8)
   less / same
   (Cards 8 and 9)
   same / more
   (Cards 9 and 7)

   time at the Day Unit?

SECTION 4

People

(1) STAFF - PRESENT PICTURE OF STAFF GROUP

i) How friendly are the staff?

   very friendly / unfriendly
   (Cards 10 and 11)
   unfriendly / bit friendly
   (Card 11 and 12)
   bit friendly / very friendly
   (Cards 12 and 10)

ii) Do the staff listen to you if you tell them important things? PRESENT SYMBOL "EAR"

   ** Ask only more able clients
a lot / never (Cards 4 and 5)
never / a little (Cards 5 and 6)
a little / a lot (Cards 6 and 4)

iii) If you tell staff important things, do they do something about it?

a lot / never (Cards 4 and 5)
never / a little (Cards 5 and 6)
a little / a lot (Cards 6 and 4)

iv) What do you think of the staff? - Mark on ratings scale (1) iv.

(2) INDIVIDUAL SESSIONS - PRESENT PICTURE OF PERSON AS NECESSARY

i) Speech and Language Therapist

a) What do you think of your sessions with Nik?

very good / very bad (Cards 1 and 2)
Very bad / OK (Cards 2 and 3)
OK / very good (Cards 3 and 1)

b) How good are your sessions with Nik?
Mark on ratings scale 2(i)

ii) Psychiatrist - Note which psychiatrist you see:

a) What do you think of your sessions with Ian/Gillian?

Very good / very bad (Cards 1 and 2)
Very bad / OK (Cards 2 and 3)
OK / very good (Cards 3 and 1)

b) How good are your sessions with Ian/Gillian?
Mark on ratings scale 2(ii)

iii) Clinical Psychologist

a) What do you think of your sessions with Karen?

Very good / very bad (Cards 1 and 2)
Very bad / OK (Cards 2 and 3)
OK / very good (Cards 3 and 1)

b) How good are your sessions with Karen?
Mark on ratings scale 2 (iii)

** Ask only more able clients
SECTION 5

Food and Drink

(1) FOOD AND DRINK - PRESENT SYMBOLS FOR FOOD AND DRINK

i) Is the food and drink at the Day Unit
   very good / very bad  (Cards 1 and 2)
   very bad / OK      (Cards 2 and 3)
   OK / very good     (Cards 3 and 1)

ii) What food and drinks do you like at the Day Unit? **

iii) What food and drinks do you not like at the Day Unit? **

iv) What other food and drinks would you like to have? **

v) How good is the good is the food and drink? - Mark on ratings Scale (1) v.

SECTION 6

(1) Overall Ratings

i) Is the Day Unit:
   very good / very bad  (Cards 1 and 2)
   very bad / OK      (Cards 2 and 3)
   OK / very good     (Cards 3 and 1)

ii) What is good about the Day Unit? **

iii) What is not good? **

** Ask only more able clients
iv) What would you like to change/make different **

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

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

v) Why do you come to the Day Unit? **

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

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

vi) How good is the Day Unit? - mark on ratings scale (1) vi.

SECTION 7
Reliability Checks

(1) OUTINGS - PRESENT OUTINGS SYMBOL

How good are the trips you go on?
Rating scale (1)

(2) SKILLS BUILDING - PRESENT SKILLS BUILDING SYMBOL

How good are the things you learn at the Day Unit?
Rating scale (2)

(3) GROUPS

How good is the - Monday group PRESENT RELEVANT SYMBOLS
- Tuesday group
- User group?

Mark on rating scales under (3)

(4) ROOMS - PRESENT PICTURES OF EACH ROOM

What do you think of:

a) Main room
b) Quiet room
c) Kitchen
d) Craft room?

Mark on ratings scale under (5)

(5) PEOPLE - STAFF PRESENT PICTURE STAFF

What do you think of the staff? Mark on scale (6)

** Ask only more able clients
(6) INDIVIDUAL SESSIONS

How good are sessions with:

i) Nik
ii) Ian/Gillian
iii) Karen

Present relevant symbols. Mark on ratings scales under 7.

(7) FOOD PRESENT FOOD SYMBOL

How good is the food and drinks at the Day Unit? Mark on ratings scale (8)

(8) OVERALL RATING

How good is the Day Unit? Mark on ratings scale (9)

** Ask only more able clients
RATING SCALES FOR USE WITH CLIENTS AT
WESTON GREEN DAY UNIT

Code:

SECTION 1 Activities
(1) (iv) OUTINGS

- VERY BAD
- VERY GOOD

(2) (v) SKILLS BUILDING

- VERY BAD
- VERY GOOD

(3) GROUPS
(v) MONDAY GROUP

- VERY BAD
- VERY GOOD
(vi) TUESDAY GROUP

Very bad

Very good

(vii) USER GROUP

Very bad

Very good

(2) ROOMS
ii) a) MAIN ROOM

Very bad

Very good
b) QUIET ROOM

- VERY BAD
- VERY GOOD

---

c) KITCHEN

- VERY BAD
- VERY GOOD

---

d) CRAFT ROOM

- VERY BAD
- VERY GOOD
SECTION 4: People

(1) (iv) STAFF

(2) (i) SPEECH AND LANGUAGE THERAPIST
SECTION 6: Overall Rating
(1) (vi) OVERALL

| VERY BAD |
| VERY GOOD |

SECTION 7: Reliability Check
(1) OUTINGS

| VERY GOOD |
| VERY BAD |

(2) SKILLS BUILDING

| VERY GOOD |
| VERY BAD |
(3) GROUPS
MONDAY GROUP

VERY GOOD

TUESDAY GROUP

VERY GOOD

USER GROUP

VERY GOOD
(4) ROOMS
MAIN ROOM

VERY GOOD

QUIET ROOM

VERY GOOD

KITCHEN

VERY GOOD

VERY BAD

VERY BAD
CRAFT ROOM

(5) TIMING

- TOO SHORT
- JUST RIGHT
- TOO LONG

(6) PEOPLE - STAFF

- VERY GOOD
- VERY BAD

(7) INDIVIDUAL SESSIONS
SPEECH AND LANGUAGE THERAPIST

- VERY GOOD
- VERY BAD
PSYCHIATRIST

VERY GOOD

VERY BAD

CLINICAL PSYCHOLOGIST

VERY GOOD

VERY BAD

(8) FOOD AND DRINKS

VERY GOOD

VERY BAD
(9) OVERALL RATING

VERY GOOD

VERY BAD

dr9: icinpro22/02/96
APPENDIX 3:

LETTER TO CARERS' EXPLAINING PROJECT,

CONSENT FORM AND

INFORMATION GIVEN TO PARTICIPANTS
Dear

re User Satisfaction Survey at Weston Green Day Unit

We are planning to conduct a survey of people's opinions of Weston Green Day Unit. As part of this survey we will be asking everyone who attends, and who is able to answer some simple questions, whether they would be willing to take part in a short interview. The interview will last no longer than 30 minutes. We are also planning to send out questionnaires to all carers of people who attend the Day Unit. All information collected will, of course, be confidential. Your participation in the project will be invaluable in enabling us to evaluate the service currently offered and to identify ways in which the Day Unit can be improved. If you do not wish to participate in our survey, or do not wish to be interviewed, please contact us before 29th March 1996.

Also, if you have any questions or concerns about the project, then please contact Imogen Collins via 0181-398-1834.

Thank you in advance for your valuable help and support

Yours sincerely

Imogen Collins
Psychologist in Clinical Training

dept:iccare
 CLIENT CONSENT FORM

CLIENT'S NAME:

DATE:

I agree to take part in the Weston Green Day Unit User Satisfaction Survey and I agree to being audio taped.

I understand that my conversation will be kept private (confidential) and that the tape will only be listened to by Imogen Collins.

Signature of client :

Signature Psychologist in Clinical Training :

Date:
INSTRUCTIONS TO PARTICIPANTS:

"My name is Imogen Collins and I am learning to be a psychologist.

The aim of today is for me to find out what you like and dislike about the Day Unit. Hopefully, we will then be able to make the Day Unit better.

I will not tell anybody else what you say to me but I will use some of the things you say, along with things that other people say, to tell the staff which bits of the Day Unit are good and which bits are bad. They will not know who said what.

I will be asking lots of questions about different parts of the Day Unit. It should take about 30 minutes.

You can take breaks to go to the toilet or have a drink if you need to - just tell me. If you don’t want to answer some of the questions, that’s O.K. If you want to stop at any stage, that’s O.K. If I say anything which you don’t follow then let me know.

Do you have any questions?

Is it O.K. for me to ask you some questions? Is it O.K. for me to tape our conversation?" (Sign form if able)
APPENDIX 4:

AUDIT REPORT PREPARED FOR TRUST

WHERE PROJECT WAS CONDUCTED

Please note: Many of the tables included in this report duplicate those found in the main body of the text. Duplicate copies of the questionnaires are not included and references to appendices have been modified so that they are consistent with this text.
AUDIT REPORT ON THE DAY UNIT USER SATISFACTION SURVEY

INTRODUCTION

Over the past few years there has been an increasing emphasis within the National Health Service on the assessment of users' satisfaction with the quality of the services which they receive. The importance of extending this endeavour to include people with learning disabilities has been highlighted by a number of researchers in the field. However, there are a number of difficulties in obtaining information which is reliable and accurately reflects the opinions of people with learning disabilities. This is particularly the case where respondents have severe learning disabilities and/or communication difficulties. These difficulties were reviewed in more detail in an earlier literature review which is available from the author.

The current project aimed to investigate satisfaction with the service provided by the Day Unit amongst people currently attending. Day Unit is a small, specialist Health Service resource for adults with learning disabilities and additional problems. Clients who attend the Day Unit require an intensive, specialist service in order to facilitate their integration into mainstream services. The Day Unit is intended to complement existing services and to provide an additional resource for clients with complex needs.

As the questionnaire used was designed specifically for the project, a second aim was to explore whether the information obtained was reliable. In parallel, the opinions of parents and/or carers of people currently attending the Day Unit were also surveyed.

METHOD

1. Users Project

Participants
Fifteen people were attending Weston Green Day Unit at the time of the project, nine men and six women. All fifteen people agreed to participate. A summary of participant characteristics is included in Appendix 1.

Data Collection Methods
A semi-structured interview protocol was developed with reference to the existing literature on interviewing people with learning disabilities and in consultation with members of the multi-
disciplined team at Weston Green Day Unit. Interviews were conducted by a Trainee Clinical Psychologist and author of the report. The interviews lasted between 15 and 30 minutes. All interviews were taped.

Participants were asked questions about a range of topics covering:

i) Activities
ii) Environment
iii) Timing
iv) Staff
v) Food and drink
vi) Overall ratings

Pictures and symbols were used to introduce and focus people's attention on each topic area.

Three types of question were used in each topic area:

1) **Open-Ended Questions**

These were used only with more verbally able participants.

2) **Analogue Scales with Symbol Anchors**

This was a modified version of a format used successfully by Dagnan & Ruddick (1995). Further details are included in the literature review cited earlier. Participants were presented with a ten centimetre line with a symbol and phrase at each end. Each participant was asked to indicate the point on the line which reflected their views. Responses could be indicated by pointing.

For scoring purposes, the line was divided into one centimetre sections which were scored one to ten.

The analogue scales were repeated at the end of the interview with the position of the anchors reversed to check for reliability and control for position bias.

3) **The Point Personal Questionnaire Format**

This was also a modified version of a format used by Dagnan & Ruddick (1995). Again further details are included in the literature review.
Participants were presented with three consecutive pairs of responses to a particular question (e.g. very good/very bad; very bad/OK/very good). Pairs were presented simultaneously in verbal and pictorial forms. For each pair the participant indicated which option reflected their views by pointing to the relevant symbol.

Earlier studies have shown that when offered a choice between two options, some people with learning disabilities show a bias towards selection of the second option. This format includes an in-built check as to whether this bias is occurring. By looking at the pattern of items chosen it is also possible to check for the reliability of responses.

Where participants responded consistently the response pattern was converted into a four point scale.

A copy of the interview protocol is included in Appendix 2. It should be noted that not all questions were relevant to everyone because of variations in days attended and professional input.

Consent Procedure
Prior to starting the project, all carers and parents of people attending Day Unit were informed that the project was planned. They were asked to contact the Trainee Clinical Psychologist if they had any queries or did not wish individual clients to participate.

At the start of each client interview, details of what would be involved were explained. It was explained that the interview was confidential, that the client was under no obligation to take part and that he/she could refuse to answer specific questions or terminate the interview at any stage. Verbal consent for the interview and to tape the interview was obtained and recorded on audio tape. Where possible written consent was also obtained. (Some clients were unable to write).

It should be noted that although no one initially refused to participate, two clients indicated that they wished to terminate the interview early. One participant indicated a desire to leave after one question and one client wished to stop half way through.
2. Carers and Relatives Project

Participants
Where relevant questionnaires were sent to a relative and/or to a carer at a residential home. 8 questionnaires were sent to residential facilities of which 7 were returned (response rate 87.5%). It seems likely that a number of questionnaires sent to the one residential facility were completed by the same member of staff. 12 questionnaires were sent to relatives of which 8 were returned (response rate 66.7%). The overall response rate was 75% which is high compared with rates obtained in other surveys.

Data Collection
A postal questionnaire was used. This consisted of a series of analogue scales covering:

i) Treatment received

ii) Staff

iii) Activities

iv) Attendance (duration and frequency)

v) Quality of information and communication.

vi) Overall rating

Participants indicated their views on the various aspects of the service by making a mark on the line. Scoring was as detailed under the users project.

Open ended questions were also included.

A copy of the questionnaire is included in Appendix 5.

RESULTS
Please note that throughout the results section and in all tables, professional groups have been identified only as A, B and C. Feedback has been provided to individual professional groups and to the staff group at the Day Unit.

1. Users Project

a) Analogue Scales with Pictorial Anchors

Most participants were able to respond to the analogue scales. Response rates varied across questions between 78.6% and 100%. However in some cases the responses were not clear and therefore could not be included in calculations of reliability. A summary of response rates for
each question including incidents of refusal/no response and cases where responses were not clear is included in Table 1.

Table 2 shows a summary of the median and range of responses obtained on each question. The opinions expressed were largely but not exclusively positive suggesting that people did feel able to express criticisms.

Data concerning the reliability of responses obtained is summarised in Table 3. Kendall's Tau is a statistical measure indicating the degree of association between the responses obtained on the first and second presentations of the analogue scales. As can be seen from the table, only 2 of the tests were significant.

A second estimate of reliability was obtained by calculating the amount by which people disagreed on the first and second presentations. Approximately 50% to 60% of people on average gave responses which could be viewed as consistent where consistent response was defined as an identical response or a response differing by only one point.

In many cases where inconsistent responses were observed this was due to one specific response bias which has been noted in much of the literature, namely pointing to last item presented (i.e. the right hand anchor on the analogue scale).
### TABLE 1

**RESPONSE RATES ON VISUAL ANALOGUE SCALES FOR EACH QUESTION**

<table>
<thead>
<tr>
<th>Trial</th>
<th>Topic</th>
<th>Number of people showing any response/Number of people presented with question (response rate)</th>
<th>Number of cases where response not clear</th>
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<tr>
<td>1</td>
<td>Outings</td>
<td>12/15 (80%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Skills Building</td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/14 (85.7%)</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>Monday Group</td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6/6 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Tuesday Group</td>
<td>7/7 (100%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>7/7 (100%)</td>
<td>0</td>
</tr>
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<td>Users' Group</td>
<td>6/6 (100%)</td>
<td>0</td>
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<td>6/6 (100%)</td>
<td>0</td>
</tr>
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<td>Main Room</td>
<td>13/14 (92.9%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Quiet Room</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Kitchen</td>
<td>12/14 (85.7%)</td>
<td>0</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/14 (78.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Craft Room</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/13 (92.3%)</td>
<td>1</td>
</tr>
<tr>
<td>1</td>
<td>Staff</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/13 (84.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Profession A</td>
<td>1/2</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>1/2</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Profession B</td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>3/3</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Profession C</td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>4/4</td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>Food &amp; Drink</td>
<td>12/14 (85.7%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>11/13 (84.6%)</td>
<td>0</td>
</tr>
<tr>
<td>1</td>
<td>Overall</td>
<td>13/14 (92.9%)</td>
<td>1</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>12/13 (92.3%)</td>
<td>0</td>
</tr>
</tbody>
</table>

**Key**

1 = 1st presentation  
2 = 2nd presentation
**TABLE 2**

**MEDIAN AND RANGE OF RESPONSES ON VISUAL ANALOGUE SCALES**

<table>
<thead>
<tr>
<th>Trial</th>
<th>Topic</th>
<th>Median</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Outings</td>
<td>10</td>
<td>3-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>9</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Skills Building</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Monday Group</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>8</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Tuesday Group</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Users' Group</td>
<td>10</td>
<td>6-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>6-10</td>
</tr>
<tr>
<td>1</td>
<td>Main Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Quiet Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>8</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Kitchen</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Craft Room</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>6</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Staff</td>
<td>10</td>
<td>3-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Profession A</td>
<td>4</td>
<td>4}* based on very</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>4</td>
<td>4} small number of</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>responses</td>
</tr>
<tr>
<td>1</td>
<td>Profession B</td>
<td>10</td>
<td>3-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>1</td>
<td>Profession C</td>
<td>10</td>
<td>10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Food &amp; Drink</td>
<td>10</td>
<td>5-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>1</td>
<td>Overall</td>
<td>10</td>
<td>1-10</td>
</tr>
<tr>
<td>2</td>
<td></td>
<td>7</td>
<td>1-10</td>
</tr>
</tbody>
</table>

**Key**

1 = 1st presentation
2 = 2nd presentation
<table>
<thead>
<tr>
<th>Topic</th>
<th>Kendall's Tau</th>
<th>No. Of cases of identical responses on both trials</th>
<th>No. Of cases where response differed by 1 point</th>
<th>No. of cases where responses differed by 2 points</th>
<th>No. of cases where responses differed by 3 points</th>
<th>No. of cases of consistent response/ No. of responses (% consistency)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings (n=11)</td>
<td>-0.059</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>6/11 (54.5%)</td>
</tr>
<tr>
<td>Skills Building (n=10)</td>
<td>-0.043</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>5/10 (50%)</td>
</tr>
<tr>
<td>Monday Group (n=6)</td>
<td>calculation not possible</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3/6 (50%)</td>
</tr>
<tr>
<td>Tuesday Group (n=7)</td>
<td>calculation not possible</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4/7 (57.1%)</td>
</tr>
<tr>
<td>Users' Group (n=6)</td>
<td>1.000</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6/6 (100%)</td>
</tr>
<tr>
<td>Main Room (n=11)</td>
<td>0.528</td>
<td>7</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>7/11 (63.6%)</td>
</tr>
<tr>
<td>Quiet Room (n=12)</td>
<td>0.556</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>9/12 (75%)</td>
</tr>
<tr>
<td>Kitchen (n=11)</td>
<td>0.374</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6/11 (54.5%)</td>
</tr>
<tr>
<td>Craft Room (n=11)</td>
<td>0.530</td>
<td>7</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>8/11 (72.7%)</td>
</tr>
<tr>
<td>Staff (n=11)</td>
<td>0.454</td>
<td>7</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>7/11 (63.6%)</td>
</tr>
<tr>
<td>A (n=1)</td>
<td>Calculation not possible</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1/1</td>
</tr>
<tr>
<td>B (n=3)</td>
<td>calculation not possible</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>2/3</td>
</tr>
<tr>
<td>C (n=4)</td>
<td>calculation not possible</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>3/4</td>
</tr>
<tr>
<td>Food &amp; Drink (n=10)</td>
<td>0.375</td>
<td>6</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>8/10 (80%)</td>
</tr>
<tr>
<td>Overall (n=12)</td>
<td>0.068</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6/12 (50%)</td>
</tr>
</tbody>
</table>
b) **Personal Questionnaire**

Once again a high response rate was obtained with this format, with rates ranging from 85.7% to 100%. Using this format far fewer ambiguous responses were obtained. Table 4 includes a summary of response rates across questions.

