A Portfolio of Academic Study, Clinical Practice and Research

Volume One

incorporating

A Qualitative Study Exploring Children’s Illness Representations: A Developmental and Cultural Perspective

by

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Major Research Project
A qualitative study exploring children’s illness representations: A developmental and cultural perspective.

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Introduction to the Portfolio

This portfolio contains a representative selection of work completed during the three year Practitioner Doctorate in Clinical Psychology, at the University of Surrey (1997-2000). The portfolio is divided into academic, clinical and research sections. The academic section contains five essays, covering a range of topics relating to both core and specialist placements. The clinical section includes details of each of the six clinical placements (4 core placements and two specialist placements) and a general summary of the work undertaken. A summary of the formal case report for the first five placements is also provided. Finally, the research section comprises a service-related research project, completed in the first year of training, a literature review completed in the second year and a major research project completed in the third year. The work within each section is presented in chronological order, to demonstrate the developmental progression in knowledge and skills over the course of training.

A separate confidential volume (Volume II) contains a clinical dossier, comprising the full versions of the five formal case reports. In addition, this volume contains placement contracts, clinical activity log books and supervisor evaluation forms for all six placements.
Academic Section
Essay 1

A comparison of antidepressants and psychotherapy
in the treatment of depression

December 1997
Year 1
Depression

Clinical depression is widely experienced, with an estimated 12% of the population facing an episode serious enough to warrant treatment at some point in their lives (Fennell, 1988). Depression is characterised by a collection of signs and symptoms including low mood, lack of energy, withdrawal, loss of enjoyment, disturbance of sleep and appetite, irritability, emotional lability or flattened affect and often suicidal ideation. It is generally time-limited, with untreated episodes tending to resolve within 6-12 months (Lavori, Keller & Klerman, 1984). However, recurrence is common, and as a result, treatment must not only focus on speeding recovery from a current episode, but also on preventing the return of symptoms after treatment (Consensus Development Panel, 1985).

Historically, antidepressant medication has been the primary treatment for depression, with psychological therapy being viewed as an adjunct. Recently however, there have been attempts to establish psychological therapy as a valid and effective treatment for depression. This has taken the form of evaluation studies, which have attempted to demonstrate the effectiveness of psychological therapy for this client group, or to establish it’s superiority or equivalence to antidepressant medication. What follows is a discussion of these two forms of treatment, and their relative effectiveness in speeding recovery from a depressive episode, and preventing relapse or recurrence.

Antidepressants

For moderate to severe depression, antidepressant medication tends to be the mainstay of treatment (Joyce & Paykel, 1989). Two main groups of antidepressants have been discovered, namely monoamine oxidase inhibitors (MAOI’s) and the tricyclics. The MAOI’s arrived first, with the discovery of iproniazid, which was found to reduce the symptoms of psychotic depression. Other drugs followed, including phenelzine and isocarboxazid. Unfortunately the MAOI’s have potentially harmful side effects, perhaps the most notable one being an interaction with certain foods, which can result in death. These side effects have led to a decrease in their prescription (Lader & Herrington, 1990).
The tricyclics are much more popular, and are thought to be more effective, than the MAOI's (Lader & Herrington, 1990). Imipramine was the first to be developed, closely followed by compounds such as amitriptyline, desipramine, iprindole and mianserin. In the last few years, antidepressants with untypical clinical profiles and anomalous biochemical properties have been introduced. Some of these have had to be withdrawn due to untoward side effects. Great interest currently revolves around the so-called selective 5-HT inhibitors e.g. Fluvoxamine and Fluoxetine (commonly known as Prozac), which are lower in toxicity than previous tricyclics, but still have several side effects (Lader & Herrington, 1990).

Side Effects
Both the MAOI's and the tricyclics have common side effects. These include drowsiness, blurred vision, feeling light headed, sleep disturbance, weight gain, seizures and impaired cardiac function (Breggin, 1991). The abrupt withdrawal of tricyclic antidepressants is also occasionally followed by acute anxiety, restlessness, malaise, muscular aches, nausea, vomiting and dizziness (Disalver & Greden, 1984, 1987; Disalver, 1989).

Mode of Action
The finding that depression can seemingly be treated effectively with MAOI's and tricyclic antidepressants, both of which enhance monoamine functioning, led to the development of the monoamine hypothesis, in which depression was attributed to a depletion of norepinephrine or serotonin (5-HT) at synapses (Bunney, 1965; Coppen, 1967). Limitations with this formulation have since led to the development of the receptor sensitivity hypothesis (Charney, Menkes & Heninge, 1981; DeMontigny & Blier, 1984), which holds that long-term administration of antidepressant medication produces clinical effects through changing the sensitivity of neuronal monoamine receptors. Research has focused primarily on 5-HT, and it has been proposed by some that this neurotransmitter may be central to the treatment effects of the antidepressants (Blier, deMontigny &
Chaput, 1987). Nevertheless, evidence suggests this mechanism cannot fully account for the effectiveness of all antidepressant medications (Price et al., 1989).

**Effectiveness of Antidepressant Medication**

70-80% of depressed in-patients and 60-70% of depressed out-patients are reported to experience substantial symptomatic relief from amitriptyline (Lader & Herrington, 1990). Similarly, data from controlled trials show imipramine to be consistently superior to placebo (Lader & Herrington, 1990), with 2/3 of patients on imipramine showing improvement, compared to 1/3 on placebo. Improvement in somatic symptoms is reported to occur first, with changes in depressive mood often not occurring until four weeks into the treatment (Lader & Herrington, 1990).

Antidepressants however, do not appear to be equally effective in all cases of depression. Stewart et al. (1983) found imipramine to produce significant improvement with moderate but not mild depression, and Paykel, Hollyman, Freeling & Sedgewick (1988) found little response of milder depression to tricyclics. Overall, evidence seems to suggest that antidepressants work best when severity and endogeneity of depression fall in the middle range (Bielski & Friedel, 1976; Joyce & Paykel, 1989), and when psychomotor retardation is present (Downing & Rickels, 1973; Paykel, 1972; Raskin & Crook, 1976). They are seemingly less effective with individuals experiencing delusions or rapid cycling bipolar disorder (Joyce & Paykel, 1989). Some have added long duration depression to this list (Rush, Roffwarg, Giles, Schlesse, Fairchild & Tarell, 1983; Keller, Klerman, Lavori, Coryell, Endicott & Taylor, 1984), although others have failed to find this relationship (Kupfer & Spiker, 1981; Loyd & Tsuang, 1985).

**Length of Treatment**

If antidepressants are withdrawn once symptoms improve, relapse is likely to occur (Lader & Herrington, 1990). Continuation of treatment has been found to reduce this risk (Frank et al., 1990) and Prien & Kupfer (1986) recommend that patients should be free of
significant symptoms for 4-5 months before treatment is discontinued. Maintenance therapy typically consists of half the full therapeutic dosage, although Kupfer et al. (1992) found a statistically significant effect for "full dosage" maintenance therapy. Similarly, Frank et al. (1990) reported a relapse rate of 17.9% for patients given daily high maintenance dosages of imipramine.

Cognitive Therapy (CT)

The cognitive model of depression developed by Beck (1967, 1976) proposes that individuals develop certain assumptions about themselves and the world as a result of their experiences in life, and that some of these assumptions may be dysfunctional or counterproductive. Problems are thought to arise when critical incidents occur which mesh with the person's dysfunctional beliefs. Once activated, the beliefs trigger negative automatic thoughts (NAT's) (e.g. "Nothing ever goes right for me") which may involve interpretations of current events, predictions about the future, or recollection of things past. These NAT's are hypothesised to them trigger depressive symptoms (e.g. feelings of helplessness). A vicious cycle is set up whereby the individual feels depressed, so tends to interpret events more negatively. This is then taken as evidence to support the dysfunctional beliefs, which serves to exacerbate the depression. Cognitions have been implicated in precipitation, maintenance and recovery from depression (Brewin, 1988).

The cognitive theory of depression is based on the notion that the affective and cognitive systems are interdependent (Bradley & Power, 1988), and that by changing an individuals cognitions you can thereby effectuate a change in affect. The cognitive therapist attempts to disrupt habitual patterns of selective attention and train depressed individuals to modify their dysfunctional patterns of thinking and behaving. A variety of techniques are used, including daily thought diaries, challenging NAT's and socratic questioning (Beck et al., 1979). Change in the cognitive structuring of experience has been proposed as the common pathway through which various systems of psychotherapy, and maybe even pharmacotherapy, produce therapeutic results (Beck, 1985; Clark, Salkovskis, Hackmann
& Gelder, 1991). The mechanisms through which cognitions may be involved however, are not fully understood (Bradley & Power, 1988).

Effectiveness of CT/CBT

Studies evaluating the effectiveness of the cognitive approach in the treatment of depression have varied in terms of whether they have labelled their approach as cognitive (CT) or cognitive-behavioural (CBT). In reality, the effects of cognitive and behavioural techniques are hopelessly confounded in treatment. Behavioural experiments are frequently used as a means of allowing clients to test out the accuracy of their beliefs and it is rare for therapists to rely purely on cognitive restructuring. It is, therefore, difficult to isolate individual components and establish their effectiveness (Brewin, 1989).

Research suggests that the majority of people with unipolar depression improve substantially following treatment with CBT (Blackburn et al., 1981; Dobson, 1989; Rush et al., 1977), and that CBT may significantly reduce the risk of relapse (Scott, 1996). Interventions such as distraction or challenging depressed thoughts, which are designed to reduce frequency or intensity of depressing thoughts, have been found to have a beneficial effect on mood in experimental studies (Fennell & Teasdale, 1984; Fennell & Teasdale, 1987). Dobson et al. (1989) conducted a meta-analysis of results from clinical trials and concluded that CT is more effective than no treatment.

Responders to CT

Not everyone responds well to CBT. Initial severity of depression and level of cognitive dysfunction are both related to poorer outcome with CT (Norman, Miller & Dow, 1988; Rude & Rehm, 1991; Sotsky, Glass & Shea, 1991), as is the presence of marital discord (Barnett & Gottlib, 1988; Beech, Sandeen & O'Leary, 1990; Coyne, 1990) and family dysfunction (Keitner, Ryan, Miller & Norman, 1992). As with antidepressant medication, depressed individuals with a co-existing personality disorder tend not to do so well with
CT. Cognitive therapists therefore, need to consider the interpersonal difficulties of patients in addition to biases in the interpretation of events (Robins & Hayes, 1993).

Length of Treatment
Studies in Primary care settings looking at the use of individual CT (Blackburn et al., 1981; Teasdale et al., 1984; Scott & Freeman, 1992) and group CT (Ross & Scott, 1985), identified gains following an 8-15 week course of treatment. Fennell & Teasdale (1984) on the other hand demonstrated benefits from only 4 sessions of CT, and Mynors-Wallis et al. (1995) found 2 sessions of CT, plus 1 follow-up session and brief problem-solving to be beneficial.

Combination of Therapies
In both general and psychiatric practice, the combination of psychotherapy and drug therapy is a common form of treatment for depression (Brandon, 1986). Overall, research suggests that the treatments in combination are significantly more effective than placebo, but either no different (Hollon, Shelton & Loosen, 1991; Murphy et al., 1984), or only slightly superior, to one of the treatments alone (Conte et al., 1986). Evans et al. (1989) for example, found little difference between the 2 year relapse rates of CT and CT plus medication. They concluded from this that using medication with CT may be a reliable way to maximise both response to acute treatment and the stability of such gains. Alternatively, one could use this finding to argue against the use of antidepressants, given the side effects, and the fact that these drugs do not improve, and may even impede CT, by reducing the client’s ability to challenge their NAT’s.