Table 4 also provides a summary of the percentage of those responding who responded consistently for each question. Generally lower rates of consistent responding were noted with this format but there is a wide range of rates. Questions on quantity or duration were particularly difficult for clients.

Inconsistencies, introduced largely via pronounced position biases, were noted for many people. In most cases people pointed habitually to the last item but in a smaller number of cases people pointed consistently to the first item.

In cases where people did respond consistently, opinions were largely but not exclusively positive. Thus, again it would seem people felt comfortable expressing a variety of opinions.

A summary is included in Table 5.
### TABLE 4:
RESPONSE RATES ON PERSONAL QUESTIONNAIRE FOR EACH QUESTION

<table>
<thead>
<tr>
<th>Topic</th>
<th>No. giving any response/No presented with question</th>
<th>No. giving consistent response/No. giving any response</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings</td>
<td>14/15 (93.3%)</td>
<td>6/14 (42.9%)</td>
</tr>
<tr>
<td>Skills Building</td>
<td>13/14 (92.9%)</td>
<td>5/13 (38.5%)</td>
</tr>
<tr>
<td>Monday Group</td>
<td>6/6 (100%)</td>
<td>4/6 (66.7%)</td>
</tr>
<tr>
<td>Tuesday Group</td>
<td>7/7 (100%)</td>
<td>4/7 (57.1%)</td>
</tr>
<tr>
<td>Users' Group</td>
<td>6/6 (100%)</td>
<td>4/6 (66.7%)</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>6/6 (100%)</td>
<td>3/6 (50%)</td>
</tr>
<tr>
<td>Rooms</td>
<td>14/14 (100%)</td>
<td>6/14 (42.9%)</td>
</tr>
<tr>
<td>How much time would like to spend at DU?</td>
<td>14/14 (100%)</td>
<td>4/14 (28.6%)</td>
</tr>
<tr>
<td>How friendly staff are?</td>
<td>14/14 (100%)</td>
<td>7/14 (50%)</td>
</tr>
<tr>
<td>Do staff listen?</td>
<td>12/14 (85.7%)</td>
<td>5/12 (41.7%)</td>
</tr>
<tr>
<td>Do they act on what told?</td>
<td>12/14 (85.7%)</td>
<td>4/12 (33.3%)</td>
</tr>
<tr>
<td>Profession A</td>
<td>1/2</td>
<td>0/1</td>
</tr>
<tr>
<td>Profession B</td>
<td>3/3</td>
<td>3/3</td>
</tr>
<tr>
<td>Profession C</td>
<td>4/4</td>
<td>2/4</td>
</tr>
<tr>
<td>Food &amp; Drink</td>
<td>13/14 (92.9%)</td>
<td>7/13 (53.8%)</td>
</tr>
<tr>
<td>Overall Rating</td>
<td>14/14 (100%)</td>
<td>6/14 (42.9%)</td>
</tr>
</tbody>
</table>
**TABLE 5**
**NUMBER OF PEOPLE ENDORSING EACH OPTION ON PERSONAL QUESTIONNAIRE**

N.B. Only includes those who gave consistent responses

<table>
<thead>
<tr>
<th>Topic</th>
<th>1 (Very Bad)</th>
<th>2</th>
<th>3</th>
<th>4 (Very Good)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Outings</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Skills Building</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Monday Group</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Tuesday Group</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Users' Group</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(never)</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>(very bad)</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>(very good)</td>
</tr>
<tr>
<td>Rooms</td>
<td>(very bad)</td>
<td>1</td>
<td>0</td>
<td>0 (very good)</td>
</tr>
<tr>
<td>Time spent at DU</td>
<td>(less time)</td>
<td>0</td>
<td>(same time) 0</td>
<td>(more time) 3</td>
</tr>
<tr>
<td>How friendly are staff?</td>
<td>(unfriendly)</td>
<td>1</td>
<td>0</td>
<td>1 (very friendly)</td>
</tr>
<tr>
<td>How much do staff listen?</td>
<td>(never)</td>
<td>0</td>
<td>0</td>
<td>0 (a lot)</td>
</tr>
<tr>
<td>Do they act on what told?</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Profession A</td>
<td>(very bad)</td>
<td>0</td>
<td>0</td>
<td>(very good)</td>
</tr>
<tr>
<td>Profession B</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Profession C</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Food &amp; Drink</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Overall</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>5</td>
</tr>
</tbody>
</table>
c) Open Ended Questions and Other Comments made During Interviews
The vast majority of people expressed positive opinions regarding the Day Unit and could not cite any ways in which things could be improved. The following provides a flavour of some of the comments made. It is not intended to be comprehensive.

Outings
Suggestions for outings included the following; Brighton, seaside, zoo, parks, cinema and a picnic at Hampton Court. Two people cited going out in the minibus as a favourite activity whilst another cited "out in the minibus" as something they wished to change.

Other Activities
Some participants expressed negative opinions about some of the skills building programmes but the complaints seemed to be specific to individuals. Requests for additional activities included: to learn drawing; computing; trampolining; swimming and learning to drive a car. There was some indication that people did use the skills they had learned at the Day Unit at home but it was not clear how reliable this self-report was.

Environment
Most people seemed to like the rooms at the Day Unit. One person disliked the Craft Room because it was "too noisy" and another was generally negative about the rooms, specifically complaining that the chairs in the Main Room were "too hard".

Timing
Of the 7 people who responded consistently to questions about wanting to come to the Day Unit more/less often, 6 expressed a desire to come more often. One person who was preparing to be discharged expressed their regret at having to leave.

Staff
Again comments were generally positive: for example one person described staff as "very good; very kindly ..... they behave very well; when I ask for something they give it to me". Only one person expressed any negative comments about the staff group expressing a preference for the "old staff" over the "new staff" because "you could joke with the old staff more". One person expressed mixed feelings about their sessions with one of the members of
the Multi-disciplinary Team. Although they said that some sessions were good, in others it was "like talking to a brick wall".

Food and Drink
Comments were largely positive and no one suggested specific additions.

"Why Do You Come to the Day Unit?"
This question produced some interesting responses including "to do drawing"; "(carer) have a jolly good rest"; "This is my school" and" the doctor put me here". Three of the people asked did not know why they came.

Overall Rating
The general impression gained from most interviews was that people liked the Day Unit. A number of people reiterated. "I like the Day Unit" several times during the interview.

2. Carers and Relatives Project
A summary of the responses for each question is included in table 6. Although ratings were generally positive, a range of opinions were expressed especially by relatives.

Some people expressed glowing praise for the work of the Day Unit; for example :

"We are satisfied with the staff and service generally"

"The Day Unit was a great help to X"

"We cannot help but give such high markings to the work of the Day Unit .......
Long may the good work continue".

"The Day Centre has been very good for Y ......."

One comment was received regarding the need for a new minibus.

The area where people made the most comments was around communication and information. There were a number of requests, from residential carers and families, for daily information
regarding activities, behaviour etc. Some comments from residential staff suggested that greater ongoing liaison between residential and Day Unit staff to share information and skills would be beneficial. One family felt that there was sometimes a delay before issues of concern were raised with families. They also felt that staff could be more positive in their attitudes at reviews and that: "A 'them' and 'us' feel isn't good".

One negative comment was expressed about counselling sessions which were seen as having a detrimental effect on the individual's mood.
TABLE 6
MEDIANS & RANGES OF RESPONSES TO CARERS QUESTIONNAIRE
* Unless otherwise indicated, the scales run from very bad (1) to very good (10)

<table>
<thead>
<tr>
<th>Topic Area</th>
<th>Residential Carers</th>
<th>Families</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Median</td>
<td>Range</td>
<td>Median</td>
</tr>
<tr>
<td>Quality of Treatment</td>
<td>8</td>
<td>8-10</td>
<td>9</td>
</tr>
<tr>
<td>Improvement 1- None</td>
<td>8</td>
<td>2-9</td>
<td>7.5</td>
</tr>
<tr>
<td>10 - Great</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Special Needs</td>
<td>8</td>
<td>7-10</td>
<td>9</td>
</tr>
<tr>
<td>Instructors</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Manager</td>
<td>9</td>
<td>9-10</td>
<td>9.5</td>
</tr>
<tr>
<td>A</td>
<td>9</td>
<td>9-10</td>
<td>8.5</td>
</tr>
<tr>
<td>B</td>
<td>9</td>
<td>7-10</td>
<td>8.5</td>
</tr>
<tr>
<td>C</td>
<td>7</td>
<td>7-8</td>
<td>7.5</td>
</tr>
<tr>
<td>Staff Friendliness</td>
<td>7</td>
<td>6-10</td>
<td>9</td>
</tr>
<tr>
<td>Staff Helpfulness</td>
<td>8</td>
<td>7-10</td>
<td>9</td>
</tr>
<tr>
<td>Staff - How Approachable</td>
<td>8</td>
<td>7-10</td>
<td>9</td>
</tr>
<tr>
<td>Outings</td>
<td>8</td>
<td>7-10</td>
<td>7.5</td>
</tr>
<tr>
<td>Skills Building</td>
<td>7</td>
<td>7-10</td>
<td>8</td>
</tr>
<tr>
<td>User Group</td>
<td>9</td>
<td>8-9</td>
<td>8</td>
</tr>
<tr>
<td>Therapy Groups</td>
<td>8</td>
<td>7-9</td>
<td>7.5</td>
</tr>
<tr>
<td>Art &amp; Craft</td>
<td>7</td>
<td>6-10</td>
<td>8</td>
</tr>
<tr>
<td>Domestic</td>
<td>7</td>
<td>7-10</td>
<td>8.5</td>
</tr>
<tr>
<td>Leisure/Sports</td>
<td>7</td>
<td>7-10</td>
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DISCUSSION AND CONCLUSIONS

As noted in the introduction, the first aim of the project was to gather information from users and carers regarding satisfaction with the service provided by the Day Unit. As has been already commented upon, in general both users and carers appeared satisfied with aspects of the service included in the questionnaire. In most cases, dissatisfaction with an aspect of the service was particular to individuals. However, there were certain areas where dissatisfaction was more widespread or where improvements could be recommended.

1. If possible, recommendations made by clients attending the Day Unit regarding additional activities and modifications to the environment should be acted upon.

2. There was evidence from the interviews that people were generally not aware of why they were attending the Day Unit. Whilst conveying such information is difficult, it may be helpful for staff to explore ways in which this could be done.

3. Comments both from residential staff and families suggest a need for increased communication with staff from the Day Unit. Whilst daily feedback would clearly require considerable work on the part of hands-on staff and consequently may not be feasible, perhaps feedback could be offered on a once or twice weekly basis. Preparation of a standardised form covering the main areas of interest, possibly with tick boxes along with space of more general comments or concerns, may help to mitigate against this becoming too arduous a task whilst maintaining a clear focus on the information required.

4. There also seemed to be scope for greater face to face liaison between staff at the Day Unit and residential staff in terms of sharing information and skills. The most appropriate mechanisms for achieving this and the implications for staff at the Day Unit require further consideration.

The second aim of the project was to explore whether the information obtained from service users was reliable. Using both question formats response rates were high and the aim of including as many people as possible, regardless of level of learning disability or communication skill, was achieved. Using question formats which allowed for non-verbal responses clearly facilitated this.
Regarding reliability, only two of the reliability coefficients for the visual analogue scales achieved statistical significance. Using an alternative measure of reliability, namely percentage of people giving identical or almost identical responses to the two presentations, more favourable results were obtained. However, some caution needs to be exercised in interpreting these results. This figure was calculated as a proportion of those who responded to both presentations. It should be noted that more disabled clients, who might be predicted to respond less reliably, were more likely to be inconsistent in whether they responded at all to both presentations. This may have slightly inflated this figure.

Reliabilities for the personal questionnaire tended to be slightly lower, possibly because this format is more complex. However anecdotal observations suggested that using both visual analogue and personal questionnaire formats was helpful as some people seemed better able to use the latter.

The people attending the Day Unit are not representative of the more general population of people with learning disabilities as they have generally a more pronounced or complex pattern of difficulties. The levels of reliability achieved using these formats with clients from the Day Unit should therefore not be taken as evidence against their use in future satisfaction surveys with a broader community sample.
APPENDIX 5:

CARER SATISFACTION QUESTIONNAIRE
CARER SATISFACTION
WITH WESTON GREEN DAY UNIT

We are currently conducting a survey of clients' and carers' opinions of the Weston Green Day Unit. We would be grateful if you could complete this questionnaire and return it in the stamped, addressed envelope provided, to:

Imogen Collins
Department of Psychology
University of Surrey
Guildford
Surrey

All responses from yourself and the clients attending the Day Unit will be completely confidential. We will be sending out copies of the results of the questionnaires in due course.

Instructions

Please place a cross on each of the lines below to indicate what you think of each aspect of the services. You may place a cross anywhere along the line. Place it closer to 'very good' if you are pleased with the service, and closer to 'very bad' if you are very unhappy about the service.

For example: This questionnaire is

You would place it closer to 'very bad' if you dislike the questionnaire.

\[ \text{very bad} \quad \text{very good} \]

You would place it closer to the centre of the line if you do not feel strongly either way.

\[ \text{very bad} \quad \text{very good} \]

You would place it close to 'very good' if you like the questionnaire.

\[ \text{very bad} \quad \text{very good} \]

Thank you for your cooperation.
CARE SATISFACTION QUESTIONNAIRE

1. TREATMENT

Overall, is the treatment provided by the Day Unit

| very bad | Very good |

Have you noticed an improvement in "__"'s problems since they started attending the Day Unit

| no improvement | Great improvement |

2. STAFF

A. What do you think of the service you receive from each of the following members of staff? Please write not applicable if this service is not received.

Special Needs Instructors

| very bad | Very good |

Manager of the Day Unit

| very bad | very good |

Clinical Psychologist

| very bad | very good |

Psychiatrist

| very bad | very good |
Speech & Language Therapist

| very bad          | very good          |

B How would you rate the staff at the Day Unit generally?

| very unfriendly   | very friendly      |

| unhelpful         | very helpful       |

| Unapproachable    | very approachable  |

3. ACTIVITIES

Outings

| very bad          | very good          |

Programmes to learn new skills

| very bad          | very good          |

User Group

| very bad          | very good          |

Therapy Groups

| very bad          | very good          |

Art and Craft

| very bad          | very good          |
Domestic

| very bad | very good |

Leisure/Sports

| very bad | very good |

Balance of Activities Generally

| very bad | very good |

Do you have any more comments about specific sessions?

| | |
| | |

4. ATTENDANCE AT DAY UNIT

How many days per week does ______________ attend the Day Unit?

Is this:

| Too many | Just right | Too few days |

Is the length of the daily programme at the Day Unit: (9.45 am - 3.15 pm)

| Too long | Just right | Too short |

5. QUALITY OF INFORMATION AND COMMUNICATION

What do you think of the quality of the information you receive from the Day Unit?

| very bad | very good |

Would you like additional information from them? Yes / No
If so, what would you like to know?


Are the four monthly reviews?

|                   | Too often | just right frequency | not often enough |

What do you think of the type and range of issues discussed at the reviews.

|                   | very bad | very good |

What do you think of the opportunity you have to contribute to the discussions?

|                   | very bad | very good |

6. GENERAL

How would you rate the Day Unit overall?-

|                   | very bad | very good |
ANY ADDITIONAL COMMENTS OR SUGGESTIONS ABOUT HOW THE DAY UNIT COULD BE IMPROVED:

_________________________________________________________________________

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Thank you very much for your help and support
COGNITIVE STYLE, PAIN AND DEPRESSION IN SICKLE CELL DISEASE

ABSTRACT

Drawing on research with other pain populations, this study explored the relationship between cognitive style, pain and depression amongst people with Sickle Cell Disease (SCD). Specifically, cognitive distortions (pertaining to pain and everyday day situations) were compared amongst three groups: people with SCD who were also depressed, people with SCD who were not depressed and a normal control group. The study also compared pain experiences between the two SCD groups and explored levels of psycho-pathology amongst men and women with SCD. It was also hypothesised that levels of cognitive distortion would account for additional variance in levels of depression after controlling for pain and disease related variables.

The results suggested that there were no significant differences between the three groups in terms of levels of cognitive distortion. No differences emerged between the two SCD groups in terms of pain experience. Men and women showed comparable levels of psycho-pathology. However, it was found that cognitive distortion and depression were significantly correlated even after controlling for pain and disease variables. Thus, some of the hypotheses were supported whilst others were not.

The interpretation of these results was discussed in the light of limitations in the current study, particularly with regards to sample characteristics. Further areas for research were also highlighted.
SECTION 1: INTRODUCTION

Sickle Cell Disease (SCD) is a group of genetically transmitted blood disorders, which predominantly affects people of Afro Caribbean origin. In Britain, it is estimated that over 5,000 people have SCD and at least 150 babies with SCD are born every year. There are three main forms of SCD: Sickle Cell Anaemia (SS), SC disease (HbSC) and Sickle B Thalassemia (SBThal). Although there is considerable variability, SS is usually considered the most severe form, followed by SBThal and SC disease respectively.

SCD is characterised by the production of a predominance of haemoglobin S (HbS) which is structurally different from the normal haemoglobin A (HbA) (Gil, 1989). As a result of these structural differences, the solubility of deoxygenated HbS within the red blood cells is altered. This causes the red blood cell to convert into a “sickle” shape. Vascular occlusion results from the blockage of small blood vessels by these sickled cells. This vascular occlusion can cause both acute and chronic problems. Acute problems include priapism and strokes. Chronic problems include leg ulcers, kidney dysfunction and aseptic necrosis of bones. Many of these chronic complications are associated with chronic pain. Chronic anaemia is also a common consequence of SCD. (Gil, 1989).

Although people with SCD experience a variety of medical complaints, acute painful crises are the most common and disabling complication. Pain in SCD is typically extremely variable and unpredictable in terms of timing, location and intensity (Shapiro, 1989). It has also been noted that the frequency and intensity of pain crises varies considerably between individuals. Whilst some people rarely experience painful crises, others may have one or two episodes per month. Platt, Thorton, Brambilla, Milner, Rosse, Vichinsky and Kinney (1991) in their survey of pain rates found the average rate was 0.8 episodes per patient-year in SS, 1.0 episodes per patient-year in one type of SBThal and 0.4 episodes per patient-year in SC disease and another type of SBThal. However, the rate varied widely within each group. 39% people with SS had no episodes of pain and 1% had more than six episodes per year. They also found that for SS patients who were over 20, those with high rates of pain episodes tended to die earlier than those with low pain rates. Baum, Dunn, Maude and Serjeant (1987) found a higher frequency of painful crises amongst those under 35 as compared with older adults. The duration of episodes can also be variable, ranging from a few hours to several weeks. The average duration is about four to six days (Gil, 1989). Shapiro (1989) has noted the variability in pain intensity across individuals and between
episodes. Severity appears to worsen in males until the age of 30, when there is a decline in the number of vaso-occlusive crises.

Shapiro (1989) notes that many painful episodes have no identifiable cause. However, certain conditions are known to provoke vaso-occlusion, including cold, dehydration, acidosis, fatigue, infection, stress and menses.

There is currently no medical cure or prevention for such painful experiences. Treatment focuses on alleviating underlying factors associated with sickling, for example hydration, and in controlling pain, primarily with analgesic and narcotic medication. Blood transfusions may be required under some acute circumstances. It has also been noted that whilst some people are able to manage their pain largely at home, others require frequent emergency treatment and hospital admission (Gil, 1989).

SECTION 1.1: PSYCHOLOGICAL ADJUSTMENT AND SICKLE CELL DISEASE

Over the last decade or so, psychologists have begun to explore the impact of having a chronically painful and potentially life threatening condition such as SCD on psychological functioning. In addition, studies have begun to look at the sort of factors that influence psychological outcome.

Midence, Fuggle and Davies (1993) in their review of studies looking at psychological adjustment amongst children with SCD concluded:

"There is some evidence for an increased risk of psychological and social problems in children and adolescents with SCD compared with non-affected peers. However, the majority of patients do not show any psychological disorder."

Although the studies have produced inconsistent findings, particular difficulties have been noted around depression, anxiety, cognitive style, body dissatisfaction and behavioural difficulties. Adolescent boys have been found to be at particular risk for difficulties. Thompson, Gil, Burbach, Keith and Kinney (1993) found that amongst their sample of 50 children (aged 7-12) 64% had parent reported behaviour problems and 50% met diagnostic criteria for one of the disorders covered in the structured clinical interview. The most commonly found problems were internalising behaviour problems especially anxiety.

In the adult literature, a number of studies have also reported evidence of psychological difficulties amongst some SCD patients. Morin and Waring (1981) presented three case
Imogen Collins Third Year Research

studies in which patients with sickle cell crises presented with depression. It was noted that in all cases there were background issues around interpersonal difficulties. Vichinsky, Johnson and Lubin (1982) report on psychiatric assessments of 31 SCD patients. Depression, anxiety and neurosis were all found to be common amongst these patients. Leavell and Ford (1983) used a structured interview and self-report measures to assess psychological functioning amongst 16 SCD patients. Levels of psychopathology within the group varied widely. However, they found higher levels of psychological problems amongst men, which they suggested was related to their higher rates of medical complications. Barrett, Wisotzek, Abel, Rouleau, Platt, Pollard and Eckman (1988) used the Chronic Illness Problem Inventory to assess the level of psychosocial functioning amongst 89 SCD patients. They noted significant difficulties in the areas of employment, sleeping and eating and finances. Anxieties around bodily deterioration were common. As with previous studies, men showed higher scores than women although many of these differences failed to reach statistical significance. Ohaeri, Shokunbi, Akinlade and Dare (1995) studied 170 SCD patients in Nigeria using the GHQ-12. 39.5% obtained scores of one or more, that is they fell at or above the cut-off for identifying psychological morbidity. Thompson, Gil, Abrams and Phillips (1992) in their study of 109 SCD patients found that 56% met the criteria for poor psychological adjustment on a self rating measure, namely the SCL-90-R (Derogatis, 1983). Scores in the clinical range of distress were obtained for 40% of patients for depression and 32% for anxiety. Belgrave and Molock (cited in Molock & Belgrave, 1994) found that 56% of their sample reported feelings of depression.

Thus, the literature would suggest that significant levels of psychological distress are evident amongst those with SCD.

SECTION 1.2: PAIN COPING STRATEGIES AND ADJUSTMENT TO SICKLE CELL DISEASE

Studies amongst both adults and children have highlighted the importance of the relationship between strategies used to cope with pain and overall adjustment to Sickle Cell Disease. Much of the work has been conducted in the United States, largely by Gil and her associates.

Gil and her colleagues have used a modified version of the Coping Strategies Questionnaire (Rosentiel & Keefe, 1983) to assess pain coping strategies. Three main factors have been identified. Negative Thinking is a pattern of coping characterised by catastrophising and self-statements of fear and anger. Passive Adherence consists of passive, concrete strategies
such as resting and taking fluids. Coping Attempts is an active coping approach including cognitive and behavioural strategies such as diverting attention and calming self-statements. Gil, Abrams, Phillips and Keefe (1989) assessed severity of pain, activity levels and health care use amongst a group of 79 SCD patients. They also assessed their pain coping strategies and psychological distress as measured by the SCL-90-R (Derogatis, 1983). Disease severity was assessed by combining SCD phenotype and the number of acute and chronic complications in the previous nine months. Using a series of hierarchical regression analyses, they found that pain coping strategies predicted significant amounts of the variance on a range of adjustment measures even after controlling for frequency of painful episodes, disease severity and demographics. They found that younger patients tended to report more severe pain than older patients and SS patients reported more frequent episodes than those with other phenotypes. After controlling for demographics and disease severity, Negative Thinking and passive reliance solely on physiological methods (Passive Adherence) explained a significant proportion of the variance in pain severity. Patients scoring highly on these factors reported more severe painful episodes. In addition, after controlling for demographics, disease severity and pain frequency, pain coping strategies predicted a significant proportion of the variance in activity levels, psychological distress and health care use. High scores on Negative Thinking and Passive Adherence were associated with greater restriction of activities, higher levels of psychological distress and greater use of health care facilities. Patients low on Coping Attempts had significantly higher levels of activity reduction compared to those scoring highly on this factor.

Gil, Abrams, Phillips and Williams (1992) subsequently conducted a 9-month follow-up study to explore the relationships between pain coping strategies, pain, disease severity, activity level and health care use. Those with frequent painful episodes and younger patients showed heavier use of health care facilities. After controlling for demographics, disease and pain severity, baseline pain coping strategies were significant predictors of subsequent health care use. Those high on Negative Thinking and Passive Adherence at baseline had more frequent and longer hospitalisations over the 9-month follow up period. Similarly, for activity level, pain coping strategies predicted significant additional proportions of the variance after controlling for the above factors. Those high on Negative Thinking and Passive Adherence at baseline showed lower levels of activity. The results of this study also demonstrated relative stability of coping strategies over time.

Thus correlational and longitudinal studies have highlighted the impact of pain coping strategies on a variety of outcome measures. In particular, the impact of negative thinking
on adjustment has been highlighted. The authors suggest that whilst the onset and duration of pain may depend on physiological mechanisms, once pain occurs, the pain coping strategies adopted appear to be related to present and future adjustment across various measures.

The importance of these factors has also been highlighted in children and adolescents. Gil, Williams, Thompson and Kinney (1991) assessed pain coping strategies, pain status, activity level and health care use and psychological distress (assessed using a child behaviour checklist, a diagnostic interview and the SCL-90-R for adolescents) amongst 72 patients aged 7 to 17. Frequency of painful episodes accounted for a significant proportion of variance in health care use. However, after controlling for the effects of demographics and pain frequency, pain coping strategy accounted for significant additional proportions of the variance in health care use. Children high on Coping Attempts had fewer emergency room visits where as those high on Passive Adherence had more visits. With regard to activity levels, after controlling for age and pain frequency, pain coping strategies accounted for significant portions of the variance. Those high on Coping Attempts were active and those high on Negative Thinking and Passive Adherence showed lower levels of activity. Negative Thinking was associated with higher levels of psychological distress and pain coping strategy made a significant additional contribution to the variance after controlling for age and pain frequency. Coping strategy was not associated with pain frequency, duration or intensity. However, it should be noted that pain coping strategy was assessed by asking the child where as data regarding pain was collected from parents.

Gil, Thompson, Keith, Tota-Faucette, Noll and Kinney (1993) conducted a 9-month follow-up study of this group. Even after controlling for age and pain frequency, baseline pain coping strategies accounted for significant amounts of the variance in health care use. In particular, those high on Passive Adherence showed higher use of health care services. Greater health care use was also associated with more frequent painful episodes and being older. Similarly, coping strategies accounted for significant additional variance in activity levels after controlling for demographics and frequency of painful episodes. Children who were high on Coping Attempts were more active. Although children showed stability in their coping strategies over 9-months, there was some suggestion that adolescents showed increased reliance on Negative Thinking and Passive Adherence, coping strategies associated with poorer outcome. It was found that changes in disease complications over time were not related to any of the adjustment measures. Increases in frequency of pain were associated
with greater reductions in activity and increased health care use but were unrelated to pain coping strategy.

Models of overall adjustment to having SCD have incorporated the above data highlighting the importance of pain coping strategies in influencing adjustment. Thompson, Gil, Abrams and Philips (1992) have outlined a transactional stress and coping model of psychological adjustment amongst adults with SCD. They suggested that chronic illness constitutes a stressor to which individual and family systems endeavour to adapt. They hypothesised that the relationship between illness and outcome parameters is not direct but rather arises as a result of an interplay between medical, psycho-social and other mediational parameters. The model includes illness parameters, demographic factors, cognitive mediational factors (appraisal of stress, locus of control and self efficacy), coping strategies for pain and other stressors and family functioning.

In a study of 109 people with SCD, Thompson et al (1992) found that the model accounted for between 44-50% of the variance in psychological distress. Illness and demographic variables accounted for 8-11% of the variance and daily stresses accounted for 28-35% of the variance. Negative Thinking/Passive Adherence coping strategies accounted for an additional 2-5% of the variance. In their discussion, Thompson et al highlighted the need to explore the influence of factors such as causal attributions on adjustment.

Thompson, Gil, Abrams and Phillips (1996) followed up those with SS phenotype from the above sample and looked at the factors influencing their long-term adjustment. Comparing those who showed stable good adjustment with those who showed stable bad adjustment, a number of significant differences emerged. The well adjusted group showed lower levels of illness related and daily stress, used less emotion focused coping and lower levels of pain coping strategies characterised by Negative Thinking/Passive Adherence.

Thompson, Gil, Burbach, Keith and Kinney (1993) discussed the application of a similar model to children and adolescents. They found that after controlling for illness and demographic variables, child pain coping strategies characterised by Negative Thinking accounted for a 21% increment in the variance on child reported of psychological distress. Thompson, Gil, Keith, Gustafson, George and Kinney (1994) conducted a 10-month follow up study of the children in the above study. After controlling for child adjustment at Time 1, illness and demographic variables and follow-up time, pain coping strategies made a significant additional contribution. Negative Thinking accounted for an increment of 19% in
child reported symptoms. Coping characterised by low levels of Coping Attempts accounted for an increment of 8% in maternal reported internalising behaviour problems. Thus, these studies provided further evidence for the importance of pain coping strategies in influencing overall psychological adjustment, over and above the influence of disease related factors and demographic variables.

Thus, there is now good evidence from cross sectional and longitudinal studies for the influence of pain coping strategies on adjustment, both in terms of psychological and everyday functioning, in adults, children and adolescents. In particular, reacting to pain by adopting strategies characterised by negative thinking and passivity has been associated with poorer adjustment.

In recent years, in keeping with developments in other areas of research on pain (Turk & Rudy, 1986; Weisenberg, 1994), attention has focused on the relationships between pain, psychological distress and cognitive style.

Gil, Williams, Keefe and Beckham (1990) explored the relationship between negative thoughts in response to pain flare-ups, psychological distress, coping strategies and pain perception. Negative thoughts were measured using a questionnaire assessing frequency of negative thoughts of three types: negative self-statements, negative social cognitions and self blame (the Inventory of Negative Thoughts in Response to Pain). Participants were also asked to evaluate the degree of control they felt they had over these thoughts. 185 adults from three different pain groups, SCD, rheumatoid arthritis and chronic pain (mainly back pain and headaches), completed the questionnaires. Gil et al found that across the three groups, higher levels of negative thoughts in response to pain were associated with more catastrophising, increased psychological distress and more severe self reported pain. Higher levels of reported control over negative thoughts during pain flare-ups were associated with lower levels of catastrophising and reduced psychological distress. It was found that the three factors on the negative thoughts questionnaire accounted for up to 31% of the variance in overall psychological distress. Some differences were observed between the groups. The chronic pain group showed more negative self statements and social cognitions and reported lower levels of control over their negative thoughts than the other groups. It was hypothesised that these differences could be attributed to the fact that SCD and rheumatoid arthritis are characterised by intermittent pain with pain free periods whereas chronic pain patients often report daily pain. The latter may result in more enduring disability and isolation and provides no opportunity for a return to normal functioning. Alternatively, the
differences in recruitment i.e. through a pain management programme for the chronic pain group as opposed to routine medical treatment for the other two groups, may also have contributed to the observed differences.

Further evidence for the importance of cognitions in response to pain has been provided by recent studies employing experimental pain sensitivity paradigms, which allow for controlled exposure to levels of pain. Gil, Phillips, Webster, Martin, Abrams, Grant, Crawford Clark and Janal (1995) explored the relationship between performance on a pain sensitivity task and responses on the Inventory of Negative Thoughts in Response to Pain amongst 73 SCD patients. They found that whilst reported negative thoughts were not associated with sensory discrimination on their pain task, reporting increased negative thoughts in response to pain was associated with an increased tendency to report more severe pain even in response to low level stimuli. Thus cognitive factors seemed to influence response bias but not sensory discrimination. The authors hypothesised that those who report higher levels of pain during noxious stimulation may also be those who tend to become inactive and require more medical treatment.

Gil, Wilson, Edens, Webster, Abrams, Orringer, Grant, Crawford Clark & Janal (1996) compared the impact of cognitive coping strategies training and education about the disease on use of pain coping strategies and performance on an experimental pain task amongst 64 SCD patients. They found that the cognitive strategies training resulted in higher levels of Coping Attempts, decreased Negative Thinking and lower tendency to report pain during the experimental task. It was also found that cognitive coping strategies training impacted on discrimination, in that those receiving training were better able to discriminate between low and high levels of stimulation. Thus within an experimental setting, cognitive coping strategies training resulted in better coping with pain. However, it was not clear whether the training programme had any impact on everyday coping with pain.