Comparison of Treatments
Several studies have found CT to be significantly more effective than antidepressant medication alone (Blackburn & Bishop, 1983; Bowers, 1990). A more recent study by Blackburn & Moore (1997) addressing the treatment of the acute phase of recurrent, major, unipolar depression found a similar trend with post-treatment recovery rates of
24% for antidepressants and 33% for CT, although the differences were not significant. Despite these results, the APA (1993) and the Agency for Health Care Policy & Research (AHCPR) (Depression Guideline Panel, 1993) recently concluded that psychotherapy may be no more effective than placebo pills in the treatment of severe depression, and may therefore be an inappropriate treatment for this population.

The above conclusions are largely based on the findings of one single study: the Treatment of Depression Collaborative Research Program (TDCRP: Elkin, Parloff, Hadley & Autry, 1985) sponsored by the National Institute of Mental Health (NIMH), which compared the effectiveness of 4 treatment conditions: CBT, Imipramine plus clinical management (a minimal supportive therapy) (ICM), interpersonal psychotherapy (IPT), and a pill placebo plus clinical management. All treatment conditions showed significant changes pre- to post- treatment, but no significant post-treatment differences were observed between the groups when the whole sample was considered together. When the sample was subdivided according to severity of depression however, ICM and IPT produced greater acute response post-treatment than pill placebo. This was not the case for CBT.

According to Elkin et al. (1989), the recovery rate for CBT in this study is consistent with that of other studies (Blackburn, Bishop, Glen, Whalley & Christie, 1982; Hollon, DeRubeis, Evans, Tuason, Weimer & Garvey, 1986; Murphy, Simons, Wetzel & Lustman, 1984), and they therefore attribute the results to a better performance by antidepressants rather than poor performance by CBT. Post-treatment recovery rates amongst completers were 57% for the medication group and 51% for CBT (Elkin et al., 1989).

Some have suggested however that there were large and robust differences in the quality of CBT across the 3 sites in the study, (Jacobson & Hollon, 1996), and that it is possible that the superiority of ICM can be explained in terms of poor quality of CBT (Jacobson & Hollon, 1996). An exploratory analysis revealed that at one site patients receiving CBT did as well as those receiving ICM, and the same was true for those receiving IPT at
another site. We therefore need to know which site produced which pattern of results to ascertain whether the site where CBT was more effective yielded the equal outcomes for CBT and ICM.

**Long-term Outcome**

In terms of long-term outcome, Blackburn & Moore (1997) found maintenance CT to be as effective as maintenance medication whether it followed acute treatment with CT or medication. They also found no evidence that severity differentiated response to CT and medication, thereby opposing the NIMH findings (Elkin et al., 1989, 1996) but supporting those of Hollon et al. (1992), Thase et al. (1991) and McLean & Taylor (1992). Simons et al., (1986) found that patients receiving CT with or without medication are less likely to relapse than those not receiving CT.

**Prevention of Relapse**

None of the treatments in the NIMH study performed particularly well in terms of their ability to produce lasting recovery from major depression (Shea et al., 1992). Only 30% of patients on CBT, 20% on pill placebo and 19% on ICM completed treatment, recovered, and remained recovered for the 18 month follow-up (Elkin et al., 1992). In contrast, several studies have found patients treated with CT to show approximately half the post-treatment relapse rate of those given antidepressant medication (Blackburn, Eunson & Bishop, 1986; Kovacs, Rush, Beck & Hollon, 1981; Simons, Murphy, Levine & Wetzel, 1986). Evans et al. (1992) reported 2-year relapse rates of 50% for pharmacotherapy and 21% for CBT.

Significant differences are not observed when continuation medication is given during the first year of the 2 year follow-up period however. Blackburn & Moore (1997) for example, report a 12 month relapse rate of 31% for patients on continuation medication during follow-up, as opposed to 24 % in the continuation CT group. It has been suggested that in certain cases, continuation of treatment may be needed for both CT (Thase et al.,
1992) and antidepressants (Frank et al., 1990). Blackburn & Moore (1997) for example, found that continuation of CT or medication during follow-up prompted continued improvements.

**Problems with Studies**

A number of problems have typically been associated with clinical trials of antidepressant medication and CBT, which make it difficult to place confidence in the research findings. The first is the definition of recovery that is employed. In many drug trials, recovery is defined as 50% reduction in symptoms, which may lead to elevated reported recovery rates. Also, recovery tends to be assessed at an arbitrary point in time, rather than over a period of weeks (Quitkin, Rabkin, Ross & McGrath, 1984) and there is variation in criterion for defining relapse. Secondly, factors other than the treatment under investigation may contribute to its apparent effectiveness. These include spontaneous remission, recovery due to nonspecific factors, a supportive environment and contact with a helping professional (Joyce & Paykel, 1989). In terms of psychotherapy for example, Elkin et al. (1989) found it impossible to separate Interpersonal psychotherapy and CBT in terms of their effectiveness. This finding is consistent with other psychotherapy research in which little difference has been found in terms of the effectiveness of different psychotherapies (Luborsky, Singer & Luborsky, 1975).

Additional problems have been created by variations in the cognitive approach employed in studies (Mahoney & Arnkoff, 1978), the diverse theoretical constructs involved (Brewin, 1989), and differences in the experience and training of the therapists involved (Elkin et al., 1989; Jacobson & Hollon, 1996). This makes it impossible to distinguish between the effect of the treatment and the effect of the therapist (Elkin et al., 1989). Similarly with antidepressants, compliance with medication has often not been monitored, nor has account been made for differences in individual's sensitivity to set dose of antidepressant medication. The unacceptability of medication for some clients may also result in a highly selected group within the antidepressant condition.
Finally, sample sizes have tended to be small, populations have varied in terms of severity and type, and widely differing exclusion criteria have been employed. Also, studies tend to have been conducted by those with an allegiance to one treatment or the other, which may lead to biases in the research findings (Jacobson & Hollon, 1996).

Conclusion
The findings from research to date suggest that CBT and antidepressant medication are both effective in treating some individuals with depression. CBT appears to be as effective as antidepressant medication in the acute treatment of depression, if not slightly better. The results are inconclusive however, for cases of severe depression. The combination of CBT and antidepressants may be somewhat superior to either treatment individually, but the differences are often not significant. Finally, CBT appears to be more effective than antidepressants in terms of preventing relapse, although the effectiveness of the latter may be improved by continuing medication at a full therapeutic dosage for several months after the symptoms have disappeared.

Given that CBT is as effective as antidepressant medication, and does not result in the frequent medical side effects of the latter, it would be advisable to consider CBT as an early option in the treatment of depression. Antidepressants may still be required in some cases, but patients should be selected with care, given an adequate dosage, for sufficient time, with their response being monitored carefully. By adopting this approach, patients can be encouraged to become actively involved in their own treatment, deciding for themselves what would be most helpful. This would minimise the risk of both unwanted side effects and relapse following treatment. It is recognised that the relative cost and resource implications of the above treatments may constitute a major barrier to the actual implementation of such a plan.
References


"The Principle Aims of Assessment are Diagnostic and Evaluative".
Discuss this Statement with Reference to the Field of Learning Difficulties.

June 1998
Year 1
Assessment
Assessment, defined by Carr & Collins (1992) as being "the process by which we gather information about a person, so that we arrive at a clear picture of that person's present state of functioning", constitutes a fundamental part of the work of a clinical psychologist. Irrespective of the specialty, client group or approach under consideration, it is inevitable that some form of assessment will be conducted by the psychologist for practically every client entering the clinical psychology service (Marzillier & Hall, 1992). Even if an assessment has already been completed by another professional within the team, the psychologist will often elect to carry out their own assessment of the problem.

Psychological assessment may be carried out for a number of different reasons. For one referral, the psychologist's involvement may be limited to conducting an intellectual assessment, with the goal being to identify the individual's current level of functioning. Alternatively, a client may be referred for treatment, with assessment providing the foundation for development of an overall package of care (Zarkowska & Clements, 1988). Although assessment may appear to be merely a perfunctory response to referral, there should always be a valid reason behind the process, which is explicitly recognised (Cullen & Dickens, 1990). According to Marzillier & Hall, (1992), assessment should always arise from important clinical questions, which relate to the client's needs. The purpose of assessment and the questions to be answered should then govern the clinician's choice of assessment method and tools (Leudar & Fraser, 1987), ensuring that the information collected is of relevance, and enables the clinician to identify, describe or understand the problems being presented (Hogg & Raynes, 1987).

There are many different types of assessment that a clinical psychologist may conduct. These include assessment of intellectual ability or specific aspects of cognitive functioning (e.g. comprehension of verbal instruction), adaptive functioning, behaviour disturbance and assessment of motivation, or a psychological or emotional presenting problem (Marzillier & Hall, 1992). In conducting the assessment, the psychologist may employ a
number of different methods, such as interviews, case history, psychometric tests, questionnaires, rating scales, or behavioural observation (Zarkowska & Clements, 1988). These methods may be used alone or in combination, with selection being influenced by factors such as the assessment purpose, setting, client group, psychometric properties of available tools, psychologist's orientation and the client's ability or motivation to participate in the process. An assessment can only fulfil its purpose if the client is engaged in the process and is willing to provide the necessary information.

The field of learning disabilities provides a rich illustration of the variety of assessments that a clinical psychologist may be involved in, and the different purposes for which they may be conducted. Comprehensive assessment is vital for effective service provision for people with learning disabilities (McCue, 1989) and a multidisciplinary approach is often advocated, given the diversity of problems experienced by this client group (Cruickshank, 1977; Torgesen, 1986). McCue (1989) identifies 4 types of assessment that are employed in this specialty. These are psycho-educational (focused on intellectual and academic presentation), psychological/neuropsychological (concerned with cognitive, language, perceptual, motor and emotional manifestations), medical/neurological (considering the medical and aetiological issues relevant to assessment and treatment) and vocational assessment (relating to functional presentation with regard to work). These types of assessment are client-focused, but the psychologist's assessment should also address the system within which the client is functioning, considering interpersonal, social, institutional and familial relationships (Marzillier & Hall, 1992).

**Purpose of Assessment**

The present essay discusses the various purposes of assessment, using examples from the field of learning disabilities to illustrate the issues under consideration. Assessment in learning disabilities has traditionally been concerned with the diagnosis and evaluation of individuals, and although these are valid and often important purposes of assessment, there are problems and limitations inherent in adopting such an approach. It will be argued in the
course of this essay that there are other valuable and powerful functions which assessment can and should serve, if optimal care is to be provided for clients, including the explanation of client difficulties or identifying specific points in the system for intervention (Halliday, 1996). For the purpose of this essay, the term ‘learning disability’ will be used to refer to individuals who have an IQ below 70, as measured by standardised assessment, and who also exhibit difficulties in 2 or more areas of adaptive behaviour (DSMIV) (Heber, 1961, cited in Hogg & Raynes, 1987).

This essay is also complicated by the variety of theoretical models that have been proposed over the past 30 years, regarding aetiology, assessment, diagnosis and intervention of learning disabilities (Torgesen, 1986). These paradigms include medical, psychological process, behavioural, cognitive and neuropsychological models, with each possessing it’s own terminology, assessment procedures and intervention strategies (Poplin, 1988; Torgesen, 1986). To simplify matters, the focus of the essay will be on general principles of assessment, with specific types of assessment only being cited to illustrate particular arguments.

**Diagnosis and Evaluation**

Assessment in learning disabilities has traditionally been focused on evaluation and diagnosis (Halliday, 1996), with emphasis on methods such norm-referenced or criterion-referenced tests, assessment of adaptive behaviour or techniques of behavioural observation (Hogg & Raynes, 1987). Diagnosis and evaluation are indeed important stages in the effective provision of services to people with learning disabilities (McCue, 1989), particularly services focused on rehabilitation. In the field of vocational rehabilitation for example, McCue (1989) identifies 2 major functions of assessment: (a) to provide information that will allow a diagnosis to be made, and (b) to identify a client’s unique pattern of strengths and weaknesses in order to guide rehabilitation efforts.
Diagnostic assessment has its roots in the medical model, where clinical entities are assigned to categories, each associated with a collection of observable signs and reported symptoms (Millon, 1991). In order to qualify for a diagnosis, an individual must meet specified diagnostic criteria (Nelson-Gray, 1991). This process presupposes the existence of discernible phenomena which can be recognised and then objectively measured (Millon, 1991), which is unfortunately questionable for many psychological constructs (e.g. depression), hence raising concerns as to validity of these diagnoses.

In the field of learning disabilities, diagnoses are mainly client-focused, involving the identification of a specific medical disorder, a learning disability, difficulty in adaptive functioning or perhaps a psychiatric problem. Diagnosis however, need not be client-focused. Problems may also be diagnosed within the environment, within relationships between the client and carers, or at a service level. In the past, diagnoses tended to be general, static and client-focused, but in recent years there has been a shift to more dynamic and domain specific diagnoses, which remove the focus on “a diseased entity” within the individual (Brown & Campione, 1986).

In addition to diagnosis, assessment may also be evaluative in nature. Evaluation is defined as “determining the relative importance of something in terms of a standard” (English & English, 1959). In terms of psychological assessment, this standard may either be the norms of a set population, as in norm-referenced tests, or a set criterion or achievement, on which the individual is scored irrespective of the performance of others, as in criterion-referenced tests (Hogg & Raynes, 1987). Evaluation may be conducted to aid or supplement diagnosis, but often such assessments will be carried out in their own right, to provide detailed information about the individual’s strengths and deficits (McCue, 1989). A comprehensive multidisciplinary approach is recommended in order to yield as full a picture of the client as possible (McCue, 1989).
Psychological assessments used for diagnosis and evaluation in learning disability are based on the concepts of performance and competence. Performance here refers to the "observable behaviours produced by a person", whilst competence refers to a set of "organised abilities assumed to underlie performance" (Gregoire, 1997). In the field of learning difficulties, assessments have tended to be predominantly performance based, despite the fact that competence assessments typically provide more valuable information (Gregoire, 1997). The Weschler scales, for example, have generally formed the basis for learning disability assessments (McCue, 1989), despite their inability to separate out and evaluate the specific perceptual and cognitive abilities related to thinking and learning that would enable clinicians to plan optimal interventions (McCue, 1989). Current research suggests that neuropsychological test batteries, such as the Luria-Nebraska (LNNB) (Golden, Purisch & Hammke, 1980) and Halstead-Reitan Neuropsychological Battery (HRB) (Reitan & Davison, 1974), may aid the diagnosis and evaluation of learning disabilities (McCue, 1989). Such batteries provide information on a wide variety of specific aspects of functioning such as attention and comprehension, allowing individual client profiles to be generated (McCue, Shelly & Goldstein, 1986; O'Donnell, Kurtz & Ramanaiah, 1983).

In addition to psychometric or neuropsychological tests, diagnosis may be aided by medical evaluation (McCue, 1989), or even neuroimaging techniques (Shoumitro, 1997). However, despite the value of evaluating neurological signs (Adams, Kocsis & Estes, 1974; Lyon, 1980), these signs cannot distinguish reliably between children with learning disabilities and their peers (McCue, 1989). Furthermore, even with neuroimaging techniques, it is impossible to determine whether a particular finding is due to a specific syndrome, or simply related to the severity of learning disability. Such findings emphasise the importance of founding a diagnosis of learning disability on a broad based, comprehensive behavioural and psychological evaluation in conjunction with neurological assessment and genetic tests (Adams, Kocsis & Estes, 1974).
Value of Diagnosis
There are a number of reasons why diagnosis may constitute a valuable focus for assessment. Firstly, diagnosis allows a condition to be clearly defined. Often, learning disabilities go unrecognised, or are mislabelled as emotional or personality problems. Such labels are unfair to both the client and their family, perhaps resulting in increased confusion and anxiety along with inappropriate or limited intervention by professionals (Pickar, 1986). A label of 'learning disability' on the other hand, which acknowledges the presence of a disability at the root of the observable problems may help remove some of the uncertainty and fear, and alleviate any guilt or blame that may have been experienced. Moreover, a diagnosis may provide access to specialist services which were previously denied.

Secondly, specific conditions often demonstrate themselves in a recognisable pattern of signs and symptoms, with certain clusters of problems co-occurring (Johnson, 1995). A diagnosis may therefore alert professionals to the likely presence of problems or symptoms which may be prevented or remediated through intervention (e.g. behavioural phenotypes). Thirdly, providing a medical diagnosis alerts professionals to the presence of various handicaps which need consideration when conducting an assessment, selecting appropriate interventions or establishing expectations for the client (Tolan, 1991). Finally, diagnosis may also allow clinicians to offer some information on prognosis (McCue, 1989).

Value of Evaluation
As mentioned previously, evaluation, if comprehensive, can provide clinicians with considerable information concerning a client's strengths and weaknesses, which facilitates the planning of interventions (Schlieper, 1982). Translation of data from evaluative assessment into functionally relevant information, should yield appropriate intervention and realistic goals (McCue, 1989). When carried out at the outset of service provision, assessment may also provide a baseline measure, which can be used to evaluate the
effectiveness of intervention and monitor client progress (DuPaul & Ervin, 1996). Similarly, evaluation may also be conducted in terms of service provision.

Limitations of Diagnosis & Evaluation

Despite their obvious value, there are a number of limitations inherent in diagnostic and evaluative assessments. Firstly, diagnosis of learning disabilities is complex and controversial, due to heterogeneity of clients and lack of clear definitions (McCue, 1989). Although a diagnosis places an individual in a category, which offers assumptions regarding their level of functioning, capabilities or difficulties, a diagnosis does not actually indicate either the specific behaviours that the individual will display, nor the limitations that such behaviours place on their future potential (Szymanski, Dunn & Parker, 1989). Diagnostic categories typically manifest considerable internal variation (Millon, 1991). In the field of learning disability and the diagnosis of autism, neurobiological studies indicate that individuals within this category differ considerably in terms of whether they suffer from epilepsy, have a learning disability or display specific behaviours related to their learning disability (Deb, 1997). Furthermore, there seems to be little empirical evidence to suggests that definitive subtypes of specific learning disabilities can be identified within an adult population (McCue, 1989).

A second problem with diagnostic and evaluative assessment is that it tends to be carried out at a set point in time, in a particular setting, by a specific assessor. There appears to be an implicit assumption here that performance is stable both across time and settings. Nevertheless, all assessments are contextualised, and it is important to identify whether the findings from an assessment, or series of assessments, be generalised (Gregoire, 1997). This is particularly important when considering an assessment of behaviour disturbance for example, where the disturbance is best viewed as dynamic, being affected by antecedent factors such as environmental change and consequences such as staff response (Leudar & Fraser, 1997). Assessment therefore needs to address the interaction between individual and environment, in order to explain behaviour and suggest appropriate interventions
(McCue, 1989). Assessment should also be a continuous process, allowing for changes within the client or environment, and monitoring the effects of such change.

A focus on evaluation can all too easily ignore the educational experiences of the individual, and the impact these may have had on motivation, persistence and cognitive functioning (Szymanski, Dunn & Parker, 1989). Similarly, environmental factors (Whitten, 1983), and the interaction between the environment and individual within the assessment setting may also be underestimated (Szymanski, Dunn & Parker, 1989). Evaluation which focuses on only one aspect of disturbance is again problematic, in that there is often a close relationship between different forms of behavioural disturbance, with one increasing in frequency or severity as the other decreases (Leudar & Fraser, 1987). It is important to remember that although psychological assessments are perhaps often treated as being definitive and encompassing the individual’s complete functioning, even the most comprehensive assessment can only address discrete aspects of the individual’s psychological make-up and their social life (Halliday, 1996).

A third set of problems relate to the psychometric tests employed in diagnostic and evaluative assessment. Concerns have been raised regarding the use of norm-referenced performance tests, where the average performance of a given population is assumed to represent the ‘normal’ level of performance, and the arbitrariness of cut-off points, where a 1 point difference determines the diagnosis of learning disability (Gregoire, 1997). As Gregoire (1997) states, “to base important decisions on the results of single tests with arbitrary cut points is to participate in a flawed process which can only undermine the validity of diagnostic assessments”. Moreover, as Shonkoff (1983) points out “human assessments are never wholly objective or value free”, due to the lack of consensus as to the boundary between normality and deviance. Additional problems relating to the validity and reliability of such assessments include scoring accuracy, adequacy of content sampling and the stability of the trait being measured (Berger & Yule, 1987). Of specific relevance to the field of learning disabilities is the finding that different methods of assessment result
in different patterns of diagnosis within a population (Braden, 1987), the problem of response sets and the use of assessment tools which have not been normed for adults with learning disabilities (McCue, 1989).

One major limitation of diagnostic and evaluative assessments is their inability to offer an explanation for the phenomena being observed, due to the lack of theoretical underpinnings (Gregoire, 1997). Although they can identify areas in which an individual is experiencing difficulty, they fail to answer questions such as why this difficulty occurs, what relationships there are between the difficulty and the individual’s ability, and how the individual can be helped (Halliday, 1996). Such questions are of great importance when planning client care. Similarly, although in theory evaluative assessment should consider the system and environment in which the client functions, in practice the emphasis tends to be on the client. Evaluation may therefore fail to identify elements of the system which are negatively affecting the client’s functioning, thereby ignoring prime targets for intervention.

Finally, it is vital to consider the impact a diagnosis of ‘learning disability’ may have on an individual’s life in terms of educational opportunities, vocational prospects, housing and social and leisure opportunities. Furthermore, it is possible that intellectual/psychological assessment will result in clients being assigned a devalued role in society and being subject to prejudice and exclusion (Halliday, 1996). We need to be aware therefore, of whether a diagnosis will truly benefit a client, or whether, as Amando (1988) points out, assessment and diagnosis is serving the needs of professionals, society or political agendas, perhaps resulting in the client’s needs being compromised.

Diagnostic and evaluative assessment often results in individuals being segregated from their peers and placed in ‘special’ classes, schools, or services. While this may be considered by professionals as being beneficial for the person, the individuals themselves often feel or are rejected and isolated, viewing segregation as a personal failure (Pickar,
Moreover, as Halliday (1996) reminds us, research suggests that such treatment actually results in "widening academic gaps (Calfee & Brown, 1979, cited in Halliday, 1996), lowered self-esteem (Madden & Slavin, 1983; Nolands, 1985, cited in Halliday, 1996) and lower rate of employment" in this population (Stern, Hoachlander, Dhys & Benson, 1985, cited in Halliday, 1996). Moreover, research also indicates that once separated, these clients remain in separate systems throughout their adult lives (Brown, Rogan & Shiraga, 1987, cited in Halliday, 1996).