There now appears to be good evidence from correlational, longitudinal and intervention studies that cognitive appraisal of pain and coping strategies employed in response to pain, influence levels of psychological distress and adjustment. Gil et al (1990) have suggested that individuals respond differently to the experience of a pain flare up. Those who respond negatively to the experience of pain, in other words viewing it in a catastrophic manner as beyond their control or as a sign of personal failure are likely to respond in a maladaptive way, becoming inactive, withdrawing from social contact and showing higher levels of psychological distress. This pattern of response is likely also to be associated with pain
being perceived as more severe and with increased reliance on medical services to cope with pain.

In contrast those who appraise their pain in a more realistic or balanced way, in other words as a manageable and time limited experience, may be more likely to adopt more functional ways of managing their pain. This is likely also to be associated with lower levels of self-reported pain and with less reliance solely on medical services.

Much of the research conducted so far has focussed solely on cognitive responses to pain. Whilst this has been demonstrated to be an important factor contributing to overall adjustment, it also seems important to look at more cognitive variables pertaining to other non-pain related situations. This may be particularly important for conditions such as SCD where many people experience relatively pain free periods interspersed with acute painful crises. In addition, much of the research has neglected to take into account cultural factors and the impact that these may have on cognitive style and response to pain.

SECTION 1.3: COGNITIVE STYLE, PAIN AND DEPRESSION IN OTHER PAIN POPULATIONS

Research on other pain populations has also explored the relationship between cognitive style, pain and psychological distress, usually depression. This research is based on a cognitive-behavioural model of pain, which postulates that the experience of pain is not in itself sufficient to result in an individual becoming depressed. Rather factors such as level of interference in everyday life and perceptions of control act as mediators or indirect links between pain experience and psychological distress (see for example, Rudy, Kerns & Turk, 1988). Research into adjustment to pain has explored the impact of a range of cognitive variables including locus of control, self efficacy and perceived control over pain (Jensen, Turner, Romano & Karoly, 1991). Coverage of all these areas is beyond the scope of this review, which will focus on studies addressing the role of attributional style and cognitive distortion in pain and depression.

Love (1988) explored differences in attributional style between depressed and non-depressed chronic lower back pain patients. He found that the depressed group were characterised by a more internal, stable and global style for negative events. No differences were found between the groups on attributional style for positive events. However, a classification analysis suggested that not all the depressed participants possessed this characteristic
attributional style. Love suggested that depressive cognitive style is not an inevitable concomitant of depression in pain patients. It should be noted that this study relied solely on self-rated depression rather than using observer ratings. The study made no attempt to assess pain levels in the two groups, thus it is not possible to assess the relative contributions of pain experience and attributional style to depression.

Ingram, Atkinson, Slater, Saccuzzo and Garfin (1990) compared negative automatic thoughts, positive automatic thoughts and attributional style in depressed and non-depressed chronic lower back pain patients and healthy controls. Depression was assessed using self-report and observer rated measures. No differences were found between the pain groups on any of the disease or pain related variables and the non-depressed pain group resembled the healthy controls in terms of their levels of depression. No differences were found between the groups on the attributional style measure, although this could have been due to the small sample size. However, the depressed pain group showed significantly higher scores than the other two groups on the negative automatic thoughts measure. On the measure of positive automatic thoughts, no differences were found between the depressed pain group and the healthy controls. However, the non-depressed pain group showed significantly higher scores than the other two groups. The findings highlighted the association between depression and negative thinking in pain populations, regardless of pain intensity. There was also some suggestion that positive thinking could act as a protective factor against depression in the face of the stresses associated with being in pain. Ingram et al. also suggested that their results highlighted the importance of assessing different aspects of cognition given that these may be related to depression in chronic pain in different ways.

Drawing on Beck’s model of depression, Lefebvre (1981) argued that differences in general cognitive style should differentiate between depressed and non-depressed pain patients. In addition, he suggested that these differences in cognitive style may help to explain why some individuals respond to the stress of chronic pain by becoming depressed whilst others do not. Lefebvre (1981) developed a Cognitive Error Questionnaire, which assessed four types of thinking error derived from Beck’s model and the extent to which these were manifested in general situations (General CEQ) and in pain situations (LBPCEQ). Participants were presented with a series of short vignettes followed by a sample thought reflecting one of the thinking errors. They were then asked to rate the extent to which this thought accorded with how they would respond in the same situation.
Four groups of participants, depressed psychiatric patients, depressed and non-depressed low back pain patients and normal controls completed the CEQ, the Beck Depression Inventory and ratings of duration, frequency and intensity of pain. It was found that on the General CEQ, the depressed patients, with and without pain, showed similar levels of cognitive distortion and showed significantly more cognitive distortion than the non-depressed participants. Depressed and non-depressed pain patients did not differ significantly on frequency or duration of pain but depressed patients rated their pain as more severe. Pain ratings were not significantly correlated with scores on either the General CEQ or LBPCEQ. On the LBPCEQ, depressed pain patients endorsed items more strongly than depressed participants without pain, although both groups showed significantly different scores from the non-depressed groups. Thus, depressed people with pain in some ways resembled other depressed people but also showed pain specific elements to their thinking. Both the depressed groups showed more distorted cognitions than the non-depressed groups.

Smith, Aberger, Follick and Ahern (1986) replicated the above, finding an association between cognitive distortion and depression, rather than somatisation, in lower back pain patients which remained after controlling for pain severity.

Smith, Peck, Milano and Ward (1988) conducted a study of the relationship between cognitive errors, depression and disability in rheumatoid arthritis (RA). 92 participants with RA completed a modified version of the CEQ, the Beck Depression Inventory and the Hamilton Rating Scale for Depression, and two forms of the Disability Index of the Stamford Health Assessment Questionnaire. A measure of disease severity was also obtained. They found that cognitive errors in general and disease related situations were significantly related to self reported and interviewer rated depression. A multiple regression analysis suggested that after controlling for the effects of disease severity, cognitive distortion accounted for a significant additional amount of the variance in self- and interviewer-rated depression. Cognitive distortion accounted for a marginally significant amount of the variance in self reported disability, independent of disease severity, but did not account for significant amounts of interviewer rated disability. When analyses were conducted separately for the two types of distortion, arthritis related cognitive errors were significantly related to both self-rated and interviewer-rated disability, independent of disease severity. However, general cognitive errors were not related to disability. More complex analyses also highlighted the important role played by cognitive factors. A series of regression analyses suggested that disease duration, disease activity and disability combined accounted for 14.5% of the variance in depression. However, cognitive distortion accounted for an
additional 11% of the variance in depression. When cognitive distortion was controlled, the amount of variance in depression accounted for by disease severity and disability dropped to 8.3%. This unmediated, direct disease-depression relationship was significant but so also was the component of the illness-depression link mediated by cognitive distortion. Thus, a significant amount of the influence of illness on depression was mediated by cognitive distortion.

Thus research with other pain groups is beginning to elucidate the relationships between cognitive variables, pain and depression. In two different pain groups, cognitive distortions have been found to be related to depression and in some cases to disability. Gil and colleagues have demonstrated in the SCD population the relationship between negative thinking, psychological distress and pain. However, little research has been conducted amongst British people with SCD to explore the relationships between these variables.

The present study aimed to explore the relationship between pain and other disease related variables, cognitive style (both in general situations and pertaining to pain) and depression amongst people with SCD. Specifically, the study focused on whether cognitive factors accounted for additional variance in depression above and beyond the variance accounted for by disease related variables. Many of the previous studies with the SCD population have failed to take into account cultural factors. This study therefore aimed to compare cognitive style amongst the SCD group with a normal control group from the same ethnic background. In addition, the study explored the relationship between gender and psychological distress amongst people with SCD.

**Hypotheses:**

1. **Distortion pertaining to everyday life situations**
   For cognitive distortion pertaining to everyday life situations, it was hypothesised that those who were depressed would show significantly higher levels of distortion than those who were not depressed. It was hypothesised that those people with SCD who were not depressed would not differ significantly from normal controls on this variable.

2. **Distortion pertaining to pain related situations**
   For cognitive distortion pertaining to pain related situations, it was hypothesised that those who were depressed would show significantly higher levels of distortion than
those who were not depressed. It was hypothesised that those with SCD who were not depressed would not differ significantly from normal controls on this variable.

3. **Disease related variables and depression**
   Amongst those with SCD, disease related variables (disease type, number of complications and frequency of painful crises) would not differ significantly between those who were and those who were not depressed. Whilst it is acknowledged that this hypothesis was phrased in the opposite way from the convention, the literature suggested that this is what would be predicted.

4. **Severity of pain and depression**
   For those with SCD, it was hypothesised that higher levels of depression would be associated with more severe rating of pain.

5. **The interaction between pain, cognitive style and depression**
   After controlling for disease severity and pain experience, degree of cognitive distortion would make a significant additional contribution to variance in depression. This would be particularly true for cognitions relating to pain.

6. **Gender and psychopathology**
   It was hypothesised that higher levels and rates of both anxiety and depression would be found amongst men with SCD than amongst women with SCD.
SECTION 2: METHODOLOGY:

2.1 Design
The study compared three groups matched as closely as possible for age, sex and ethnic group:

1. People with SCD who are below the cut off for depression;
2. People with SCD who are above the cut off for depression;
3. People without SCD who are below the cut off for depression.

2.2 Participants

2.2.1. Sickle Cell Disease groups

Participants for the two Sickle Cell Disease groups were selected from the patient database at the Haematology departments at the City Hospital NHS Trust, Birmingham. A second hospital in Birmingham was also approached to see if they would participate in the study but the Consultant Haematologist declined. A local SCD support group was also unable to assist with recruitment.

The following selection criteria were applied:

1. A diagnosis of Sickle Cell Anaemia(SS), SC disease (HbSC) or Sickle B Thalassemia (SBThal);
2. Aged between 16 and 45. The upper age limit was based on life expectancy data for SCD patients (Davies & Oni, 1997);
3. Of Afro-Caribbean origin;
4. No current or previous history of psychotic psychiatric disorder.

2.2.2. Non-Sickle Cell Disease groups

Participants for this group were recruited via the North Birmingham College, a college of further education offering both vocational and academic courses and via Hillcrest School. Both institutions fell in the geographical area covered by the two hospitals. In addition, four churches in the area, with predominantly Afro-Caribbean congregations, were approached to

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help with recruitment. Only one of the churches, Holy Trinity, Perry Barr, agreed to participate in the study.

The following selection criteria were applied:

1. Of Afro-Caribbean origin. People of mixed race were not included;
2. No diagnosis of SCD;
3. No other chronic physical health problems or chronic pain conditions;
4. Aged between 16 and 45;
5. No current or previous history of psychotic psychiatric disorder;
6. A score below the cut off for depression on the Hospital Anxiety and Depression Scale (see below).

2.3. Procedure

Ethical Committee approval was sought and obtained from the Research Ethics Committees at the City Hospital NHS Trust and the University of Surrey.

2.3.1. SCD groups

For the SCD groups, names and addresses of people meeting the study criteria were obtained from the patient database at the hospital. Letters from the Consultant Haematologist were sent to all these patients, informing them that the study would be happening and inviting them to take part (Appendix 1). An information sheet providing more details was also enclosed (Appendix 2). People were asked to indicate whether they were interested in taking part in the study by returning a reply slip to the investigator. A stamped addressed envelope was enclosed for this purpose. If a reply had not been received within the space of four weeks then follow-up telephone calls were made to those people for whom telephone numbers were available. Follow-up letters were sent to all those who had not replied and for whom telephone numbers were not available. In-patients were approached whilst they were in hospital to check whether they had received the information about the study and to ask whether they were interested in taking part.

If people expressed an interest in taking part in the study, then an appointment was made either at the patient’s home or at the hospital. This provided an opportunity for further discussion of the study. If patients were still willing to participate then they were asked to sign a consent form (Appendix 3). The various measures were then administered. As part of the interview, participants were asked if they had ever had any contact with a mental
health professional and, if so, what the reason for referral had been. This was used as a way of assessing whether the individual had any history of psychotic psychiatric disorder. None of the people interviewed had any history of this kind.

49 initial letters of invitation were sent out to people meeting the criteria for the study. 8 people indicated that they definitely did not wish to take part, either by returning their reply slips or during follow up telephone conversations. 26 people agreed to take part in the study, constituting 53.1% of those who were originally contacted. Interviews were conducted with all but one individual who had to withdraw from the study because she was too unwell to be able to participate in the interview. One further individual was reported to have died during the course of recruitment for the study. No reply was received from the remaining 14 people.

2.3.2. Non-SCD groups

For the control group, information about the study was distributed via college tutors and teachers at the school. Invitations to participate were extended both to students and to eligible members of staff. People were asked to indicate their interest in participating by completing a reply slip, which could be placed in a sealed box at a central location. As no replies were obtained, as a follow-up people were approached in classes, in the library and in the canteen. People were given an information sheet giving details of the study (Appendix 4) and were asked if they would be interested in taking part. It was made clear that people were under no obligation to take part in the study. If the person indicated that they would be willing to take part, a time was arranged for them to sign the consent form (Appendix 5) and to complete the measures. As with the SCD groups, as part of the interview participants were asked whether they had any previous contact with mental health professionals.

For the church, the recruitment procedure was slightly different. Information about the study was distributed via the church newsletter and a verbal notice during a church service. People were asked to indicate their interest in taking part by contacting the author at the end of the service or via the University. A time was then made to go over the details of the study and, if the person was still willing to take part, to sign the consent form and complete the measures.

20 people agreed to take part in the study, 15 from the Further Education College, 2 from the school and 3 from the church. However, two people had to be excluded because they scored
above the cut off for depression on the Hospital Anxiety and Depression Scale and were
directed to the college counselling services. No one who was interviewed reported any
previous psychiatric history.

2.4. Measures

2.4.1. The Hospital Anxiety and Depression Scale (HAD) (Zigmond & Snaith, 1983)
Mayou and Hawton (1986) have highlighted the difficulties associated with assessing
anxiety and depression amongst those with physical health problems. For example, many
commonly used screening measures include fatigue and other somatic symptoms. Where
people have physical causes for such symptoms, use of such measures can lead to the over­
estimation of the prevalence of anxiety and depression amongst those with chronic physical
health problems. The HAD avoids many of the problems associated with other measures in
that it was designed specifically to measure anxiety and depression in people with physical
health problems. It includes only psychological manifestations of distress and excludes
physical symptoms. It is also sensitive to mild forms of disorder, avoiding the “floor effect”
noted with some other measures (Herrmann, 1997).

The HAD consists of two subscales, one measuring anxiety (HADA) and the other
depression (HADD). Each subscale consists of seven items and each item is rated on a four­
point scale. A score of 11 or above indicates a clinical state; a score of 8-10 indicates a
borderline state and a score of 7 or less is normal (Zigmond & Snaith, 1983).

Hermann (1997) recently reviewed validity and reliability studies using the HAD in a variety
of settings, including both medical patient and general population samples. Internal
consistencies of 0.80- 0.93 have been reported for the anxiety and 0.81- 0.90 for the
depression subscales. Retest reliability was 0.80 at two weeks, decreasing with longer
intervals. Thus, the HAD was reported to be stable enough to be resistant to situational
influences but was also sensitive to changes in mood over time. The validity of the HAD has
also been confirmed (see for example Aylard, Gooding, McKenna & Snaith, 1987).
Herrmann (1997) concluded that whilst there was evidence that the two subscales were
correlated in most groups, several studies have shown that the HAD anxiety subscale shows
significantly higher correlations with measures of anxiety (versus depression) whilst the
depression subscale correlates better with measures of depression (as opposed to anxiety).
For the purposes of this study a score of 8 or above was taken as indicative of depression. Zigmond and Snaith (1983) recommended the use of this lower cut off where inclusion of all possible cases is required. Barczak, Kane, Andrews, Congdon, Clay and Betts (1988) in their study based at a GUM clinic suggested that this cut-off produced optimal results, giving sensitivities of 82% and 70%, and specificities of 94% and 68%, for depressive and anxiety disorders respectively. Scores on the depression subscale of this measure were used to allocate people to the depressed or non-depressed groups of participants.

A copy of the questionnaire is included in Appendix 6.

2.4.2. The Cognitive Error Questionnaire (Lefebvre, 1981; Smith, Peck, Milano & Ward, 1988)

This questionnaire was developed to measure four different types of cognitive error or distortion derived from Beck’s cognitive theory of depression (Beck, 1976). It consists of two subparts, the General CEQ and the LBP (Lower Back Pain) CEQ. Each subpart consists of 24 short vignettes followed by a dysphoric cognition about the vignette that reflects a cognitive error. Participants are asked to rate on a five-point scale how similar the cognition is to the thought that they would have in a similar situation. The General CEQ consists of vignettes about everyday situations involving work, leisure, relationships etc. The LBP CEQ consists of vignettes in which the experience of pain interferes with everyday functioning in work, leisure, relationships etc.

The types of cognitive error measured by the questionnaire are:

1. Catastrophising: that is anticipating that the outcome of an experience will be disastrous or misinterpreting an event as calamitous;
2. Overgeneralisation: that is assuming that the negative outcome of one event or experience will be applicable to all future similar events or experiences;
3. Personalisation: that is overestimating personal responsibility for negative events or interpreting such events as having personal significance;
4. Selective abstraction: that is over attending to negative aspects of an experience and ignoring other, more positive aspects.

Each item is scored as follows:

<table>
<thead>
<tr>
<th>Rating</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Not at all like I would think:</td>
<td>0</td>
</tr>
<tr>
<td>A little like I would think:</td>
<td>1</td>
</tr>
<tr>
<td>Somewhat like I would think:</td>
<td>2</td>
</tr>
</tbody>
</table>
A lot like I would think: 3
Almost exactly like I would think: 4.