**Beyond Diagnosis and Evaluation**

Despite the values of diagnostic and evaluative assessment, a number of limitations have been identified with this approach. Moreover, in order to offer maximum value to the clinician providing care for individuals with learning disabilities, assessment should serve a number of additional purposes. Firstly, as has been stated earlier, the clinical psychologist needs information which provides some explanation of the client's difficulties and leads to a comprehensive formulation of the problem (Halliday, 1996). Secondly, the assessment needs to offer prescriptions for intervention (McCue, 1989).

One approach to assessment which has been shown to be effective in meeting both of these purposes, whilst considering the individual as part of a system, is functional analysis (e.g. Day, Horner & O'Neill, 1994). Functional assessment refers to "the use of multiple assessment strategies in order to delineate specific antecedents and consequent events that set the occasion for and/or maintain a target behaviour" (Horner, 1994). Such an approach is not only appropriate for assessing a client difficulties, but also for assessing problems within a particular system or service.

Recent approaches to functional assessment have been based on a three-tiered model, involving a descriptive analysis, an experimental or functional analysis and an evaluation of possible interventions (e.g. Kern, Childs, Dunlap, Clarke & Falk, 1994). This approach should also incorporate multiple forms of assessment, with a variety of individuals within
the system (DuPaul & Ervin, 1996). Functional assessments however, are also not without their problems. Firstly, it can be difficult to decide which behaviours and environmental variables to assess (Hayes & Follette, 1992). Secondly, the procedures are both time-consuming and resource-intensive (DuPaul & Ervin, 1996), which means that they may not always be a viable option given the constraints imposed by the current NHS system.

Conclusion
There are a number of different reasons why a clinical psychologist may conduct an assessment. Although diagnosis and evaluation are two important reasons, there are limitations with conducting an assessment solely for these purposes. In order to plan appropriate and effective treatment for clients, the psychologist needs to collect information which will also offer some explanation for the client’s difficulties, and generate a comprehensive formulation which will provide direction for intervention. These aims are often not achieved when assessment is solely diagnostic and/or evaluative.

Whatever the purpose of assessment, there is acknowledgement that, in learning disabilities, this process should involve multiple types of assessment, perhaps across different settings, carried out by different individuals, taking account of the system within which the individual is functioning. Assessment must also be ongoing, monitoring change and evaluating the effectiveness of interventions. Finally, it is important that professionals be aware of the purpose of assessment, and consider the possible impact of that assessment on the client and his/her future.
References


Essay 3

Childhood bereavement has a less deleterious effect upon children’s psychological outcome than does marital discord and divorce. Discuss.

December 1998
Year 2
Introduction

Considerable research has accumulated over the years concerning the psychological and emotional impact of major life events (Pillow, Zautra & Sandler, 1996). Only recently however, has attention focused specifically on the effect of such events on children and adolescents (Goodyer, 1990; Rutter, 1990, cited in Goodyer, 1993). Perhaps the most critical events for this client group, given the importance of the family for the child's emotional and psychological development (Framo, 1994, cited in Reid & Cristafuli, 1990), are those pertaining to the family. Such events typically score highly on life event rating scales (Holmes & Rahe, 1967) and include divorce, death of a relative, marital separation, remarriage and marital conflict.

Numerous studies have been conducted recently, in an attempt to determine the relationship between these stressful life events and subsequent psychopathology (Compas, 1989; Goodyer, 1990). Unfortunately, such research has typically been plagued by problems. Studies conducted in 1950's and 1960's, for example, tended to treat one parent families as a homogenous group, thereby failing to differentiate between the effects of divorce and bereavement (Shaw, 1991). Similarly, there was little consideration of factors such as sex of the child, social class and pre-existing relationships within the family, which may influence the relationship between divorce (Shaw, 1991) or bereavement (Kranzler, Shaffer, Wasserman & Davies, 1990) and outcome. With regard to marital discord, studies have employed a variety of methodologies, with diverse populations, and have generated contradictory findings (Reid & Crisafulli, 1990).

The present essay will discuss three life events, which are thought to have a major impact on children. These are bereavement, divorce and marital discord. Research pertaining to each of these events will be presented in turn, with consideration of the short-term and long-term effects and recognised mediating factors. Several factors have potential importance for adjustment to all of these events, and will be discussed together at the end of the essay. It will be argued that despite some similarities, factors such as heterogeneity
of outcome, methodological problems with studies (e.g. lack of consistent outcome measures, inadequate definitions) and the influence of multiple mediating factors, preclude consideration of the relative impact of bereavement, divorce and marital discord on childhood adjustment. Such a view is congruent with the lack of such comparisons in the current literature.

Bereavement

Given the question under consideration, this section will focus solely on parental death. Within the childhood bereavement literature, there has been considerable debate as to whether children grieve following a loss. Several theorists have argued that since young children cannot fully understand a loss, due to limited cognitive ability and incomplete identity formation, they cannot grieve (Freud, 1917; Wolfenstein, 1969, cited in Kranzler et al., 1990). More recently, evidence has emerged suggesting that pre-school children do exhibit grief-related emotions (Kranzler, et al., 1990; Raphael, 1982), although these responses may be "less pervasive, more intermittent and more situation specific" than those experienced by adults (Kranzler et al., 1990). Worden (1991) proposes that mourning is qualitatively different during the early years of life, due to limited emotional and cognitive development, but is more similar to adult mourning beyond the age of 7 years (Worden, 1991). Hence, the various attempts to impose adult models of bereavement onto children's mourning.

A number of stages, or tasks, of mourning have been described in the adult bereavement literature, with the notion that individuals follow a linear progression through these stages (Parkes, 1970, cited in Trolley, 1994; Bowlby, 1980). Parkes and Bowlby, for example, describe a progression from emotional reactions to behavioural reorganisation and hope. More recently, mourning has been conceptualised as an ongoing process, where the individual can travel both backwards and forwards through the cycle (Silverman, Nickman & Worden, 1992). Despite this fluidity, there are typical reactions which many children can be observed to experience at various points.
Outcome
Shock, disbelief and unreality tend to constitute immediate responses to bereavement (Dyregrov, 1994). Other reactions include dysphoria, social withdrawal, changes in sleep or appetite, depression, confusion, minor illnesses and school difficulties (Dyregrov, 1994). Longer-term reactions vary considerably, with no particular pattern of cognitive, behavioural or affective symptoms being considered typical. Indeed, heterogeneity of response to parental loss has been a consistent finding in the literature (Rutter, 1966; Van Eerdewegh, Bieri, Parrilla & Clayton, 1982). Problems described include conduct disorders, depressive reactions (Brown, Harris & Copeland, 1977), personality disorder (Dietrich, 1979, cited in Kranzler et al., 1990), cognitive and functional impairment (Lifschitz, 1976, cited in Kranzler et al., 1990), somatic complaints, psychoneurotic reactions, anxiety, anger, withdrawal and sleep disturbances (Dyregrov, 1994). Problems may also include loss of motivation, slowed cognitive functioning, attentional difficulties and intrusive thoughts and images (Herbert, 1996).

Although some studies report problems to have dissipated by one year post-bereavement (Van Eerdewegh, Clayton & van Eerdewegh, 1985), others continue to report high symptom rates at 3 years (Elizur & Kaffman, 1983). A one year prospective study, by Van Eerdewegh et al. (1982), comparing a community sample of bereaved children with control groups, found a significant increase in dysphoric mood among the bereaved sample, with symptoms of crying, sadness or irritability, sleep difficulties, loss of appetite, behavioural withdrawal and tantrums. More children within the bereaved sample were rated as being mildly depressed, although there was not a significant increase in diagnoses of clinical depression. Furthermore, most differences were maintained at 13 month follow-up, although there had been a significant decrease in dysphoric mood and an increase in sibling conflict, abdominal pain and a lack of interest in school. Several problems were noted with the study, including children being targeted through a study of bereaved parents. Reliance on interview data from parents may have led to an under-estimation of difficulties (Payne, Goff & Paulson, 1979), although some authors report acceptable
agreement between parent and child descriptions (Reich, Herjanic, Welner & Gandly, 1982, cited in van Eerdewegh et al., 1982).

Despite reports of increased risk of psychopathology following the loss of a parent, several studies have failed to corroborate this finding (Sood, Weller & Weller, et al., 1992; Fristad et al., 1993). In reality, most children do not go on to exhibit psychopathology following parental loss. The literature also cites examples of positive changes in a proportion of children and adolescents who experienced parental bereavement at a younger age. These include increased maturity, compassion and responsibility and development of coping skills (Balk, 1990; Martinson, Davies & McCloowry, 1987).

Problems with studies
Kranzler et al. (1990) highlight a number of difficulties with research on childhood bereavement. These include an emphasis on retrospective designs, problems with the samples used, lack of control groups, and failure to adequately control for potential mediating factors. As a result, contradictory findings have emerged, rendering it difficult to draw conclusions. Kranzler et al. (1990) highlight the need for prospective studies, to address the relationship between acute childhood responses to loss and subsequent psychopathology. This would enable researchers to plot the course of childhood bereavement and identify when, and how, problems develop.

Summary
Considerable heterogeneity has consistently been reported, in terms of childhood reactions to bereavement. In the majority of cases, reactions are thought to be relatively short-lived, with some children demonstrating positive outcomes. However, a small number do go on to exhibit signs of psychopathology. In order to explain the range of outcomes, several authors have proposed that parental bereavement generates a ‘vulnerability’ in the child, but that increased risk of psychopathology is determined by the presence of certain mediating factors (Harris, Brown & Bifulco, 1986; van Eerdewegh et al., 1982). These
include factors relating to the child (e.g. developmental stage at the time of the loss, previous losses, temperament), the nature and mode of the loss, family factors (e.g. relationship with the remaining parent and siblings, communication, parental adjustment) and environmental factors (e.g. school, peers, external support network, opportunity to express feelings).

**Divorce**

Within today's society, divorce constitutes a common life event for children. Rather than representing a simple unitary event, divorce is now recognised as involving a complex series of transitions, to which children and parents must adapt (Shaw, 1991). There is also increasing recognition that many of the changes and transitions actually begin long before the actual divorce takes place (Shaw, 1991), although such factors have often been neglected in the literature (Wallerstein, 1991). A distinction has been made in the literature, between the short and long-term effects of divorce for children (Emery, 1988, cited in Fonagy, Steele & Steele et al., 1994; Hetherington, 1979). Hetherington (1981) (cited in Shaw, 1991) has conceptualised the short-term view in terms of a crisis model, where the family is required to manage the stresses associated with parental separation, including marital conflict, loss and uncertainty. In the longer-term, the family must adapt to the many changes resulting from the divorce (Shaw, 1991). Clinical presentation at each of the stages may differ, although this is yet to be fully investigated.

**Outcome**

delinquency, aggression and disobedience) (Emery, 1982), with studies reporting more aggressive behaviour in boys from divorced families than from two parent families (Hetherington et al., 1978; Zill, 1978, NSC data, cited in Shaw, 1991). Moreover, both boys (Goldstein, 1984, cited in Shaw, 1991) and girls (Kalder, Riemer, Brickman & Chen, 1985, cited in Gately & Schwebel, 1992) from divorced families report increased involvement in delinquency. Unfortunately two potentially confounding variables, race and SES, have thus far prevented the isolation of the effects of divorce per se (Rutter & Giller, 1983, cited in Shaw, 1991). Researchers also have reported additional factors associated with divorce (e.g. inconsistent discipline) which may further complicate the picture (Loeber, 1982).