To obtain the total score for each scale, the scores for each of the 24 items in that scale are added together.

Studies conducted during the development of the questionnaire suggested that both subparts had high test-retest reliability (0.80-0.85), alternate form reliability (0.76-0.82) and internal consistency (0.89-0.92). Both subparts were moderately correlated with the Hammen and Krantz Depressed-Distorted Scale (0.53-0.60 concurrent validity) (Lefebvre, 1981).

Smith, Peck, Milano and Ward (1988) used a modified version of the questionnaire with patients with Rheumatoid Arthritis, a condition in which people experience recurrent, acute periods of pain much like those with SCD. They reported internal consistencies for the individual, revised arthritis distortion scales ranging from 0.81-0.86. The internal consistency of the total arthritis distortion scale was 0.92. The internal consistencies of the individual general distortion scales ranged from 0.72 to 0.78. The total general distortion score was reported to have an internal consistency of 0.90.

The questionnaire used in this study was modified to take account of differences in American and English language and to take account of the age group of participants. Participants in the current study were younger than those in the earlier studies. These modifications involved, for example, altering references to taking part in golf to ten-pin bowling. The vignettes in the pain CEQ were modified so that they referred to pain arising from SCD. The modified questionnaire was piloted informally on a group of three Afro-Caribbean students. They made suggestions for minor alterations to wording but generally reported that they found the vignettes meaningful.

A copy of the questionnaire is included in Appendix 7.

2.4.3. The Structured Pain Interview (Gil, Abrams, Phillips & Keefe, 1989)
This interview was developed specifically for use with people with SCD. It consists of three sections: pain status (ratings of frequency, duration and severity); activity pattern and health care utilisation. This measure has been used extensively in studies with both adults and children with SCD and reliability and validity data have been reported for both groups. Gil, Abrams, Phillips and Williams (1992) compared responses given in the interview with self-
monitoring records conducted over a two-week period. Significant and positive Pearson product moment correlations were obtained for pain ratings and health care contacts and uptime on interview was inversely correlated with downtime on self-monitoring. Significant correlations were also obtained for reported health care use as compared with medical records. Gil, Williams, Thompson and Kinney (1991) reported satisfactory inter-rater reliability between adolescents and their parents for reports of pain intensity and duration and health care use. Significant positive correlations were found between reported health care use and medical records.

A copy of the interview is included in Appendix 8.

2.4.4. Disease Severity
In keeping with previous studies (e.g. Gil, Abrams, Phillips & Keefe, 1989; Gil, Williams, Thompson & Kinney, 1991), disease phenotype was combined with number of acute and chronic complications in the previous year to provide an estimate of disease severity. People were asked to provide this information at the end of the Structured Pain Interview (see Appendix 8.)

2.4.5. Demographic variables
Details of the following demographic variables were recorded: age, sex, ethnic origin, number of years in education (counting from the start of primary school), marital status and employment status. (See Appendix 9).

Participants in the SCD groups completed all of the above measures. Participants in the non-SCD groups completed all of the measures except the Structured Pain Interview and the measure of disease severity. Basic background information and information on pain experience and disease severity was collected by interview. Most participants completed the HAD and the CEQ for themselves. However, some of the SCD participants who were in-patients preferred to have the questions read aloud to them.

2.5. Statistical Analysis
Data was coded and analysed using the Statistical Package for the Social Sciences (SPSS) for Windows 5.1.
SECTION 3 : RESULTS

3.1. Characteristics of participants

Of the 25 people with SCD interviewed for the study, six scored 8 or above on the depression subscale of the HAD (HADD) and thus constituted the depressed SCD group. Thus the final numbers in each group were:

1. SCD and not depressed = 19
2. SCD and depressed = 6
3. Non SCD and not depressed = 18.

Descriptive data for the three groups in terms of age in years, number of years in education, gender mix, marital status and employment status are shown below.

Table 1: Descriptive data for age, number of years in education and gender mix

<table>
<thead>
<tr>
<th>Group</th>
<th>Age Mean (S.D.)</th>
<th>Years in education Mean (S.D.)</th>
<th>Gender Male</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed</td>
<td>25.89 (8.90)</td>
<td>12.89 (2.72)</td>
<td>8</td>
<td>(42.10%)</td>
</tr>
<tr>
<td>(N =19)</td>
<td></td>
<td></td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>SCD and depressed</td>
<td>28.00 (2.96)</td>
<td>13.50 (3.39)</td>
<td>4</td>
<td>(66.67%)</td>
</tr>
<tr>
<td>(N=6)</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Non SCD and not depressed</td>
<td>26.56 (7.42)</td>
<td>15.22 (2.96)</td>
<td>10</td>
<td>(55.56%)</td>
</tr>
<tr>
<td>(N=18)</td>
<td></td>
<td></td>
<td>8</td>
<td></td>
</tr>
</tbody>
</table>

Prior to conducting any comparison between the groups, the variables of age and number of years in education were tested for the assumptions of normality and the statistical tests used checked for homogeneity of variance using Levene’s test. For age, the assumptions of normality were not met and the results of Levene’s test also suggested that assumption of homogeneity of variance was not met for this variable (F(2,40)=5.52, p<0.05). A non-parametric test of variance, the Kruskal Wallis One Way Analysis of Variance was therefore applied to the age data. The results suggested that there was no significant difference between the three groups in terms of age (chi square = 0.68, d.f.=2, p=0.713, n.s.).
The assumptions of normality were not met for number of years in education although the Levene’s test suggested that the assumption of homogeneity of variance was met for this variable ($F(2,40) = 0.18, p=0.836, \text{n.s.}$). A Kruskal Wallis One Way Analysis of Variance was applied to the data. The results suggested that there was no significant difference between the three groups in terms of number of years in education ($\chi^2 = 5.39, \text{d.f.}=2, p=0.067, \text{n.s.}$).

Overall, 51.2% of participants were male and 48.8% were female. The original intention was to conduct a Chi-Square analysis to explore the association between group membership and gender balance. However, this was not possible because more than 20% of the cells had expected frequencies of less than 5 and thus the requirements for the valid use of Chi-Square were not fulfilled (Kinnear & Gray, 1994).

Table 2: Descriptive data for marital status

<table>
<thead>
<tr>
<th>Group</th>
<th>Marital Status</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed (N=19)</td>
<td>Single</td>
<td>17 (89.47%)</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>2 (10.52%)</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>0</td>
</tr>
<tr>
<td>SCD and depressed (N=6)</td>
<td>Single</td>
<td>6 (100%)</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>0</td>
</tr>
<tr>
<td>Non SCD and not depressed (N=18)</td>
<td>Single</td>
<td>16 (88.89%)</td>
</tr>
<tr>
<td></td>
<td>Married</td>
<td>1 (5.56%)</td>
</tr>
<tr>
<td></td>
<td>Separated</td>
<td>1 (5.56%)</td>
</tr>
</tbody>
</table>

The vast majority of people in all three groups, 90.7% of all participants, were single and therefore the groups were well matched as regards marital status.
Table 3: Descriptive data for employment status

<table>
<thead>
<tr>
<th>Group</th>
<th>Employment status</th>
<th>Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>SCD and not depressed</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>(N=19)</td>
<td>(21.05%)</td>
<td>(36.84%)</td>
</tr>
<tr>
<td>SCD and depressed</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>(N=6)</td>
<td>(16.67%)</td>
<td>(16.67%)</td>
</tr>
<tr>
<td>Non SCD and not depressed (N=18)</td>
<td>7</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(38.89%)</td>
<td>(5.56%)</td>
</tr>
</tbody>
</table>

1=Full time employment 2=Part time employment 3=Student 4=Unemployed 5=Not working due to sickness

Overall, 27.9% of all participants were in full time employment, 41.9% were students, 25.6% were not working due to sickness, 2.3% were unemployed and 2.3% were working part-time. Once again it was not possible to conduct a Chi-Square analysis on the above data because more than 20% of the cells had expected frequencies of less than 5. As might be expected, all of those not working due to sickness came from the two SCD groups, especially the SCD and depressed group.

Although it was not possible to perform all of the intended analyses, where analyses were conducted no significant differences emerged between the groups. Overall the three groups appeared to be reasonably well matched on all of the matching variables except possibly for employment status.

Descriptive data for scores on the HAD depression and anxiety subscales are shown overleaf in table 4. In addition numbers and percentages of people in each group scoring above the cut off (cut off = 8) on the HAD anxiety (HADA) subscale are shown in table 5 overleaf.
Table 4: Descriptive data for depression and anxiety scores

<table>
<thead>
<tr>
<th>Group</th>
<th>Depression scores</th>
<th>Anxiety scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>SCD and not depressed (N=19)</td>
<td>4.26</td>
<td>2.21</td>
</tr>
<tr>
<td>SCD and depressed (N=6)</td>
<td>10.50</td>
<td>1.87</td>
</tr>
<tr>
<td>Non SCD and not depressed (N=18)</td>
<td>2.61</td>
<td>2.09</td>
</tr>
</tbody>
</table>

Table 5: Numbers and percentages of people in each group scoring above cut off for HAD anxiety (HADA) subscale

<table>
<thead>
<tr>
<th>Group</th>
<th>Number of people scoring 8 or above on HADA</th>
<th>Percentage of people scoring 8 or above</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed (N=19)</td>
<td>11</td>
<td>57.89%</td>
</tr>
<tr>
<td>SCD and depressed (N=6)</td>
<td>6</td>
<td>100%</td>
</tr>
<tr>
<td>Non SCD and not depressed (N=18)</td>
<td>4</td>
<td>22.22%</td>
</tr>
</tbody>
</table>

Given the design of the study, it would be expected that the SCD depressed group would show significantly higher depression scores than either of the other two groups. However, the design of the study also assumed that the two non-depressed groups would be comparable in terms of depression score. Statistical analysis was therefore conducted to test this assumption. The depression scores data met the assumption of normality and the Levene’s test suggested that the assumption of homogeneity of variance was also met (F(2,40)= 0.25, p=0.78, n.s.). A One Way Analysis of Variance suggested that there were significant differences between the groups in terms of depression scores (F(2,40)= 31.33, p<0.001). A post-hoc analysis, Tukey’s Honestly Significant Difference, revealed significant (p<0.05) differences in depression score between the SCD & depressed and the SCD & not depressed groups and the SCD & depressed and the non SCD & not depressed groups. There were no significant differences between the SCD & not depressed and the non SCD & not depressed groups.
Thus, as would be expected, the SCD & depressed group showed significantly higher depression scores than either of the other two groups. The other two groups were comparable in terms of depression scores.

The anxiety scores data also met the assumptions of normality and the Levene’s test suggested that the assumption of homogeneity of variance was also met (F(2,40) = 2.52, p=0.09, n.s.). A One Way Analysis of Variance suggested that there were significant differences between the groups in terms of anxiety scores (F(2,40) = 11.32, p<0.001). A post hoc analysis, Tukey’s Honestly Significant Difference, revealed significant (p<0.05) differences between the SCD & depressed and the SCD & not depressed groups and the SCD & depressed and the non SCD & not depressed groups. Significant differences were also found between the SCD & non depressed groups and non SCD & not depressed groups. Thus, both SCD groups showed elevated anxiety scores as compared with normal controls. The SCD & depressed group also showed elevations in anxiety scores as compared with the other SCD group.

The data in Table 5 also indicates the high rates of clinical levels of anxiety amongst those with SCD as compared with normal controls. Overall 68% of all SCD participants scored 8 or above on the HADA.

Properties of scales
Although the size of the sample prohibited comprehensive analyses of the properties of the scales, preliminary analyses were conducted. The internal consistencies of the two subscales of the Cognitive Error Questionnaire and the two subscales of the HAD were calculated. Cronbach’s alphas for each of these scales are shown in table 6 below.

<table>
<thead>
<tr>
<th></th>
<th>General CEQ</th>
<th>SCD CEQ</th>
<th>HADD</th>
<th>HADA</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cronbach’s Alpha</td>
<td>0.881</td>
<td>0.899</td>
<td>0.749</td>
<td>0.811</td>
</tr>
</tbody>
</table>

Pearson’s correlation was calculated to explore the strength of the relationship between the General CEQ and the SCD CEQ. The correlation between the two scales was highly significant (r = 0.800, p<0.001). Pearson’s correlations were also calculated to explore the relationships between scores on the two subscales of the CEQ and the two subscales of the HAD. The results are shown in table 7 overleaf.
Table 7: Pearson’s correlations for relationships between General CEQ, SCD CEQ, HADD and HADA scores

<table>
<thead>
<tr>
<th></th>
<th>General CEQ</th>
<th>SCD CEQ</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADD</td>
<td>$r = 0.343$</td>
<td>$r = 0.385$</td>
</tr>
<tr>
<td></td>
<td>(p&lt;0.05)</td>
<td>(p&lt;0.05)</td>
</tr>
<tr>
<td>HADA</td>
<td>$r = 0.289$</td>
<td>$r = 0.198$</td>
</tr>
<tr>
<td></td>
<td>(p=0.06, n.s.)</td>
<td>(p=0.20, n.s.)</td>
</tr>
</tbody>
</table>

The results for each of the experimental hypotheses will now be discussed.

**Hypothesis 1**

For cognitive distortion pertaining to everyday life situations, it was hypothesised that those who were depressed would show significantly higher levels of distortion than those who were not depressed. It was hypothesised that those people with SCD who were not depressed would not differ significantly from normal controls on this variable.

Descriptive data for scores on the General subscale of Cognitive Error Questionnaire are shown below in table 8. The figures in brackets show the means and standard deviations reported by Lefebvre (1981) for his non-depressed lower back pain, depressed lower back pain and non-depressed non-pain subjects, using the original version of the questionnaire.

Table 8: Descriptive data for scores on the General CEQ (Data from Lefebvre (1981) shown in brackets)

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed (N=19)</td>
<td>27.37  (8.1)</td>
<td>16.72 (6.5)</td>
</tr>
<tr>
<td>SCD and depressed (N=6)</td>
<td>44.33  (23.3)</td>
<td>14.57 (19.1)</td>
</tr>
<tr>
<td>Non SCD and not depressed (N=18)</td>
<td>28.83  (10.7)</td>
<td>17.26 (6.8)</td>
</tr>
</tbody>
</table>
As above, the data was tested for the assumptions of normality and homogeneity of variance. The assumption of normality was met for the data and the Levene's test also suggested that the assumption of homogeneity of variance was also met (F(2,40)=0.22, p=0.80, n.s.). A One Way Analysis of Variance revealed no significant differences between the groups (F(2,40)=2.48, p=0.10, n.s.).

**Hypothesis 2**

For cognitive distortion pertaining to pain related situations, it was hypothesised that those who were depressed would show significantly higher levels of distortion than those who were not depressed. It was hypothesised that those with SCD who were not depressed would not differ significantly from normal controls on this variable.

Descriptive data for scores on the SCD (Pain) subscale of the Cognitive Error Questionnaire are shown below in table 9. The figures in brackets show the means and standard deviations reported by Lefebvre (1981) for his non-depressed lower back pain, depressed lower back pain and non-depressed non-pain subjects, using the lower back pain version of the questionnaire.

**Table 9: Descriptive data for scores on the SCD CEQ (Data from Lefebvre (1981) shown in brackets)**

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean</th>
<th>Standard deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed</td>
<td>38.52</td>
<td>17.56 (12.2)</td>
</tr>
<tr>
<td>(N=19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCD and depressed</td>
<td>49.83</td>
<td>17.29 (16.0)</td>
</tr>
<tr>
<td>(N=6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non SCD and not depressed</td>
<td>39.78</td>
<td>18.48 (11.1)</td>
</tr>
<tr>
<td>(N=18)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The data fulfilled the assumptions of normality and the Levene's test suggested that the assumption of homogeneity of variance was also met (F(2,40)=0.11, p=0.90, n.s.). The One Way Analysis of Variance (F(2,40)=.94, p=0.40) did not reveal any significant differences between the groups.
Hypothesis 3
Amongst those with SCD, disease related variables (disease type, number of complications and frequency of painful crises) would not differ significantly between those who were and were not depressed.

Descriptive data for these three variables are provided in tables 10 and 11.

Table 10: Descriptive data for disease type

<table>
<thead>
<tr>
<th>Group</th>
<th>Sickle Cell Anaemia (SS) Number (Percentage)</th>
<th>SC disease (HbSC) Number (Percentage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SCD and not depressed</td>
<td>13 (68.42%)</td>
<td>6 (31.58%)</td>
</tr>
<tr>
<td>(N=19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCD and depressed</td>
<td>4 (66.67%)</td>
<td>2 (33.33%)</td>
</tr>
<tr>
<td>(N=6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

It was not possible to perform a Chi-square analysis on the above data because the expected frequencies in some of the cells fell below 5 (Kinnear & Gray, 1994). However, a Fisher’s Exact Probability Test was performed. The results suggested that there was no significant association between group membership and disease type (p=0.651, n.s.).