Evidence for an increased incidence of internalising problems, such as depression, is less convincing. Numerous studies have been conducted to investigate the effects of parental loss through either death or divorce, with a handful suggesting an increase of such problems among girls (Furstenberg & Allison, 1989). Several studies have found differences in self-concepts of children from divorced families, when compared to children from intact families (Forehand, McCoombs, Long et al., 1988). Other studies have found increased distress, as reported by girls from disrupted marriages (Furstenberg & Allison, 1989), and greater depression or withdrawn behaviour among both sexes at 5 year follow-up (Peterson & Zill, 1986). Nevertheless, several studies have found no differences (Raschke & Raschke, 1979, cited in Shaw, 1991; Slater & Haber, 1984). This inconsistency has been partly attributed to inconsistencies in operationalising the term ‘internalising disorder’ and difficulty inferring such states from behaviour (Shaw, 1991).

Regarding cognitive deficits, there has again been a failure to separate the effects of divorce and potential confounding variables (e.g. single parent families, SES), although some have found poorer academic task performance among children from divorce, even when controlling for SES and reason for single parent status (Santrok, 1972, cited in Shaw, 1991). The evidence seems to suggest that although children from single-parent
families tend to perform worse academically than children from 2 parent families, divorce acts to exacerbate this trend (Shaw, 1991). Based on Guidubaldi et al.’s (1984) (cited in Kelly, 1988) findings, it has been hypothesised that poorer academic performance is perhaps mediated by deterioration of behaviour at school following the divorce (Shaw, 1991).

Although individual variation is to be expected in the long-term consequences for children (Hetherington, Cox & Cox, 1982, cited in Kelly, 1988; Hetherington, 1989), adjustment is generally thought to improve over time (Hetherington, 1981, cited in Shaw, 1991; Wallerstein & Kelly, 1983, cited in Shaw, 1991). Moreover, despite the prevailing focus on pathology, and the volume of research documenting negative outcomes and adjustment problems, there is evidence to suggest that in some cases divorce may promote psychological growth and enhanced functioning (Gately & Schwebel, 1992). Four main areas in which positive outcomes are thought to occur post-divorce are self-esteem (Slater et al., 1983, cited in Gately & Schwebel, 1992), maturity (Kurdek & Siesky, 1980a, cited in Gately & Schwebel, 1992), empathy (Hetherington, 1989) and lack of sexual identity (Kurdek & Siesky, 1980c, cited in Gately & Schwebel, 1992). Further control-matched longitudinal studies are required to expand on this list of positive outcomes (Gately & Schwebel, 1992) and to suggest interventions which could promote and enhance positive adjustment in children post-divorce (Gately & Schwebel, 1992).

Outcome Research

Numerous methodological problems plague studies investigating outcome following divorce. These include a failure to control for confounding variables, use of non-representative samples, lack of adequate control groups, problems with measures (e.g. not double-blind, poor reliability and validity) and the absence of multivariate interaction models which can explain the range of outcomes described (Gately & Schwebel, 1992). Moreover, the prevalence of negative outcomes may in part be an artefact of a focus on pathology in theoretical models (Kanoy & Cunningham, 1984, cited in Gately &
Schwebel, 1992) and research measures (Blechman, 1982, cited in Gately & Schwebel, 1992), a tendency to use clinical samples and reliance on informant reports (Kanoy & Cunningham, 1984, cited in Gately & Schwebel, 1992).

Mediating factors
A number of factors are thought to mediate the effects of divorce on children’s outcome. Shaw (1991) lists eight family process variables which have been identified as potential mediating factors. These include interparental conflict, separation from attachment figure, temporal influences (e.g. time since divorce), parenting practices, child-parent relationships, remarriage and family economics. Sex of the child has also been linked to outcome.

Summary
As with bereavement, heterogeneity of child outcomes has consistently been reported following divorce. The transition from to single parent status may be difficult time for many children, due to the various changes and transitions which occur, but adjustment appears to be mediated by a complex interplay of factors. Many of these factors also mediate the effects of childhood bereavement.

Marital Discord
Marital discord represents a third family event reported to influence child adjustment (Fincham & Osborne, 1993). Although marital discord may often occur in conjunction with parental separation or divorce, evidence suggests that children may be detrimentally affected by disturbed family interaction patterns, even in the absence of separation (Wolkind & Rutter, 1985). Research in this area has typically been hampered by the use of poorly defined terms, such as ‘marital satisfaction’, and inconsistent measurement (cf Fincham & Osborne, 1993). However, the shift to studying ‘marital conflict’, has resulted in more consistent relationships being found with child adjustment problems (Emery & O’Leary, 1982; Johnson & O’Leary, 1987).
Outcome
Clinical experience has long suggested an association between marital conflict and later psychopathology (Baruch & Wilcox, 1944; Minuchin, 1974, cited in Shaw, 1991), but only recently has this become the focus of empirical investigation (Hughes, 1988, cited in Kashani et al., 1992). Studies have since reported behaviour problems following marital conflict in a variety of family structures and settings (Emery & O’Leary, 1982; Hetherington, Cox & Cox, 1985; Shaw, 1989, cited in Shaw, 1991), including those who have undergone divorce or separation (Wallerstein & Kelly, 1983, cited in Shaw, 1991). Moreover, some have proposed that marital conflict, either pre- or post-separation, is more strongly related to outcome than the separation itself (Hetherington, Cox & Cox, 1979, cited in Emery, 1982). Perhaps the strongest evidence for this comes from studies which have found fewer emotional difficulties in children from conflict-free single parent families, than in children from conflictual, maritally intact families (Rutter, 1978, cited in Shaw, 1991).

Both marital conflict and lack of parental affection have been linked to increased risk of emotional disturbance and personality disorder in later life (Brown, Pelcovitz & Kaplan, 1983, cited in Kashani et al., 1992). A consistent finding is that children who experience marital conflict tend to exhibit more internalising problems (e.g. anxiety, depression) than control groups (Brown et al., 1983, cited in Kashani et al., 1992), although findings are influenced by the measures employed in the studies (Kashani et al., 1992). Hughes (1988) (cited in Kashani et al., 1992) found that children who had been physically abused themselves, in addition to witnessing family violence, exhibited greater distress, than those who had only witnessed violence. Furthermore, witnessing parental violence may encourage children to perceive violence as an appropriate means of conflict resolution (Jaffee et al., 1990, cited in Kashani et al., 1992), thereby resulting in externalising problems.
Reviews of the literature report a positive association between marital conflict and child disturbance (O’Leary, 1984, cited in Fincham & Osborne, 1993), with the relationship being stronger for boys than girls (Emery, 1984, cited in Reid & Crisafulli, 1990). This relationship is supported for boys, in a meta-analysis by Reid & Crisafulli (1990), but not for girls. Widom (1989) concludes that intergenerational transmission of violence is not inevitable, and that children who witness domestic violence will demonstrate heterogeneity in outcome. Moreover, marital discord may actually promote positive outcomes in some cases, such as improvements in conflict resolution skills (Fincham & Osborne, 1993).

Problems with Studies

Studies pertaining to family violence have typically contained methodological problems, such as retrospective designs, reliance on self-report, failure to employ baseline data, small sample sizes and a lack of adequate comparison groups. (Kashani et al., 1992). Studies have been largely correlational in nature, with little attempt to investigate the direction of relationships (Fincham & Osborne, 1993). They have also employed diverse populations and inconsistent methodologies (Reid & Crisafulli, 1990). This has all resulted in contradictory findings and a lack of general conclusions.

Mediating Factors

Certain factors are hypothesised to mediate the relationship between marital conflict and child adjustment, thereby generating the heterogeneous outcomes. Parental depression (Emery, Weintraub & Neale, 1982, cited in Emery, 1982) and parent-child relationships (cf Fincham & Osborne, 1993) are both thought to mediate the relationship in some way (Fincham & Osborne, 1993; Shaw & Emery, 1987), although neither can totally explain it. The nature of the conflict is also important (Emery, 1982). Within the wider literature, there is recognition that conflict varies along dimensions of frequency, intensity, duration and diversity of content (cf Peterson, 1983, cited in Fincham & Osborne, 1993). Each of these has been reported to influence adjustment following marital conflict (cf Fincham & Osborne, 1993). An association has also been reported between marital conflict and
physical aggression towards the child (Jouriles, Barling & O'Leary, 1987), with the latter being found to be associated with child adjustment problems (Hughes, Parkinson & Vargo, 1989). Unfortunately, covariance between parent-child aggression and marital conflict impedes attempts to establish the independent contribution of each (Fincham & Osborne, 1993).

Summary
The literature pertaining to marital discord again indicates heterogeneity of outcome among children. Although some children apparently cope well with the conflict, many experience some emotional or behavioural difficulties. Several researchers have suggested that these problems may be greater than those exhibited by children following separation and divorce, although further clarification of this is required. As with bereavement and divorce, a number of factors are thought to mediate the effects of marital discord on child adjustment.

Mediating Factors
A complex range of factors have been proposed within the bereavement, divorce and marital discord literature, as potential mediators of the relationship between each event and subsequent adjustment or psychopathology. As mentioned earlier, these factors generally fall into the categories of child, family and environmental variables. These factors are typically thought to interact in a complex way, to either facilitate, or potentiate, the effects of these life events. As such, they may represent valuable targets for clinical interventions. It is not possible to discuss each factor here, but several key factors, of importance to all three events, will be considered briefly below. Examples from the literature will be used to demonstrate the importance of each variable under consideration. Factors include sex of the child, resiliency, developmental stage and parent-child relationship.
Sex

Sex differences in outcome have consistently been found following divorce or marital conflict, with boys being reported to be more immediately and overtly affected than girls (Emery & O'Leary, 1982; Wallerstein & Kelly, 1980, cited in Shaw, 1991), and demonstrating an increased risk of antisocial and aggressive behaviour (Wallerstein & Kelly, 1980, cited in Shaw, 1991). Numerous explanations have been offered for this difference. These include increased negative sanctions following divorce, mothers being less attuned to the son's needs, comparison with divorced husband, being viewed more negatively than girls by others and living with the opposite sex parent (Hetherington, 1981, cited in Shaw, 1991). Indeed, some have reported better adjustment among children living with same sex parent (Santrok & Warshak, 1979, cited in Shaw, 1991), although others have generally highlighted marital conflict as being a more important determinant of outcome than custody arrangements.

Similar sex differences have been reported within the bereavement literature. Kranzler et al. (1990), found bereaved boys to exhibit significantly higher symptom scores on the Child Behaviour Checklist (CBCL-P, CBCL-T) than controls (Achenbach & Edelbrock, 1983), but this differences was not observed with girls. Bereaved girls only differed from controls in terms of anxiety and depression. One possible mechanism through which gender may take effect, is by influencing the manner in which grief is expressed. Research suggests that boys tend to have more difficulty talking about their feelings than girls (Dyregrov, 1988), even at the ages of 3 and 4 years old. The above findings would also suggest that while boys may tend to demonstrate their difficulties in coping through external behaviour problems, girls are more likely to evidence their difficulties via internalising problems.

Developmental Issues

The age of a child at the time of a stressful life event has consistently been presented as an important mediator of adjustment. Theoretical models suggesting that a child’s
interpretation of parental separation will be influenced by their level of cognitive and emotional development (Bowlby, 1980), have led researchers to explore whether there are vulnerable ages at which adjustment to such events is more problematic. Some have reported the pre-school years to be the vulnerable period (Hetherington, 1979; Lifschitz, 1976, cited in Kranzler et al., 1990; Wallerstein & Kelly, 1980, cited in Shaw, 1991), due to limited cognitive and affective abilities and greater reliance on adults for meeting their emotional and physical needs (Krupnick, 1984, cited in Kranzler et al., 1990), while others suggest the school years, due to increased empathy with parents (Dyregrov, 1994; Wallerstein & Kelly, 1979, cited in Shaw, 1991). Data from the National Survey of Children (Furstenberg & Allison, 1989) found poorer adjustment when divorce occurred before 6 years of age, with less transitory effects for older children.

Adolescents have also been identified as being more vulnerable following bereavement (Wallerstein & Kelly, 1979, 1980, cited in Shaw, 1991), due to pronounced feelings of responsibility, although there remains disagreement about this (Hetherington, 1981, cited in Shaw, 1991). Wolkind & Rutter (1985) suggest that older children and adolescents are more likely to show extended grief reactions and are less able to transfer affections to a new parent. However, in a prospective study, Wallerstein & Kelly (1980) (cited in Shaw, 1991) found positive outcomes for children of divorce as age and time since divorce increased.

Overall, there has been relatively little empirical research to test these hypotheses (Shaw, 1991) and findings thus far, have been mixed (Kranzler et al., 1990; Shaw, 1991). With regard to divorce, Shaw (1991) concluded that at present, age at the time of the event does not appear to be a reliable predictor of adjustment, although it will undoubtedly influence interpretations of events. Dyregrov (1994) similarly concluded that little is known about the ages associated with increased risk following childhood bereavement. Evidence concerning the influence of age on adjustment to marital discord is also decidedly lacking (Emery, 1982).
There are a number of ways in which a child's age may influence adjustment, including comprehension of the event, mode of expressing emotions, and the child's current needs. The bereavement literature offers suitable examples to illustrate these points. It is generally recognised that children have a need for information following a death, but the nature of this information, and the child's capacity to comprehend the death, need to be carefully considered (Furman, 1974). Concepts of death are thought to evolve gradually over time, with the child's ability to comprehend and make sense of death, being dependent on their cognitive, emotional and physical stage of development (Herbert, 1996). Under the age of 4 years, children have limited understanding of death and it's implications. There is likely to be no understanding of the permanence of death, and there may also be misattribution of causality, due to the child's egocentricity and magical thinking (Herbert, 1996). Information regarding the death and loss therefore needs to be simple and concrete at this stage, with effort being made to ensure that the child has understood, and to correct misunderstandings.

By the age of 6-7 years, the child will typically begin developing a sense of the finality and irreversibility of death, although this will be moderated by experience. By age 9, the child is thought to demonstrate a more complete notion of death, becoming aware of aspects such as immobility, irrevocability, causality, dysfunctionality, universality and insensitivity. By adolescence, there is generally the capacity for more abstract thought and the development of individual theories about death and afterlife.

Developmental influences may also influence the manner in which emotions are expressed. Studies have found that younger children tend to exhibit less interest in everyday activities, and more tantrums of bedwetting following loss than do older children (Van Eerdewegh et al., 1982; Kaffman & Elizur, 1983, cited in Kranzler et al., 1990). The child's age will also perhaps determine the mode of communication favoured. Pre-school children may be helped by enacting the events through play. For adolescents, talking about the loss has
been particularly identified as being helpful (Gray, 1989). These ideas should therefore guide the focus and approach for clinical interventions.

There is often much misunderstanding as to a child’s needs following a loss, and little awareness of the child’s actual thoughts and feelings. There is typically a tendency to underestimate the child’s need for information, but also to try and shield or protect them, by withholding details. Research however, indicates more favourable outcomes for children receiving open communication. Children need to make sense of what has happened. Adults may also not fully appreciate the full extent and intensity of the child’s reactions. Lack of support and opportunity to express grief have been hypothesised to be more important in determining maladjustment, than the bereavement itself (Rutter, 1966; Furman, 1974). In many cases, children will actively try to support the remaining parent, which may lead parents to miss their child’s grief.

An important target for intervention is parental education regarding the children’s reactions to loss and bereavement. It is crucial to encourage clear, open communication, appropriate for the age and needs of the child. Maintaining, or re-establishing routines, and providing the child with an opportunity to say goodbye, are also important (Dyregrov, 1994), as is keeping a momento, as this enables children to maintain their relationship with the deceased (Silverman, Nickman & Worden, 1992).

Resiliency

Temperament and personality factors are not surprisingly reported to influence outcome (Hetherington, 1989). In particular, work on resilience has consistently highlighted several characteristics demonstrated by children who continue to function well, despite the presence of environmental stress (Milgram & Palti, 1993; Rutter, 1990, cited in Goodyer, 1993). In their theoretical discussion of resilience, Fonagy et al. (1994) list several ‘characteristics of psychological functioning’ which are thought to distinguish resilient children from their counterparts. These include high IQ (E.G. Kandel et al., 1988), ability
to problem solve (e.g. Werner, 1990), task related self-efficacy (e.g. Moos & Shaefer, 1986), adaptive coping style (e.g. Cowen et al., 1990), autonomy or internal locus of control (e.g. O'Grady & Metz, 1987), higher self-worth (Werner, 1990), propensity and capacity to plan (Quinton & Rutter, 1988) and a sense of humour (Masten, 1982) (all cited in Fonagy et al., 1994). Nevertheless, there remains little understanding of the relative importance of these characteristics, or of important targets for intervention (Fonagy et al., 1994). Similarly, there has been little attempt to develop a theoretical framework, within which these factors could be conceptualised or the findings applied. Fonagy et al. (1994) propose that one way forward may be to conceptualise resilience within a model of attachment, but further investigation is required.

**Family Variables**

A consistent caring home environment is thought to protect children against the impact of bereavement, although this may be difficult for many families to maintain due to parental difficulties coping with the trauma or loss (Dyregrov, 1994). Childcare following loss, has been identified by some as a factor which may mediate the relationship between childhood bereavement and later depression (Harris et al., 1986) or adult psychopathology (Breier et al., 1988). Similarly with divorce, the quality of parent-child relationship, both with the residential and non-residential parent, is thought to be crucial (Hetherington, Cox & Cox, 1982, cited in Kelly, 1988). Although many children have little contact with the non-residential partner, evidence suggests that quality may be more important than quantity (Shaw, 1991).

Following parental death, separation, divorce and perhaps marital conflict, the homeostatic balances within the family are disrupted and new equilibriums must be achieved (Shaw, 1991). In the first years following a separation, or parental death, there will be considerable disruption, requiring reorganisation and often dramatic changes. The concept of diminished parenting by the residential parent, has been proposed as one possible mechanism through which the parent-child relationship may potentiate negative outcomes
for children following family life events (Wallerstein & Kelly, 1980, cited in Shaw, 1991). This concept would also seem applicable to families characterised by marital conflict.

A range of additional factors are hypothesised to mediate the relationship between the family life events discussed and outcome. Among these are custody decisions (Santrok, Warshak, Lindbergh & Meadows, 1982), remarriage (Hetherington et al., 1982, cited in Kelly, 1988) and additional parental separation or divorce (Furstenberg & Spanier, 1984, cited in Shaw, 1991). There is some evidence to suggest that remarriage following divorce may have benefits for boys (Chapman, 1977, cited in Shaw, 1991), but not for girls (Santrock et al., 1982), although this needs further investigation. Loss of income is another important factor, especially when the surviving parent is the mother (Shaw, 1991), although it is difficult to distinguish between the effects of income loss and those of single parent status per se (Emery, 1988, cited in Fonagy et al., 1994). Outcome effects may be mediated through consequences such as moving house, changing schools, losing contact with friends or child care arrangements (Emery, 1988, cited in Fonagy et al., 1994). Parental health, both mental and physical, is also thought to be important (Guidubaldi & Cleminshaw, 1985), particularly depression in the surviving parent following bereavement (Van Eerdewegh et al., 1985; Kranzler et al., 1990). Subsequent life events are also important (Hetherington, Cox & Cox, 1985), as are current coping resources (Hetherington, 1989).

Conclusion
To conclude, the picture concerning the impact of bereavement, divorce or marital discord on children's adjustment, is highly complex. Not only is the nature of each event quite unique in many ways, but the process involved will differ for each family. The literature consistently highlights the complex interplay of factors, relating to the event, the child, the family and the environment, which will impact on child adjustment. It is also recognised, that pre-event factors, in addition to factors surrounding and following the event, will
affect outcome. Moreover, it would appear that the context and circumstances of the event are probably more important than the event per se.

The literature at present, does not allow us to compare the relative impact of bereavement, divorce and marital discord. Furthermore, the theoretical and clinical relevance of such an endeavour would appear limited. Further research is needed to highlight the similarities and differences between the three events, with particular focus being on mediating factors and problems in adjustment. This would not only enhance understanding of how children react to stressful life events, but also inform and enhance clinical interventions.
References


What is the potential for psychotherapeutic work with people with dementia?

June 1999
Year 2
Introduction

Until recently, the issue of establishing appropriate and effective treatments for dementia has been largely neglected in the literature (Phinney, 1998). Traditionally, dementia has been conceptualised within a medical model framework, where deterioration of function is seen as a 'problem' to be 'treated' and 'cured'. Within this model, little attention is given to the individual and their subjective experience (Cotrell & Shultz, 1993; Robertson, 1990). In recent years, the relevance and validity of the traditional treatment goals of this perspective have been questioned with regard to dementia, and emphasis has been placed on adopting a person-centred, rather than symptom-driven, approach (Cheston, 1998; Kitwood, 1997). This shift has accompanied growing interest in social constructionist approaches, and their potential for guiding therapeutic work in dementia (Cheston, 1996; Sabat & Harre, 1992).

Rejection of the medical model has opened the arena for applying psychotherapeutic approaches to dementia care. This essay evaluates the potential for completing psychotherapeutic work with this client group and presents the limited evidence available concerning the effectiveness of key treatment approaches. Due to time constraints, some interventions may be excluded from the discussion. Moreover, despite the potential for conducting psychotherapeutic work with carers and relatives (Huckle, 1994), only interventions focused primarily on the person with dementia will be discussed. In order to set the context, the definition of psychotherapy, issues involved in psychotherapeutic work with older adults, and a discussion of dementia and its consequences will be presented initially.

Psychotherapy

The term 'psychotherapy' has been assigned various definitions and meanings over the years, fostering a sense of confusion and ambiguity (Bloch, 1982). In the field today, the term is applied in both general and specific ways (Brown & Pedder, 1991). In its broadest sense, 'psychotherapy' is an umbrella term, incorporating within it, the many schools of
psychological therapy in existence today (Bloch, 1982). In this respect, psychotherapy has been defined as “the treatment of emotional and personality problems and disorders by psychological means” (Noyes, 1977), and as “an interpersonal process, designed to bring about modifications of feelings, cognitions, attitudes and behaviour, which have proven troublesome to the person seeking help from a trained professional” (Strupp, 1978). In it’s more specific sense, the term has also been used to describe a particular form of therapy, namely behavioural, or perhaps more frequently, psychoanalytic psychotherapy (Brown & Pedder, 1991). With regard to this essay, the term psychotherapy will be used in it’s broadest sense, although psychoanalytic concepts and therapy will be referred to.