Table 11: Descriptive data for crisis frequency and numbers of complications in the previous 12 months

<table>
<thead>
<tr>
<th>Group</th>
<th>Number of crises</th>
<th>Number of complications</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean S.D. Range</td>
<td>Mean S.D. Range</td>
</tr>
<tr>
<td>SCD and not depressed</td>
<td>8.00 8.01 0-25</td>
<td>1.63 1.50 0-5</td>
</tr>
<tr>
<td>(N=19)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SCD and depressed</td>
<td>14.33 16.23 0-40</td>
<td>2.17 1.17 1-4</td>
</tr>
<tr>
<td>(N=6)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
The assumptions of normality were not met for the data on number of crises during the last 12 months. Levene’s test for homogeneity of variance was applied to the data and the results indicated that the assumption of homogeneity of variance was not met for this variable (F= 8.20, p < 0.05). A non-parametric test, the Mann Whitney U test was therefore applied to the data. The results, corrected for ties, suggested that there was no significant difference between the two groups (U= 46.0, n=25, p=0.48, n.s.). The data highlighted the extreme variability of crisis frequency amongst people with SCD.

The assumptions of normality were not met for the data on number of complications in the last 12 months, although the Levene’s test suggested that the assumption of homogeneity of variance was met for this variable (F= 0.315, p=0.58, n.s). A Mann Whitney U test did not reveal any significant differences between the groups (U=41.5, n=25, p=0.31, n.s.).

**Hypothesis 4**

For those with SCD, it was hypothesised that higher levels of depression would be associated with more severe rating of pain.

The assumption of normality was not met for the data on ratings of severity of pain. Therefore, the strength of the association between rating of pain severity and depression was calculated using Kendall’s Tau. The results suggested that there was no significant relationship between the two variables (r = 0.155, n=25, p=0.321, n.s.).

**Hypothesis 5**

After controlling for disease severity and pain experience, degree of cognitive distortion would make a significant additional contribution to depression. This would be particularly true for cognitions relating to pain.

Partial correlations were calculated for the relationship between General CEQ score and depression and SCD CEQ score and depression. In both cases, the following variables were controlled for: number of complications, crisis frequency and pain severity. Disease type was not included as a control variable partly because it was a categorical variable and also because within disease type there is known to be considerable variability in terms of pain experience and disease complications. The analysis suggested that even after controlling for the above variables, there was still a significant relationship between General CEQ score and depression (r =0.462, n=25, p<0.05) and between SCD CEQ score and depression (r =0.436, n=25, p<0.05).
Hypothesis 6
It was hypothesised that higher levels and rates of both depression and anxiety would be found amongst men with SCD than amongst women with SCD.

Descriptive data for scores on the depression (HADD) and anxiety (HADA) subscales of the HAD according to gender are shown below in table 12. In addition, numbers and percentages of people scoring above the cut offs for anxiety and depression and for both anxiety and depression are shown in table 13.

Table 12: Descriptive data for scores on HADD and HADA for men and women

<table>
<thead>
<tr>
<th>Gender</th>
<th>HADD scores</th>
<th>HADA scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>S.D.</td>
</tr>
<tr>
<td>Male (N=12)</td>
<td>6.33</td>
<td>3.77</td>
</tr>
<tr>
<td>Female (N=13)</td>
<td>5.23</td>
<td>3.14</td>
</tr>
</tbody>
</table>

The data satisfied the assumptions of normality and the assumption of homogeneity of variance (Levene’s test for depression scores: F=0.74, p=0.40, n.s.; Levene’s test for anxiety scores: F=0.36, p=0.56, n.s.). A T-test for independent samples suggested that there were no significant differences between the two genders for either depression (t(23)=0.80, p=0.43, n.s.) or anxiety (t(23)=0.25, p=0.81, n.s.).

Table 13: Numbers and percentages of people with SCD scoring above cut offs for depression, anxiety and for depression and anxiety

<table>
<thead>
<tr>
<th>Gender</th>
<th>Depression</th>
<th>Anxiety</th>
<th>Depression and Anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>%</td>
<td>Number</td>
</tr>
<tr>
<td>Male (N=12)</td>
<td>4</td>
<td>33.3%</td>
<td>9</td>
</tr>
<tr>
<td>Female (N=13)</td>
<td>2</td>
<td>15.4%</td>
<td>8</td>
</tr>
</tbody>
</table>

The original intention was to conduct a series of 2 x2 Chi-square analyses on the data for depression, anxiety and depression and anxiety to see if there was any association with
gender. This was not possible for any of the above data because there were cells where the expected frequency was less than 5 and thus the assumptions for Chi-square were not met (Kinnear & Gray, 1994). However, Fisher's Exact Probability Tests were performed to explore the relationship between gender and depression and gender and anxiety. The analyses suggested that there was no significant relationship between gender and depression status (p=0.281, n.s.) nor gender and anxiety status (p=0.387, n.s.).
SECTION 4: DISCUSSION
This section will first consider the general strengths and limitations of the study. In the light of these constraints, the findings pertaining to each of the individual hypotheses will be considered. Finally, overall conclusions and areas for further research will be delineated.

4.1. Research strengths and limitations

4.1.1. Sample characteristics
The analyses conducted to compare the characteristics of the three groups suggested that the groups were well matched in terms of age, number of years in education, marital status and gender. In addition, all three groups came from a similar geographical area. The groups were less well matched on employment status with a sizeable number of those with SCD unable to work due to sickness. The selection criteria applied to the non-SCD group by their nature excluded those who had physical health problems and therefore excluded anyone who was unable to work due to sickness. This discrepancy may have clouded the interpretation of any differences that emerged between SCD participants and non-SCD participants as it may not have been clear whether these were due to differences in disease status or differences in employment status. Thus the study could have been improved by the inclusion of more unemployed people in the control group. However, this would need to be balanced against a consideration of whether unemployment due to sickness is comparable with unemployment due to other reasons in terms of impact on cognitive style and levels of depression and anxiety.

Consideration also needs to be given to how representative the samples were. It could be argued that recruitment of the majority of the control sample via a Further Education College may have introduced biases, for example in terms of level of education. However, overall this group was not significantly different from the SCD groups in terms of the duration of their education. It should also be noted that control subjects were recruited both from staff at the college, including tutors and administrative staff, and students from more academic and vocational courses. However, unemployed people were under represented in the control group. Thus the study could have been improved by recruiting the control group through multiple sites, for example, community centres, G.P. practices and churches.

With regards to the SCD groups, two issues need to be addressed. Firstly, how representative was the sample of the patients at the hospital where the study was conducted and secondly, how representative were they of the SCD population generally. As the author
did not have direct access to the patient database, it was not possible to ascertain precisely how representative those who took part were of the patients who attended the hospital. Anecdotal reports from medical staff and voluntary agencies suggested that people with SCD often view the health care system with some suspicion and can be quite reluctant to take part in research projects. At the hospital through which the SCD groups were recruited, the SCD clinic was notoriously poorly attended as compared with other out-patient clinics. Thus, the fact that 53% of the people who were contacted agreed to take part in the project represented an excellent level of participation. A number of potential sources of bias may have been introduced into the sample. Firstly, it could be argued that those who were extremely depressed may have been less likely to respond to the initial invitation letter. However, follow up phone calls and contacting people during in-patient stays provided alternative ways of establishing contact with people which required less initiative on their part. Other factors may also have influenced people’s willingness to take part in the study. During follow-up phone calls a couple of people indicated that they did not wish to take part because they did not regard themselves as having any problems as a result of their SCD. This could have been a factor influencing other people’s willingness to participate. In addition, those who have regular crises and more complications are likely to be in more regular contact with health care professionals and may thus be easier to contact. This could have resulted in a sample bias towards the more severe end of the disease spectrum. However, balanced against this it should be noted that participants encompassed a wide range of severities, in terms of disease type, numbers of complications, crisis frequency and pain severity. Thus, there was no strong indication that the current sample contained significant biases.

A further issue for consideration is how representative the current SCD sample was of the wider SCD population. Again anecdotal reports from healthcare professionals in the area suggested that hospitals varied considerably in their management of people with SCD. This in turn may impact on people’s perception of their condition and their responses to their pain.

In terms of disease type, the majority of the sample had SS. This is as would have been expected given that SS is the most common form of SCD. Evaluating how representative the sample was in terms of crisis frequency was complicated by the extreme variability of crises across the population as a whole. In terms of rates of psychopathology, in the current sample 24% of people scored above the cut off for depression, 68% of people scored above the cut off for anxiety and 24% scored above the cut offs for both anxiety and depression. Rates for depression were lower than those found in earlier studies where as rates of anxiety were
higher than those previously reported. This may be attributable to variations in the methods used to assess anxiety and depression and may partly result from differences in sampling.

There are a number of ways in which the representativeness of the sample could have been improved. Firstly, by recruiting patients through more than one hospital. In addition, enlisting the help of local SCD support groups may have broadened the range of people who got involved. The author did contact the local support group and a Consultant at another hospital regarding the study. They were, however, reluctant to assist in recruitment for the study.

4.1.2. Measures
Molock and Belgrave (1994) have highlighted the difficulties in assessing anxiety and depression amongst the SCD population. In part, these difficulties are shared with other groups with physical health problems in that symptoms of anxiety and depression may overlap with symptoms associated with the condition. However, additional complications arise with SCD because most patients are of Afro-Caribbean origin. As Molock and Belgrave point out many self-report measures were developed with the Caucasian population and may not take into account cultural variations in symptom presentation and base rate frequency. They highlight the need for far more research into manifestations of depression and anxiety in the broader Afro-Caribbean population in addition to those with SCD. Consideration of this cultural dimension could have been enhanced in the present study by the inclusion of an additional non-SCD, depressed control group.

The measure of depression and anxiety employed in this study was the HAD. Although the HAD has been widely used in populations with pain and other physical health problems (Hermann, 1997) and has been demonstrated to be both valid and reliable, there was no documented use of this measure with the SCD population. In addition, the HAD was primarily developed for use with the Caucasian population rather than the Afro-Caribbean population. Therefore some questions arise as to whether the measure was sensitive to manifestations of anxiety and depression in the Afro-Caribbean population.

A preliminary analysis of the internal consistencies of the two HAD subscales revealed promising results, with Cronbach’s alphas of 0.749 found for the HADD and 0.811 for the HADA. These results were comparable with those reported by Hermann (1997) for other groups. However, these results need to be interpreted very cautiously given that the sample size used was considerably smaller than would normally be recommended for exploration of
the statistical properties of scales. Experience of using the scale during the study suggested that it was quick and easily administered and that participants found the questions meaningful. Thus, there would seem to be scope for further exploration of the reliability, validity and sensitivity of the HAD with the Afro-Caribbean population and those with SCD in particular.

An additional problem with the study was the reliance on a self-report depression measure and a self-report measure of cognitive style. Coyne and Gotlib (cited in Haaga, Dyck & Ernst, 1991) have suggested that the use of such a combination of measures constitutes a "thinly veiled tautology", especially as many self-report measures of depression include items referring to negative cognitions. Thus the study could have been improved by the inclusion of an appropriate interviewer based assessment of depression or a standardised clinical interview. Both would need to take account of the complications associated with assessing depression in people with physical health problems who are of Afro-Caribbean origin.

The CEQ had been previously used with other pain populations and had been demonstrated to have good levels of reliability and validity. However, the scales had not previously been used with the Afro-Caribbean population or with people with SCD. The scales used in this study were modified to take account of cultural and age related differences. Those completing the scales found the questions meaningful and were able to relate to the situations described. Preliminary analysis of internal consistency was promising, with Cronbach's alphas of 0.881 found for the General CEQ and 0.899 for the SCD CEQ. Again these were comparable with the results reported by Lefebvre (1981) and Smith, Peck, Milano and Ward (1988) for earlier versions of the scale. However, given the small size of the sample these results need to be interpreted cautiously and further analysis of the reliability and validity of these scales, utilising larger samples, is clearly needed.

It was interesting to note that both the General CEQ and the SCD CEQ showed small but significant correlations with scores on the HADD (0.343 with the General CEQ and 0.385 with the SCD CEQ, both p<0.05) but not with the HADA. Whilst any interpretation of this finding needs to be cautious given the small sample size, this may suggest that the CEQ scales do assess cognitive factors associated with depression rather than more general psychopathology.
Lefebvre (1981) reported a correlation of 0.61 (p<0.001) between BDI and General CEQ score across all his participants. However, he suggested that this was influenced by the artificial separation of BDI scores which arose from sampling for depressed and non-depressed participants. Similar correlations conducted only for particular groups were smaller (r=0.39, p<0.01 for the depressed groups and r= 0.37, p<0.003 for the non-depressed groups). A correlation of 0.53 (p<0.001) was reported between LBP (Lower Back Pain) CEQ and BDI score. However, separate correlations for particular sub groups were not significant. With a larger sample of lower back pain patients, Smith, Aberger, Follick and Ahern (1986) reported correlations between the MMPI depression scale and the General CEQ of 0.30 (p<0.01) and the MMPI depression scale and the LBP CEQ of 0.39 (p<0.01).

The study also used the Structured Pain Interview to assess pain experience and other complications. This measure was developed specifically for use with the SCD population and has been widely used by Gil and her colleagues in the United States. However, the measurement of pain in SCD has some complications and this aspect of the study could have been improved. Firstly, the measurement of pain in SCD was complicated by the fact that people with SCD experience acute pain associated with sickle crises but also more chronic pain associated with arthritis and bone necrosis. Following the literature, in this study, chronic pain was included under complications where as ratings of pain severity and frequency were focused on acute pain related to cell sickling. During the course of the study, it emerged that some people reported that they could distinguish the two types of pain, although it was not possible within the constraints of this study to assess how reliable people were in making this distinction. In other cases people reported that this was a difficult distinction to make. These issues were highlighted, for example, in the case of one man who reported that he had not experienced a crisis over the last 12 months but that he had experienced chronic joint pain, which was worse when he was mobile. He reported that this pain often felt like the early stages of a crisis and that he often worried that the pain might indicate the onset of a crisis. He had limited his level of activity because of the fact that his pain was exacerbated by activity. This ongoing appraisal of potential threat and the associated limitation in functioning was associated with both marked anxiety and depression.

Secondly, the study was limited by reliance on retrospective self-report of both pain experience and number of complications. The study could have been improved by verifying the patient’s report of medical complications by referring to their medical records. This would have needed to include both hospital and G.P. records as people varied in their level
of contact with the hospital. However, this was not possible in this case because the author did not have access to patient records.

Validating self report of frequency and severity of pain is more difficult. Hospital records may have provided some additional information regarding crisis frequency. However, it was noted that people varied in their reliance on hospital services to manage their crises. Whilst some people reported that they required admission during every crisis, others managed minor crises at home and only required admission for more severe crises. A number of people reported that they actively avoided admission to hospital even though they were experiencing severe pain, choosing to use other analgesia or to use supplies of pethidine provided by their G.Ps. This avoidance of hospitals was often associated with the belief that hospital professionals regarded people with SCD with suspicion particularly around the issue of their use of opiate based pain control. In addition, a recent review suggested that the majority of incidences of pain amongst people with SCD were managed in the community (Davies & Oni, 1997). An alternative method of validating people’s self report was employed by Gil, Abrams, Phillips and Williams (1992) who compared self report in interviews with daily self monitoring of pain. The current study could have been improved by the use of similar daily pain diaries. However, this would have been complicated by the extremely variable nature of SCD crises and by the fact that crisis frequency tends to increase at certain times of the year. For example, many participants commented that they experienced more crises during the winter months when the weather was colder and people were more prone to infections (both cold weather and infections can trigger sickle crises).

4.1.3. Sample characteristics and data analysis

Both the overall sample size and the relative sizes of the different groups had implications for data analysis. For example, as has already been suggested, the small overall sample size imposed limitations on the sophistication of the analysis which could be conducted on the scales properties. The small numbers in some of the cells also prohibited certain statistical analyses, for example comparison of employment status across groups. In addition, the small size of the SCD depressed group, especially as compared with the other two groups was problematic for certain types of analysis. It is known, for example, that where sample sizes are unequal, this can have a detrimental effect on the robustness of One Way Analysis of Variance (Howell, 1992). The implications of these difficulties for the interpretation of the results will be discussed further under consideration of specific hypotheses.
4.1.4. Summary of ways in which study could be improved
1. Recruitment of a more representative control sample, via multiple centres, including more unemployed participants.
2. Recruitment of SCD groups via several hospitals and voluntary groups to ensure that sample is representative of the wider SCD population.
3. Inclusion of an interviewer based assessment of depression in addition to a self-rated measure of depression.
4. Inclusion of a non-SCD, depressed control group.
5. Reference to medical records to validate participant reports of medical complications.
6. Use of pain diaries to validate participant reports of pain frequency and severity.
7. Larger overall sample size and larger SCD depressed group to allow more sophisticated analysis of scale properties and relevant study variables.

4.2. Discussion of hypotheses
In the light of the problems highlighted above, the findings pertaining to each individual hypothesis will now be discussed. The hypotheses will not be re-stated as these have already been detailed in both the method and results sections.

4.2.1. Hypotheses 1 and 2
Neither hypothesis 1 nor hypothesis 2 were supported by the analyses in that, in both cases, no significant differences were found between the groups.

Given that a modified version of the CEQ was used in this study, some caution needs to be exercised in comparing the results obtained in this study with those obtained in earlier studies using earlier versions. However, the figures in Table 8 suggest that all groups showed higher scores on the General CEQ than those reported by Lefebvre (1981). The figures in Table 9 also suggest that the scores obtained on the SCD CEQ were higher than those reported by Lefebvre (1981) using the LBP CEQ for all groups except the depressed pain group. These differences cannot be attributed purely to differences between disease groups given that scores were also elevated for the non-SCD group. Further exploration is needed to clarify whether this difference can be attributed purely to differences in the scales used or whether they suggest that the groups in this study really did show higher levels of cognitive distortion than those in Lefebvre's study. If the latter is the case, it would be interesting to explore whether these differences are due to cultural differences associated with the distinction between American and British culture, cultural differences associated

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with the distinction between a largely Caucasian sample and a largely Afro-Caribbean sample or to differences in other variables such as socio-economic status.