**Psychotherapy for Older Adults**

Over the last decade, there has been growing evidence regarding the efficacy of psychological interventions, including psychotherapy, with older adults within the community (Borson, Liptzin, Nininger & Rabins, 1989; Newton & Lazarus, 1992). Nevertheless, the conceptual and research framework for their application with this client group remains in it’s infancy (Smyer, Zarit & Qualls, 1990). Moreover, despite similar prevalence rates for psychological disorders in older and younger adults (Roth & Fonagy, 1996), and the increased occurrence of debilitating conditions, such as dementia, in old age, there remains an issue regarding the inaccessibility and under-utilisation of mental health services for older adults (Smyer et al., 1990).

The reasons offered for this include client biases (e.g. reluctance to seek professional help), generational trends (e.g. differences in systems of beliefs and values), and perhaps more importantly, barriers raised by the health service (e.g. staff attitudes, social and political agendas) (Smyer et al., 1990). Within the client’s social network, the attitudes and beliefs of significant others may similarly limit access to services. Depression, for example, may be viewed as a purely biological, and inevitable part of dementia, rendering psychosocial interventions inappropriate (Cohen, 1989).
Developmental Tasks

Although writers, such as Freud, questioned the appropriateness of psychotherapy for older adults (Roth & Fonagy, 1996), professionals adopting a developmental perspective would hold that psychological distress may occur at any stage of life. According to Erikson (1950), personality development continues across the lifespan, with different stages being characterised by specific developmental tasks. Within this framework, psychological difficulties arise when an individual experiences difficulty in negotiating the task associated with a specific stage. The task proposed for older adults is developing an “integrated sense of self and defending against despair and meaninglessness” (Zweig & Hinrichsen, 1996). Indeed, maintaining an internal sense of self-continuity in the face of both physical and environmental change, is a challenge often faced by older adults (Atchley, 1989).

Research suggests that difficulties in resolving relevant developmental tasks, disruptions in self-continuity and the ill-timing of specific life events, may all contribute to psychopathology in later life (Zweig & Hinrichsen, 1996). Psychodynamic theories extend this view, proposing that an individual’s response to a life stress reflects a complex interplay between factors such as early life experiences, personality structure, psychological defences and unconscious fears and impulses. Hence, the individual’s response is deemed to be both complex and idiosyncratic.

Dementia

As with ‘psychotherapy’, the term ‘dementia’ has also been defined in numerous ways. The following definition, offered by McKhann et al. (1984), has been widely used within medical contexts in the USA:

“Dementia is the decline in memory and other cognitive functions in comparison with the patient’s previous level of function, as determined by a history of decline in performance and by abnormalities noted from clinical examination and neuropsychological tests.”
In the main, dementia represents a consequence of a variety of irreversible diseases. Alzheimer's disease, which is often perceived to be synonymous with dementia, is just one possible cause of the condition, with vascular dementia representing the other main type. Dementia, however, may also result from a range of other conditions which cause damage to the brain structure. These include Pick's disease, meningitis, AIDS and alcohol-related brain damage.

Dementia is characterised by progressive cognitive deterioration, primarily manifested in memory impairments. As the disease progresses, other abilities are affected, including comprehension, judgement and planning (Kitwood, 1997). Difficulties, such as apathy, depression, agitation or delusions may also be experienced. Reports suggest, for example, that at least one third of clients with dementia will warrant a diagnosis of depression at some stage of the disease (Carpenter & Strauss, 1995, cited in Kitwood, 1997). Such psychological and emotional problems not only affect the client, but are reported to exert the greatest impact on caregiver burden and predict early institutionalisation (Gilleard, 1984; Haupt, Kurz & Greifenhagen, 1995). Changes in personality are attributed to dementia, but reports from long-term carers suggest that discontinuity in personality does not occur (Bell & McGregor, 1995, cited in Kitwood, 1997). Although clients may sometimes appear to act out of character, this has been conceptualised as a response to a loss of resources, or a breakdown of psychological defences, rather than a change in personality (Kitwood, 1997).

Unlike cognitive impairment, the psychological and emotional difficulties are not thought to be directly attributable to structural brain lesions (Haupt, 1996). Rather, they are held to stem from an interaction of factors such as memory impairment, environmental stress, threats to identity, recognition of loss and impaired sense of reality. Pharmacological treatments have been advocated for such difficulties, with some positive findings from research (Salzman, 1988; Schneider, Pollock & Lynness, 1990), but the likelihood of side
effects (e.g. deterioration of cognitive abilities) and the proposed psychological basis of the difficulties, warrants the consideration of non-pharmacological therapeutic approaches.

**Environmental Factors**

There is increasing awareness of the need to address social dimensions of dementia (Lyman, 1989). Kitwood (1993) discusses the notion of a “malignant social psychology”, in which the person with dementia is “devalued, de-skilled and even dehumanised by the care environment”. He argues that often, care environments enforce a sub-optimal level of functioning on the client, by failing to support their remaining skills and abilities. This recognition has prompted the development of care environments based on basic psychological principles, such as the “Domus philosophy” (Dean, Briggs & Lindesay, 1993). A one year evaluation of the approach has indicated positive improvements in terms of cognitive functioning, self-care skills, communication and increased activity and social interaction (Dean et al., 1993). Despite the methodological weaknesses of the study (e.g. lack of a control group) the findings are important, given the progressive deterioration typically observed in dementia (Roth & Fonagy, 1996).

**Focus for Intervention**

Given the irreversibility of dementia in general, and the inevitable picture of progressive cognitive deterioration, the aims of intervention involve minimising symptoms and enhancing quality of life, rather than ‘curing’ the disease (Haupt, 1996). Certain interventions directly address cognitive impairment and attempt to either halt, or reverse the deterioration, as with pharmacological treatment, or enabling clients to employ remaining skills to compensate for lost abilities (e.g. memory aids, Josephsson, Backman, Borell, Bernspang, Nygard & Ronnberg, 1993). Nevertheless, we have, as yet, no means by which to prevent or ‘cure’ this progressive disease. Preliminary research suggests that rehabilitation programmes conducted in the early stages of Alzheimer’s disease, and focusing on relatively preserved skills (e.g. procedural memory), produce some improvements in cognitive functioning (Josephsson, Backman, Borrell et al., 1993;
Psychotherapeutic Work in Dementia

In the last decade, models of dementia care have begun to routinely address clients’ emotional and psychological needs (Cheston, 1998). Evidence from clinical practice suggests that dementia is not a ‘contraindication for successful psychotherapy’ (Zweig & Hinrichsen, 1996) and indeed, the use of psychotherapeutic approaches with this client group, has been advocated vociferously in recent years (Bender, 1999; Cheston, 1996; Sinason, 1992). Reports suggest that clients in the early stages of dementia may utilise psychotherapy productively, to cope with depression, preserve self-esteem, manage emotional responses and to maintain a sense of identity (Cohen, 1989; Forrest, 1992; Miller, 1989). Many argue that the success of such therapeutic endeavours is dependent on the preservation of cognitive abilities, which enable the client to communicate meaningfully, identify problems to be worked on, and retain information over time (Lewis & Rosenberg, 1990). Not surprisingly, reports suggest that psychotherapy is more likely to produce benefits, and achieve its goals, when conducted with clients in the early stages of dementia (Hausman, 1992).

In recent years, there have been challenges to the assumption that beneficial, and therefore effective, therapy is dependent on the client’s capacity to verbalise their concerns (Bender, 1999). Although the ability to communicate verbally decreases as dementia progresses (Bryan & Maxim, 1996), prompting a change in the nature of the client-therapist relationship (Mills, 1997), it has been argued this does not necessarily render psychotherapeutic work impossible. Admittedly, clients may be less able to engage meaningfully in ventures such as cognitive and psychodynamic therapy, which rely heavily on verbal skills, but therapeutic work may still take place, through a variety of other
sensory modalities (Bender & Bauckman, 1998). Alternatively, behavioural approaches may assume greater clinical value (Teri & Gallagher-Thompson, 1991).

**Suitability**
Cheston (1998) contends that suitability for psychotherapy depends on the aims and objectives of the work being completed. He proposes that important factors to consider concerning suitability, and appropriate intervention, are the client’s current cognitive functioning, premorbid personality, developmental history and use of defence mechanisms, such as denial or repression. Clients who possessed proficient verbal skills and interpersonal functioning prior to diagnosis, are often deemed to be most likely to benefit from psychotherapy (Jones, 1995). With regard to psychodynamic therapy, suitability is complicated by whether loss of insight is attributed to the decline in cognitive function, or to the activation of defence mechanisms, intended to shield the individual from the emotional and psychological implications of the disease (Cotrell & Lein, 1993). In the former case, psychotherapy is only deemed possible in the early stages of dementia, while insight remains (Miller, 1989). In the latter case, loss of insight becomes the target for therapeutic intervention, although it is important to recognise that defence mechanisms may represent the only responses available to clients who have experienced significant losses in many areas of their lives (Cheston, 1998).

**Types of Psychotherapeutic Intervention**
Psychotherapeutic work in dementia may take many forms. Some of the main types of intervention include grief work regarding loss, preservation of identity, Cognitive Behavioural Therapy (CBT) (including modifying dysfunctional assumptions, behavioural reinforcement programmes, engendering a sense of control, enhancing coping skills and stress management), and specific therapies designed for work with older adults, such as reminiscence, reality orientation and validation therapy. Each of these therapies will be discussed briefly below, with a summary of the evidence regarding their effectiveness.
Addressing Loss

A cornerstone of any psychotherapeutic work in dementia, is to address issues of loss for the client and to support the grieving process (Hausman, 1992; Solomon & Szwabo, 1992). Depression has been conceptualised as an emotional response to a devastating disease, which is recognised to have profound implications (Kitwood, 1997). Mills & Coleman (1994) argue that encouraging clients to express their emotions and thoughts regarding dementia, and it’s consequences, represents an important therapeutic endeavour. Similarly, there is potential for intervention with carers and relatives, with the emphasis on grieving the loss of the client to the disease. There has recently been considerable interest in the stories, metaphors and narratives of individual’s with dementia, and their use in exploring the experiences of clients with dementia and the subjective meanings generated from them (Cheston, 1996; Unterbach, 1994). Such approaches may be of particular use in guiding grief work with clients.

Identity Work

Diagnosis of a chronic medical condition has potential for significant impact on an individual’s identity and sense of self (Radley, 1994). Research suggests that successful adaptation to a medical condition depends, in part, on the individual’s ability to conceptualise the condition as only one aspect of their identity (Burish & Bradley, 1983). The loss of cognitive function in dementia depletes the person’s ability to maintain a coherent sense of identity and would therefore be assumed to complicate adjustment. Loss of identity has traditionally been viewed as an inevitable consequence of dementia, with the goal of therapy being to preserve the individual’s sense of ‘self’ for as long as possible (Slater, 1995).

Psychodynamic theories discuss identity in terms of the individual’s internal structures (e.g. object relations) and significant relationships in their life. Therapy requires the therapist to become a self-object for the client (O’Connor, 1993), validating their abilities and offering reassurance and support. In contrast, social constructionists view identity as a
product of social communication and interaction (Cheston, 1996; Buchanan & Middleton, 1993). Individuals are believed to strengthen their social identity, thereby preserving a sense of continuity in life, through the sharing of stories (Cheston, 1998). Social constructionists further contend that a loss of one’s personal self is not inevitable, even in the latter stages of dementia (Sabat & Harre, 1992). Moreover, the observed loss of ‘public selves’ and past roles is conceptualised as the consequence of others failing to acknowledge and validate ‘possible selves’ which the client wishes to present, and labelling their behaviour as confused. Within this framework, interventions should focus on helping the client gain validation for the ‘public selves’ they wish to portray.