The failure to find any differences between groups in terms of cognitive style was contrary to the findings of earlier studies such as those of Ingram, Atkinson, Slater, Saccuzzo and Garfin (1990) and Lefebvre (1981). Both these earlier studies found significant differences between depressed and non-depressed pain groups on measures of negative thinking and cognitive distortion. Love (1988) also reported differences in attributional style for negative events between depressed and non-depressed lower back pain patients. However, he also noted that depressive attributional style was not an inevitable concomitant of depression in that only 56.8% of the depressed group were correctly classified as depressed on the basis of attributional style. Thus 43.2% of the depressed group were classified as false negatives.

There are a number of possible interpretations for the discrepancy between the findings of this study and those of earlier authors. Firstly, this may represent a genuine difference between depression in SCD and groups such as lower back pain patients. Perhaps, as suggested by Love (1988) depressive cognitive style is not an inevitable concomitant of depression in pain patients. Alternatively, the result may be due to other factors related to sample size and data analysis. In the latter case, acceptance of the null hypothesis on the basis of these results would constitute a Type 2 error.

As has already been noted, the relatively small size of the depressed SCD group as compared with the other groups is likely to have had a detrimental effect on the robustness of the One Way Analysis of Variance. Consequently, it was less likely that any genuine differences between the groups would have been detected. This was likely to have been exacerbated by the fact that in the current analysis scores close to the cut off but still falling in the non-depressed range (i.e. scores of 7) were treated in the same way as scores at the lower end of the continuum.

Thus whilst the results of the analysis did not provide any clear basis for the rejection of the null hypothesis, caution needs to be exercised in concluding that the alternative hypothesis was false. Further research using more balanced sample sizes and a larger overall sample size is needed before any firm conclusions can be drawn.
4.2.2. Hypothesis 3
This hypothesis was supported in that no differences emerged between the two groups as regards number of crises and number of complications.

This finding was in keeping with the findings of earlier studies exploring the relationship between pain and depression. For example, Ingram, Atkinson, Slater, Saccuzzo and Garfin (1990) found no differences between their depressed and non-depressed groups on pain related variables including duration and intensity. Lefebvre (1981) found that his depressed and non-depressed groups did not differ significantly in terms of frequency or duration of pain. These findings were also in keeping with the more general predictions of cognitive behavioural models of pain (e.g. Rudy, Kerns & Turk, 1988). These models postulate that pain experience per se is not a sufficient condition for the development of depression and suggest that cognitive factors mediate much of the relationship between pain and depression.

However, this lack of difference between groups needs to be interpreted with caution. As has been commented on above, the depressed SCD was relatively small and this is likely to have reduced the likelihood of finding any difference which in reality existed between the two groups. Thus it is possible that with larger groups of depressed and non-depressed participants differences would have emerged.

4.2.3. Hypothesis 4
This hypothesis was not supported in that no association was found between rating of pain severity and level of depression.

This finding was also not in keeping with those of earlier studies. Lefebvre (1981) found that his depressed group tended to rate their pain as being more severe than his non-depressed group. However, it was consistent with other studies such as those of Ingram, Atkinson, Slater, Saccuzzo and Garfin (1990) who found no differences between depressed and non-depressed participants in terms of pain severity. This finding was also consistent with the predictions of the cognitive behavioural model of pain outlined above. However, once again failure to find any association between the two variables needs to be interpreted with caution given the size of the sample. In addition, the analysis used tested for a linear association and it is possible that some other type of association existed between the two variables. A scatterplot was produced in an attempt to clarify this but it was not clear from the plot whether or not there was a linear association between the variables.
4.2.4. Hypothesis 5

The analyses supported this hypothesis. With regards to General CEQ, even after controlling for disease and pain related variables, there was still a small but statistically significant relationship between General CEQ score and depression score. Likewise after controlling for the same variables, the association between SCD CEQ and depression remained small but statistically significant. There was, however, no indication of a stronger association between SCD CEQ and depression as compared with General CEQ and depression.

This finding was in keeping with the results of earlier studies by Smith and his colleagues with both lower back pain and rheumatoid arthritis patients (Smith, Aberger, Follick & Ahern, 1986; Smith, Peck, Milano & Ward, 1988). The findings were also in keeping with those of Gil and her colleagues (Gil, Abrams, Philips & Keefe, 1989; Gil, Williams, Thompson & Kinney, 1991) that pain coping strategies characterised by negative thinking made a significant additional contribution to explaining the variance in psychological distress, after controlling for disease and pain related variables. The findings were also in keeping with the predictions of the cognitive behavioural model outlined above.

The implications of this finding, however, are less clear. The design of the study was purely cross sectional and correlational and therefore did not allow for tests of causality. Thus it is not clear whether negative cognitions play a causal role in the onset or maintenance of depression or whether negative cognitive style merely co-occurs with depression. The widespread use of correlational designs which limit exploration of causality is a failing which has been noted in much of the existing research on pain (Jensen, Turner, Romano & Karoly, 1991). It should also be noted that much of the more general research on the relationship between cognitive style and depression has relied heavily on correlational designs and that there is still some lack of clarity regarding the role of negative cognitions in the onset and maintenance of depression (Haaga, Dyck & Ernst, 1991). Thus there is a need to move towards designs which do test predictions around causality. This issue will be discussed in more detail in the section on areas for further research.

4.2.5. Hypothesis 6

The analysis did not reveal any differences between men and women in terms of scores on the HADD or the HADA. Thus the hypothesis was not supported. It was not possible to conduct the appropriate Chi-square analyses due to limitations imposed by sample size.
This finding was contrary to much of the literature which has found evidence of higher levels of psychopathology amongst men with SCD as compared to women with SCD (Leavell & Ford, 1983; Barrett, Wisotzek, Abel, Rouleau, Platt, Pollard & Eckman, 1988). These discrepancies may arise in part from differences in measures used to assess psychopathology and from differences in sampling. For example, Leavell and Ford employed both interview and self-report measures. However, their sample size was small and it was not clear how representative the sample was of the broader SCD population. Barrett, Wisotzek, Abel, Rouleau, Platt, Pollard and Eckman (1988) employed a screening tool, the Chronic Illness Problem Inventory. It was not clear the extent to which problems identified using this measure correlated with clinically significant difficulties identified in other ways. In addition, Barrett and colleagues only included people with SCA recruited through a specialist Sickle Cell Centre.

Firm conclusions regarding the differential rates of depression and anxiety amongst men and women must await larger scale research in this country, exploring the rates of psychopathology amongst people with SCD. Such research could also usefully explore the influence of pain and disease related variables and cognitive style on any differences which emerge.

4.3. Conclusions and areas for further research

Many of the limitations of this study have been highlighted previously in the text. Interpretation of the findings of the study was restricted to some extent by these limitations. However, the study does provide an extension of the existing literature in an under-researched field and highlights a number of areas worthy of further research.

The overall findings were in keeping with both the existing research on adjustment to SCD and with findings from research with other pain groups. They suggested that the experience of pain was not a sufficient condition for the development of depression and that, after controlling for pain and disease related variables, cognitive style was still significantly correlated with depression. Whilst no conclusions regarding causality could be drawn on the basis of this finding, the results suggested that further exploration of the role of cognitive style in depression in SCD is warranted. In particular there is a need for more longitudinal research and studies incorporating cognitive interventions before any conclusions regarding causality can be drawn.
There are a number of areas related to this study in which further research is needed. Firstly, there is a need for further research into the manifestations and assessment of depression in the British Afro-Caribbean community. Related to this there is a need for further investigation of cognitive style within this community and how it compares with other groups. Whilst these topics are worthy of interest in their own right, there is also a need for clarification in these areas before any conclusions can be drawn regarding the impact of SCD on cognitive style and levels of depression.

Secondly, there is a need for large scale research projects to clarify rates of psychopathology within the SCD population in Britain. Related to this is a need to explore the provision of psychological care to this group and whether there is a need for more specialist psychological input to SCD clinics. Certainly a number of the participants within the current study talked about the need for more consideration of the psychological factors associated with SCD. For example, two participants commented on the relationship between being under stress and the increased likelihood of having a painful crisis. Several participants mentioned how valuable they had found having an opportunity to talk about their experiences of having SCD and to share their feelings of being misunderstood both by health care professionals and by other members of the Afro-Caribbean community. Another participant felt that it would be invaluable to have a counsellor attached to the ward to support those experiencing painful crises, especially those who were on the ward for long periods of time. He also felt that it would be useful to have specialist services for the few people who became addicted to pethidine.

Thirdly, there is a need to explore the efficacy of psychological interventions with people with SCD. Kesse (1995) suggested that psychologists could be involved in pain management, stress management, therapy for difficulties around adjustment to SCD and in advising on relapse prevention and how to avoid precipitating crises. He also highlighted the dearth of research in these areas.

Fourthly, there is a need for further research into the relationships between cognitive style, pain and disease related variables and depression, particularly incorporating longitudinal designs. The measure employed in the current study explored cognitions pertaining to both everyday life situations and pain but there are other areas which could also be usefully considered. For example, research with other groups (Ingram, Atkinson, Slater, Saccuzzo & Garfin, 1990) has highlighted a possible protective role for positive thinking which is worthy of exploration in this group. In addition, given the high rates of anxiety found amongst...
people with SCD, exploration of the cognitive factors associated with anxiety, including appraisals of threat, would be invaluable.

Finally, given the gender differences in rates of anxiety and depression amongst people with SCD highlighted in some earlier studies, further studies are needed to clarify whether such differences exist and, if so, the extent to which they are influenced by pain and disease related factors and cognitive style.
REFERENCES:


APPENDIX 1

Letter inviting Sickle Cell Disease patients to take part in the study.
Dear Sir or Madam,

RE: Study on Cognitive Style, Depression and Pain in Sickle Cell Disease

I am writing to you to ask whether you would be willing to take part in a study looking at how people who have Sickle Cell Disease think and feel about their painful crises and other everyday life situations. The study is particularly focusing on people in the age range 16 to 45. Imogen Collins, a Psychologist in Clinical Training at the University of Surrey, is conducting the study as her final year project. The enclosed information sheet provides more details.

I would be grateful if you could complete the form below, indicating whether you would be interested in participating, and send it to:

Imogen Collins,
Department of Psychology,
University of Surrey,
Guildford, Surrey.
GU2 5XH.

Alternatively, you can phone Imogen on 01483-259441 to register your interest or to ask any questions about the study. This does not commit you to taking part should you change your mind later. If the response slip has not been returned within a couple of weeks, we will phone you to check whether you wish to take part.

If you do decide to take part, Imogen will arrange a time to meet so that you can ask more questions about the study and complete the questionnaires. Meetings can take place either at your home or at the hospital and travel expenses can be provided.

I do hope that you will consider taking part in the study as it will greatly assist in the understanding of the experiences of people with Sickle Cell Disease. Thank you in advance for your co-operation.

Yours sincerely,

Dr D. Bareford
Consultant Haematologist.

I am / am not interested in taking part in the study on Cognitive Style, Depression and Pain in Sickle Cell Disease.

NAME:
ADDRESS:

DAYTIME TELEPHONE NUMBER:

EVENING CONTACT TELEPHONE NUMBER:
APPENDIX 2

Information sheet sent to Sickle Cell Disease patients.
INFORMATION SHEET FOR STUDY ON COGNITIVE STYLE.

DEPRESSION AND PAIN IN SICKLE CELL DISEASE

Over the last few years, psychologists have looked at how people cope with painful conditions and their findings have been used to develop programmes to help people cope more effectively with their pain.

I am planning to look at how people with Sickle Cell Disease think during times when they are in pain and in other everyday situations. I am also hoping to explore the relationships between being in pain, feeling down and how people think. Gaining a clearer understanding of these issues should help in the development of more effective programmes to help people cope with their pain and to reduce the distress which is often associated with the experience of pain. As part of this study I am recruiting people with Sickle Cell Disease, aged 16-45, including both people who are depressed and people who are not depressed.

Taking part in the study would involve spending about 40 - 50 minutes completing a series of questionnaires. Although your name will be recorded on the consent form, names will not be recorded on the questionnaires. Questionnaire responses will be treated in the strictest confidence and will be used solely for research purposes. If you do not want to take part you do not have to and if you refuse this will not influence your treatment. You are free to withdraw from the study at any stage.

If you are interested in taking part but have some further questions, then please feel free to contact me at:

Imogen Collins,
Department of Psychology,
University of Surrey,
Guildford, Surrey.
GU2 5XH
Tel: 01483 - 259441

This will not commit you to taking part.

If you do choose to take part, I will be more than happy to provide feedback on the findings of the study if you would like to receive this. Unfortunately, I cannot provide feedback on individual questionnaire responses.

Many thanks for taking the time to read this information sheet. I do hope that you will consider taking part in the study, which should help to further our understanding of the experiences of people with Sickle Cell Disease. If you think that you would be interested in taking part then please complete the enclosed slip and return it to me at the University of Surrey. I will then arrange a time to meet to discuss the study further, sign the consent form and complete the questionnaires.

If you have any concerns about this study and wish to contact someone independent at the Research Ethics Committee, you may telephone 0121 - 507 - 4396.

Imogen Collins,
Psychologist in Clinical Training at The University of Surrey, Guildford.
APPENDIX 3

Consent form for Sickle Cell Disease patients.
CONSENT FORM FOR COGNITIVE STYLE, PAIN AND DEPRESSION STUDY

Please circle your answer for each of the items below.

Have you read the information sheet about the study? YES / NO

Have you had an opportunity to ask questions and discuss the study? YES / NO

Have you received satisfactory answers to your questions? YES / NO

Have you received enough information about the study? YES / NO

Do you understand that you are free to leave the study at any stage? YES / NO

I ______________________ agree to take part in the study. I understand that all the information collected for the study is strictly confidential and that my answers will not have any effect on the treatment I receive.

Signed: ___________________________ Date: ________________
APPENDIX 4

Information sheet given to non-Sickle Cell Disease group.
INFORMATION SHEET FOR STUDY ON COGNITIVE STYLE, DEPRESSION AND PAIN IN SICKLE CELL DISEASE

Over the last few years, psychologists have become very interested in how people cope with painful conditions. In particular, they have looked at what goes through people's minds when they are in pain and how they feel during painful episodes. These studies have been used to develop programmes to help people cope more effectively with their pain. Most of these studies have talked to people who have painful conditions such as chronic lower back pain or Rheumatoid Arthritis. Very few studies have talked to people who have Sickle Cell Disease and most of the studies were carried out in the United States of America.

As part of my training as a Clinical Psychologist, I am conducting a study looking at how people with Sickle Cell Disease think during times when they are in pain and in other everyday situations. I will also be looking at the influence of depression and severity of pain on how people think in these situations. I am particularly focusing on people aged between 16 and 45.

Gaining a clearer understanding of how people think when they are in pain as a result of Sickle Cell Disease should help in the development of more effective programmes to help people cope with their pain and to reduce the distress which is often associated with the experience of pain.

As part of this study, I need a comparison group of people who do not have Sickle Cell Disease or any other chronic physical health problems or painful conditions. These people need to be of a similar age, gender mix and ethnic origin to the Sickle Cell Disease group.

If you agree to take part in the study, you will be asked to sign a consent form and complete a series of questionnaires. This should take about 40 minutes. Although your name will be recorded on the consent form, names will not be recorded on the questionnaires. Questionnaire responses will be treated in the strictest confidence and will be used solely for research purposes. Participation or non-participation in the study will in no way influence your studies / church involvement. You are free to withdraw from the study at any stage.

If you do choose to take part, I will be more than happy to provide feedback on the findings of the study if you would like to receive this. Unfortunately, I cannot provide feedback on individual questionnaire responses.

If you have any concerns or queries about the study, then please feel free to contact me at the University of Surrey.

Many thanks in advance for your co-operation.

Imogen Collins
Psychologist in Clinical Training at
Department of Psychology,
University of Surrey,
Guildford, Surrey.
GU2 5XH
Tel: 01483 – 259441
APPENDIX 5

Consent form for non- Sickle Cell Disease group.
CONSENT FORM FOR COGNITIVE STYLE, PAIN AND DEPRESSION STUDY

Please circle your answer for each of the items below.

Have you read the information sheet about the study? YES / NO

Have you had an opportunity to ask questions and discuss the study? YES / NO

Have you received satisfactory answers to your questions? YES / NO

Have you received enough information about the study? YES / NO

Do you understand that you are free to leave the study at any stage? YES / NO

I __________________ agree to take part in the study. I understand that all the information collected for the study is strictly confidential and that my answers will not have any effect on my studies / church involvement.

Signed: _______________________________ Date: _______________
APPENDIX 6

The Hospital Anxiety and Depression Scale.
Clinicians are aware that emotions play an important part in most illnesses. If your clinician knows about these feelings she or he will be able to help you more.

This questionnaire is designed to help your clinician to know how you feel. Ignore the numbers printed on the left of the questionnaire. Read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

I feel tense or 'wound up':

- Most of the time
- A lot of the time
- From time to time, occasionally
- Not at all

I still enjoy the things I used to enjoy:

- Definitely as much
- Not quite so much
- Only a little
- Hardly at all

I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly
- Yes, but not too badly
- A little, but it doesn't worry me
- Not at all

(continued overleaf)
### The Hospital Anxiety and Depression Scale

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<tr>
<td>I can laugh and see the funny side of things:</td>
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<td>As much as I always could</td>
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<td>Not quite so much now</td>
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<td>Definitely not so much now</td>
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<td>Not at all</td>
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<td>Worrying thoughts go through my mind:</td>
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<td>A great deal of the time</td>
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<td>A lot of the time</td>
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<td>From time to time but not too often</td>
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<td>Only occasionally</td>
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<td>I feel cheerful:</td>
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<td>Sometimes</td>
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<td>Most of the time</td>
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<tr>
<td>I can sit at ease and feel relaxed:</td>
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<td>Definitely</td>
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<td>Not often</td>
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<td>Not at all</td>
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<tr>
<td>I feel as if I am slowed down:</td>
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<td>Nearly all the time</td>
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<td>Very often</td>
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<td>Sometimes</td>
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<td>Not at all</td>
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<td>I get a sort of frightened feeling like ‘butterflies’ in the stomach:</td>
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<td>Not at all</td>
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<tr>
<td>Occasionally</td>
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<td>Quite often</td>
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<tr>
<td>Very often</td>
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(continued overleaf)
I have lost interest in my appearance:

- Definitely
- I don't take as much care as I should
- I may not take quite as much care
- I take just as much care as ever

I feel restless as if I have to be on the move:

- Very much indeed
- Quite a lot
- Not very much
- Not at all

I look forward with enjoyment to things:

- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all

I get sudden feelings of panic:

- Very often indeed
- Quite often
- Not very often
- Not at all

I can enjoy a good book or radio or TV programme:

- Often
- Sometimes
- Not often
- Very seldom

Now check that you have answered all the questions

For office use only:

D: [ ] Borderline 8–10
A: [ ] Borderline 8–10

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APPENDIX 7

Cognitive Error Questionnaire.
THOUGHTS QUESTIONNAIRE

This questionnaire describes a number of situations that might occur in daily life, each of which is followed by a thought that a person might have in that situation. Underneath is a choice of statements that describe how similar the thought is to how you would think in that situation. Please read each situation description and imagine that it is happening to you. Then, read the thought (which is in italics) following the description. Circle the statement underneath each thought which best describes how similar that thought is to how you would think in that situation. Because you may not have had the experiences described in some of the situations, it is important that you imagine the situation happening to you. Some of the situations assume that you have a problem with pain associated with Sickle Cell Disease. If you are not presently experiencing pain associated with Sickle Cell Disease, try to put yourself in that situation and then rate how similar the particular thought would be to your own thoughts in the situation described. Be sure that you do not rate the situation, rather make sure that you rate how much the thought resembles how you would think in that situation.

The following is an example.

Situation: You have just come out of the supermarket and notice a dent in your car that wasn’t there before you went in. You think to yourself: “Oh no, the car is wrecked”.

The thought (in italics and quotation marks) is:

almost exactly like       a lot like          somewhat like           a little like        not at all like
I would think            I would think      I would think           I would think        I would think

Mark your answer by circling the statement that best describes how similar the thought is to how you would think in the situation described.

Please work through each of the situations. In each case indicate how similar the thought is to how you would think if you were in that situation. Please do not miss out any items. Feel free to ask if you have any queries.
1. Your boss just told you that, because of a general slow down in the industry, he has to lay off all of the people who do your job including you. You think to yourself: “I must be doing a lousy job or else he wouldn’t have laid me off”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

2. You have been going out with your boy/girlfriend for several months. Things have not been going well and you have decided to break up with them. You have been putting off the decision for days, and you think to yourself, “I just know that when I finish with him/her that he/she will go mad at me and make my life hell”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

3. Last week you resprayed your car and your partner said it looked really great. When you were cleaning up, you found that you got paint on the seat covers and thought, “That wasn’t a very good job”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

4. You work in a job that involves you moving around a lot. Yesterday, by the end of the day, you were in a lot of pain as a result of your Sickle Cell Disease. Driving home from work, you found yourself thinking, “If this keeps up, I’ll be in agony and won’t be able to work or even walk”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

5. You have always enjoyed sport. This weekend you were in a lot of pain as a result of your Sickle Cell Disease and you think to yourself, “The way my pain is getting, I’ll never be able to play any sport at all anymore”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

6. You have a lot of pain associated with Sickle Cell Disease which limits the amount of physical activity you can do. You enjoy baby-sitting for your younger cousins. Sometimes, when you notice that the children seem to be in a bad mood, you think to yourself, “The kids wouldn’t be in such a bad mood if I was able to play with them more”.

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This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

7. You and your boy/girlfriend went out to see friends the other day. You had a bad time because your pain was flaring up and you had to ask your friend if you could lie down for half an hour. When your boy/girlfriend asks you to go to a party on Saturday night, you think to yourself, "I don't want to go because I'm going to have to lie down again".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

8. You went ten-pin bowling today. Initially you were playing really well and were having a great time. Towards the end your pain started to flare up and you kept sending the ball straight down the side of the alley, missing completely. Later on, you find yourself thinking, "With the pain I get from Sickle Cell Disease, it seems like I'm always playing badly".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

9. You noticed recently that a lot of your friends have taken up rollerblading. You would like to learn but remember the difficulty you had when you tried to go ice-skating. You think to yourself, "I couldn't learn ice-skating so I doubt I can learn rollerblading".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

10. You and your partner recently went to an office party at the place where your partner works. You didn't know anybody and had a terrible time. When your partner asks if you want to go out with his/her friends to the cinema, you think, "I'll have a terrible time just like at that office party".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

11. You just finished spending two hours cleaning your car. Your boy/girlfriend, however, doesn't say anything about it. You think to yourself, "He/She must think I did an awful job."

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  I would think  I would think  I would think  I would think

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12. Last night your partner said he/she thought you should have a serious discussion about sex. You think to yourself, “He/She hates the way we make love.”

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

13. You have been working for six months as a car salesperson. You have never been a salesperson and were just fired because you had not been meeting your quotas. You think, “Why try to get another job; I’ll just get fired again.”

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

14. Your job requires a lot of travel. You had hoped to drive 300 miles today but you hit bad weather that slowed you down. When you stopped for the night, you thought, “I didn’t make that 300 miles; today was a complete waste of time”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

15. You have just finished playing on your friend’s SEGA megadrive. Although you started off getting really high scores, towards the end you just couldn’t seem to get it right. You think to yourself, “Today I played really badly”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

16. Your friends just asked you to go out shopping. You remembered how much pain you were in after you went clubbing the other day, and you think to yourself, “I guess there is no way I could manage if I went shopping with them”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

17. You went ten-pin bowling for the first time today with some of your friends who love to go regularly. Everyone played badly and the group seemed discouraged. You thought to yourself on the way home, “I guess I made too much noise or did something that distracted everyone”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.
18. You have Sickle Cell Disease and sometimes you experience pain after having sex. Last time it happened, you thought, “Someday, I won’t even be able to have sex”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

19. Last week you had classes all day at college. When you were finished, you experienced a lot of pain due to your Sickle Cell Disease. You have classes again today and you think, “I won’t be able to tolerate sitting through this class.”

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

20. You went swimming with one of your friends today. Your friend wanted to go home early, and you hardly did any swimming at all. On the way home, you thought to yourself, “I guess he/she knew that I was in pain”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

21. Your friends are all going out to Alton Towers. Last time you went, one of the rides broke down briefly while you were on it and you think to yourself, “What if the ride breaks down again; I could be stuck on it for hours”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

22. You have been coaching a team of school children at football. Although they usually play quite well, they lost their last game. You think to yourself, “They would not have lost if I had worked them harder in training”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.

23. You are taking a coffee break when your boss stops by and reminds you of some work that has to be done today. You think to yourself, “If I don’t start getting back to work earlier, I’m going to lose my job”.

This thought is:

almost exactly like a lot like somewhat like a little like not at all like
I would think I would think I would think I would think I would think.
24. Your favourite sport is basketball. Even though the pain associated with your Sickle Cell Disease has been bad lately, you want to keep playing. Today when you are playing as usual, you begin to ache before you were finished. You think to yourself, "Pretty soon, I won't be able to play at all."

This thought is:

almost exactly like | a lot like | somewhat like | a little like | not at all like
I would think       | I would think | I would think | I would think | I would think.

25. You have pain as a result of your Sickle Cell Disease which limits the amount of heavy lifting you can do. Last month you tried to move some furniture and had to ask someone for help. Now you need to carry some small boxes up from the cellar. You think, "With this pain, I doubt I can manage these boxes alone. It seems like I need help with everything."

This thought is:

almost exactly like | a lot like | somewhat like | a little like | not at all like
I would think       | I would think | I would think | I would think | I would think.

26. Recently your job has been so demanding that you have worked straight through your lunch hour. You noticed that this pace has made your Sickle Cell pain worse. Coming home from work, you think, "If I don't get some time to relax during the day, I'm going to be in agony."

This thought is:

almost exactly like | a lot like | somewhat like | a little like | not at all like
I would think       | I would think | I would think | I would think | I would think.

27. You have a lot of pain as a result of Sickle Cell Disease but have continued to work. Although you got quite a bit done today, you left work a little early because you were in pain. You think to yourself, "What a terrible day. It seems like I can't get anything done."

This thought is:

almost exactly like | a lot like | somewhat like | a little like | not at all like
I would think       | I would think | I would think | I would think | I would think.

28. Your supervisor has just announced that as a result of temporary business difficulties, all of the sales personnel will be working reduced hours. You think to yourself, "This probably wouldn't be happening to me if I didn't have Sickle Cell Disease."

This thought is:

almost exactly like | a lot like | somewhat like | a little like | not at all like
I would think       | I would think | I would think | I would think | I would think.

29. Although your Sickle Cell Disease limits physical activity, you usually try and spend some time each week playing with your five year old cousin. Today he seems in a bad mood. You think to yourself, "If I didn't have Sickle Cell Disease, I would play with him more and he wouldn't be so miserable."
This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

30. You went to a football match with friends. You enjoyed the first half but then your Sickle Cell Disease pain started bothering you. You find yourself thinking, "What an awful way to spend an afternoon".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

31. You have noticed that many of your friends have taken up playing keyboards and are now urging you to play too. You tried to play the drums in the past and had difficulty learning. You think to yourself, "I had so much trouble learning to play the drums. I doubt if I could learn to play keyboards".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

32. You normally do well at college in your assignments. Last week an assignment was returned with some corrections and you have to do the work again. You think to yourself, "Now, I'm having problems at college, I better go and talk to my tutor."

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

33. Earlier today your boy/girlfriend asked to have a serious talk with you after work about things that were bothering them. You have no idea what is going on. You think, "We don't communicate enough: He/She is going to break up with me".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

34. On your last job, you did not receive a pay rise even though a colleague with similar experience did. You are now up for a pay rise in your current job and think, "I didn't get a rise in my last job and I won't now".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think       I would think       I would think       I would think       I would think.

35. Your brother has just invited some friends over. Last time they came round a few weeks ago, they really got on your nerves by making too much noise and getting in your way. You think, "If they come round again, I'll get annoyed again."
36. You and your partner went out with some friends. You were having a really good time until it started getting late and your Sickle Cell Disease pain began to bother you. You think to yourself, “Tonight was not very much fun”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

37. One of your friends has stopped by to ask you to take a short bike ride for some exercise. You recall that you had a lot of pain after you came back from a day out shopping and you think to yourself, “There is no way I could manage even the shortest bike ride”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

38. You work as a nursery nurse. Today the mother of a child that you have been finding difficult to manage, phones and tells you that she will removing her child from the nursery. You think, “She probably thinks I wasn’t handling him as well as I should”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

39. You have just returned to work after sick leave during which you were recovering from an episode of severe pain as a result of your Sickle Cell Disease. You have worked hard in the afternoon but didn’t finish everything you wanted to. You think to yourself, “Because of my Sickle Cell Disease, I can’t do my job”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

40. You took your younger cousins to the park. Although they urged you to play with them, you were enjoying relaxing in the sun. Later you look up and see them fighting, you think to yourself, “If I had played with them, they probably wouldn’t be fighting now”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

41. You went shopping for some new clothes today and were unable to find anything you liked. You think, “What a waste of a day”.

283
This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

42. You and your friends always used to go out together on Saturday afternoon. Lately, you haven’t been able to go out with them because of your Sickle Cell Disease. As you notice them going out, you think to yourself, “Unless I start going with them, I won’t have any friends any more”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

43. You met with your college tutor today to discuss how you have been doing in your course. He said he thought you were doing really well, but he asked you to try and improve in one small area. You think to yourself, “He really thinks I’m a lousy student”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

44. Your boss has just posted the new work schedules and you notice that you will be working a split shift instead of a more strenuous straight eight hour shift. You think to yourself, “I know he gave me that shift because of my Sickle Cell Disease. He must think I can’t do the job”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

45. You work at a school. The last time it was your turn to watch the children during their play time, you were in pain during the rest of the afternoon. You notice that it is your turn again and think, “If I have to watch those kids again at play time, I know that I will be in pain for the rest of the day”.

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.

46. You are generally reluctant to go out with friends since you need to take rests because of your Sickle Cell Disease to control your pain. Recently, several friends persuaded you to go out with them for the day. On the way home, everyone was quiet in the car. You think, “Because of my Sickle Cell Disease pain, no one had a good time.”

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like
I would think  I would think  I would think  I would think  I would think.
47. Last time you went ice skating, you took a hard fall and got shook up. You're supposed to go ice skating again today but think, "I'll probably fall and break my leg and there will be no one to help me".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  
I would think  I would think  I would think  I would think  I would think.

48. To avoid pain associated with your Sickle Cell Disease, you and your partner have made some changes in your usual sexual patterns. While you've both enjoyed trying different ways, you've recently felt discouraged and think to yourself, "I can't even have a normal sex life anymore".

This thought is:

almost exactly like  a lot like  somewhat like  a little like  not at all like  
I would think  I would think  I would think  I would think  I would think.

When you have completed the questionnaire please go back and check that you have completed all the items. Many thanks for your help.
APPENDIX 8

Structured Pain Interview and Disease Severity Measure
STRUCTURED PAIN INTERVIEW – ADULT

I. Pain

For all these questions, a painful episode is defined as pain located in any part of the body for which there is no identified cause other than the blockage of blood vessels due to sickled red blood cells.

A. Frequency: How many painful episodes have you had in the last 12 months? _________________________

B. Duration: How long, on average, do your painful episodes last in hours or days? _________________________

If you find it difficult to give an average:
How long is a short episode?
How long is a long episode? ______________

Please state in minutes, hours or days as appropriate.

C. Severity: Using a 0 - 10 scale (0 = no pain and 10 = pain as bad as it can be), on average, how would you rate your own pain during painful episodes, during the past 12 months? ______________

D. Location: When you are in pain, where is it usually located?

II. Activity pattern

A. Time up: During a painful episode, how many hours do you spend up and out and not lying down? Use a typical day of 16 hours ___________

B. Housework: During a painful episode, how much do you cut back on doing work around the house? (Please mark on the line below)

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<tr>
<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't cut back</td>
<td>Cut back by half</td>
<td>Cut back completely</td>
</tr>
<tr>
<td>Do a lot, cut back a little</td>
<td>Cut back a lot, able to do some things</td>
<td></td>
</tr>
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</table>

C. College / Work: During a painful episode, how much do you miss school, college or work? (Please mark on the line below)

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</thead>
<tbody>
<tr>
<td>Don't cut back</td>
<td>Cut back by half</td>
<td>Cut back completely</td>
</tr>
<tr>
<td>Do a lot, cut back a little</td>
<td>Cut back a lot, able to do some things</td>
<td></td>
</tr>
</tbody>
</table>
D. Social Activities: During a painful episode, how much do you cut back on spending time with others e.g. going out, seeing friends, sport?
(Please mark on the line below)

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<th>0%</th>
<th>50%</th>
<th>100%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't cut back</td>
<td></td>
<td>Cut back by half</td>
<td>Cut back completely</td>
</tr>
<tr>
<td>Do a lot,</td>
<td></td>
<td>Cut back a lot,</td>
<td></td>
</tr>
<tr>
<td>cut back</td>
<td></td>
<td>able to do some things</td>
<td></td>
</tr>
<tr>
<td>a little</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

III Health care utilisation in the past 12 months

A. Accident & Emergency visits: How many times have you gone to A & E because of pain in the past 12 months?

B. Hospitalisation: How many times have you been hospitalised because of pain in the past 12 months?

How long have each of these stays lasted?

C. Doctor visits or calls: How many times have you gone to see or called a doctor or other health professionals because of your pain in the last 12 months?

D. Pain medication:
What analgesic medications (e.g. paracetamol, aspirin) do you take for pain?

What narcotic medications (e.g. pethidine, dimorphine) do you take for pain?
**DISEASE SEVERITY**

**Phenotype:**
- Sickle Cell Anaemia (SS)
- SC Disease (SC)
- Sickle B Thalassemia (SBThal)
- Other

Sickle Cell Disease is often accompanied by a number of complications such as leg ulcers, seizures, acute chest problems, etc. in addition to painful crises. Not including painful crises, how many of such complications have you experienced over the last 12 months? Please list
APPENDIX 9

Personal Details Form.
PERSONAL DETAILS FORM

Please note: All the information in this form will be treated as strictly confidential and will only be used for research purposes.

Participant Number: __________________________________________

Please note: If you would like to receive feedback about the findings of the study then please include your name and address on the back of your consent form.

Age: __________________ years

Sex: Male / Female (Please circle as appropriate)

Number of years in education:
(Counting from start of primary / first school)

Ethnic Origin:

Marital status: Single [ ]
Married [ ]
Divorced [ ]
Separated [ ]
Widowed [ ]

Employment status: Full - time employment [ ]
Part - time employment [ ]
Student [ ]
Unemployed [ ]
Not working due to sickness / disability [ ]
Other [ ]
Please specify __________________________

Have you ever seen a psychiatrist, psychologist or other mental health professional?
YES / NO

If yes, what was the reason for the referral? ____________________________