Cognitive-Behavioural Therapy (CBT)

CBT has various applications in dementia, although intervention may be most effective in the early stages of the disease (Cheston, 1998). It has been used in a traditional way for alleviating depressive symptomatology (Teri & Gallagher-Thompson, 1991), reducing anxiety (Haggerty, 1990) and fostering adjustment (Roth & Fonagy, 1996), by helping clients identify dysfunctional thoughts regarding their condition. However, it is important to recognise that catastrophic thoughts and fears may constitute appropriate cognitive responses to dementia, and that challenging these may serve to alienate the client and devalue their experiences.

Training in problem-solving techniques may enhance the client’s capacity to make choices in their life (Miller, 1989), and engender a sense of control. A focus on coping skills may facilitate adjustment and enable the client to compensate for lost abilities, by building on skills which have been retained. One specific skill which may be of use is stress management. Techniques such as meditation, visual imagery (Haggerty, 1990) and relaxation training (Welden & Yesavage, 1982) have produced benefits with this client group, with the latter being reported to both reduce anxiety and enhance memory.
CBT has had limited application in dementia. Teri & Gallagher-Thompson (1991) have reported positive outcomes from 16-20 sessions, in terms of challenging cognitive distortions and fostering adaptive interpretations of specific events. They note that while CBT may prove a valuable intervention for this client group, further work is needed in adapting the approach, to maximise benefits. Issues include allowing more time for clients to acquire the basic skills of CBT and addressing the difficulties in fostering adjustment to such a devastating disease.

**Behaviour Therapy**

Behavioural approaches have similarly been absent in dementia care (Whitehead, 1991). They have been used for tackling depression (Teri & Gallagher-Thompson, 1991), under the rationale that depression is maintained through an imbalance of negative and positive interactions between the person and the environment. Thus, by increasing the proportion of positive interactions, depression should be alleviated (Teri & Gallagher-Thompson, 1991). As with CBT, cognitive deterioration will prevent the use of interventions which require new skills and techniques to be learned and remembered. As the disease progresses, work will increasingly need to be conducted with carers (Haupt, 1996).

Haupt (1996) supports this use of behaviour modification programmes with caregivers. He describes a ‘mediator-centred’ interactional approach (Haupt, 1993), which aims to induce change in the client’s experience and to foster a sense of identity, self-reliance and sense of self-worth, by changing the carer’s responses to them. There have been few attempts to evaluate the effectiveness of such interventions, but clinical evidence suggests they may be effective in reducing, or eliminating, behavioural problems (Haupt, 1996). The client’s environment has potential to impact significantly on the experience of dementia, their quality of life and overall adjustment (Woods & Britton, 1985). As such, it is important to assess how the client’s strengths and needs, fit, or interact with the constraints, or resources, available in their environment. Another important aspect of intervention,
therefore, involves adapting the environment to best fit the abilities and needs of the client (Haupt, 1996).

**Reality Orientation**

Although reality orientation falls under the rubric of psychological interventions for dementia, it perhaps only meets the broadest criteria for ‘psychotherapy’. Nevertheless, it is included here, due to its position as the most extensively evaluated psychological intervention for dementia (Roth & Fonagy, 1996). Reality orientation can be applied on both a formal and informal basis. The former involves regular sessions, typically run with small groups of clients. Although current events may be discussed, the emphasis of the session is on completing focused activity tasks (Woods & Britton, 1985). Informal intervention involves carers presenting the client with information regarding current events (e.g. time of day, current events) during interpersonal interactions. Memory aids, such as signs, are used to support the orientation work. Within this approach, confused speech is systematically not reinforced.

Reality orientation has been described as using repeated presentation of verbal information and visual aids to “correct confused behaviour” and to enhance the potential for independent living in the community (Stokes & Goudie, 1990). Reports suggest that staff and carers may find the endless correction of factually inaccurate statements and comments frustrating (Morton & Bleathman, 1988) and the clinical relevance of verbal orientation has been questioned (Woods, 1999). The approach has also been criticised for being harsh, as clients are repeatedly confronted with a stark reminder of their failed attempts to understand and negotiate the world (Dietch, Hewett & Jones, 1989). Moreover, little consideration appears to be given to the individual’s psychological defence mechanisms, and to understanding their emotional experiences (Goudie & Stokes, 1989). Proponents of the approach dismiss such criticisms, arguing that the true practice of reality orientation involves both acknowledgement and validation of the client’s emotions, even when disorientation is apparent (Holden, 1988).
There have been several reviews of reality orientation in the literature (e.g. Hanley, 1984; Holden & Woods, 1995). Studies conducted across a variety of settings, have reported benefits following formal reality orientation (Backman, 1992; Zanetti, Frisoni, De Leo, Dello Buono, Bianchetti & Trabucchi, 1995). Small, but significant improvements in verbal orientation have consistently been reported when compared to control groups (Woods, 1999). Improvements have also been reported in terms of spatial orientation (Reeve & Ivison, 1985) and on cognitive and behavioural measures (Williams et al., 1987) and in staff-client interactions (Salmon, 1993), using informal approaches. Debate continues, however, as to whether cognitive improvement extends beyond measures of orientation (Woods, 1999). Changes in function and behaviour are deemed less likely than changes in cognition, although some contend that this is an artefact of using insensitive assessment measures (Woods, 1999). Overall, research supports the use of reality orientation for the cognitive management of dementia.

**Validation & Resolution Therapy**

Validation therapy was devised in response to dissatisfaction with the mechanistic style of approaches like reality orientation (Feil, 1993). The approach is based on the belief that disorientation and confusion in old age may prompt individuals to return to past conflicts, in an attempt to resolve them. In this approach, meaning is held to lie behind the client’s ‘seemingly confused verbalisations and behaviour’ (Goudie & Stokes, 1989), in terms of unexpressed emotions concerning past conflicts. Addressing these conflicts is thought to represent an important therapeutic endeavour (Bleathman & Morton, 1988; Feil, 1990). Validation Therapy is a multi-component intervention approach, designed to assist clients with dementia to communicate using memory fragments and any cognitive, affective or motor functions which are preserved. The aim of intervention is to acknowledge and ‘validate’ the emotions being expressed, highlight the conflict underlying the client’s behaviour (Cheston, 1998) and promote resolution (Goudie & Stokes, 1989).
The application of validation therapy to dementia has often been criticised. Although designed for use with confused older adults, and perhaps especially clients with pseudo-dementia (Stokes & Goudie, 1990), some argue that it was not intended for those with a primary diagnosis of dementia (Babins, 1988). Feil (1993), however, is clear that the approach was designed for this use. There has also been concern that therapists may project thoughts and feelings onto the client about the past, which actually relate to current concerns (Kitwood, 1992), thereby increasing the client’s confusion and frustration. Nevertheless, the approach may be valuable in terms of reducing the severity of depression (Goldwasser, Auerbach & Harkins, 1987) and in helping carers understand something of the client’s subjective experience of dementia.

Resolution therapy (Stokes & Goudie, 1990) is similar to validation therapy in many ways, aiming to enhance the insight of carers, increase empathy for the client and thereby enable them to respond in more helpful ways to the client’s seemingly confused verbal and behavioural responses. Intervention involves identifying the emotions behind the client’s responses, through their verbal and non-verbal communications. This is then reflected back, without interpretation, in terms of the client’s current experiences, in order to clarify meaning (Goudie & Stokes, 1989). Despite debate regarding the extent to which clients can move beyond their disorganisation, due to cognitive deficits (Solomon & Szwabo, 1992), many recommend the intervention for facilitating cathartic ventilation of deeply held emotions (Greene, Ingram & Johnson, 1993; Miller, 1989).

Validation and resolution therapy are recognised as important approaches, in terms of the emphasis placed on the client, their experiences and the resulting impact on their quality of life. Nevertheless, there has been little systematic evaluation of either approach (Toseland, Diehl, Freeman et al.; 1997; Woods, 1999) and existing studies have typically suffered from methodological weaknesses (e.g. uncontrolled designs) (Toseland et al., 1997). A recent longitudinal evaluation of validation therapy, conducted by Toseland et al. (1997), demonstrated both reduction in physical and verbal aggression and increases in staff
perceptions of the effectiveness of their interventions. Intervention failed to produce reductions in the need for psychotropic medication, the use of physical restraints or time devoted to behavioural problems.

**Reminiscence Therapy**

Reminiscence has been presented as a positive and natural activity for older adults to engage in. It has been linked to better adjustment following events such as war (McMahon & Rhudick, 1984) and is also proposed to help older adults adjust to the losses they have experienced in life, protecting them against threats to identity and self-esteem (Lewis, 1971) through reaffirmation of what, and who, they have been. Reminiscence may take many forms (Cohen & Taylor, 1998), but it's use in dementia tends to be based on the approach recommended by Butler (1963).

Despite the clinical application of reminiscence therapy in both group and individual settings (Norris, 1986; Gibson, 1994) there have been few evaluation studies regarding the effectiveness of reminiscence in dementia (Roth & Fonagy, 1996). Early studies investigating the psychological benefits of reminiscence for older adults failed to yield consistent and meaningful results (Coleman, 1986). Some studies failed to find any relationship between reminiscence and adaptation to stressful life events (Lieberman & Falk, 1971), whilst others found a relationship, but failed to establish the direction of causality (Havighurst & Glasser, 1972). Recent evaluation studies have similarly reported conflicting results with respect to improvements in interaction (Head, Portnoy & Woods, 1990), changes in orientation and functioning outside the home (Baines et al., 1987). Although there appear to be clear benefits within group sessions (Woods & McKiernan, 1995), there is less evidence of changes outside sessions (Woods, 1999). Questions, therefore, remain regarding the long-term effectiveness of reminiscence and also concerning the most effective application of the intervention. There is also a need to distinguish reminiscence from a preoccupation with the past which results in failure to address current concerns (Coleman, 1986).
Evaluation Studies

With the exception of reality orientation, there has been a lack of empirical evaluation of psychotherapeutic interventions for dementia (Roth & Fonagy, 1996). Moreover, the few studies conducted have typically been flawed, due to a range of methodological problems. In their editorial comment, Orrell & Woods (1996) list a range of problems with psychological evaluation research in dementia, which have prevented conclusions being drawn regarding the effectiveness of particular approaches. Problems include differences in definitions of the ‘therapy’ being applied, non-standardised application of interventions, lack of consistency in evaluation measures, small sample sizes, brief follow-up periods and a lack of matched control groups. A further issue concerns the lack of assessment tools which can measure small, yet perhaps clinically meaningful changes in the client’s subjective experience or behaviour. For example, scales such as the Holden’s Communication Scale (Holden & Woods, 1982) are typically used to assess the effectiveness of reality orientation and reminiscence, when perhaps more appropriate measures would be ones which assess social behaviour rather than self-care skills (Woods & Britton, 1985).

A key issue in the evaluation of psychotherapeutic interventions is consensus regarding what represents a successful outcome? The redundancy of concepts such as ‘recovery’ and ‘cure’, and the need to adjust treatment goals as the disease progresses (Woods, 1999), support the appropriateness and validity of adopting treatment goals which focus on the client’s or carer’s subjective experience. Appropriate outcome measures may include quality of life or caregiver burden (Woods & Britton, 1985). Recent success in enabling dementia sufferers to communicate their experiences (Sabat & Harre, 1992), has implications for evaluation (Goldsmith, 1996). Bender (1999) advocates the use of a person-focused approach, which attempts to understand the experience of dementia from the client, rather than the carers perspective. Such an approach has potential for improving care practices and developing services which promote the client’s self worth and assists individuals in generating meaning from their experiences (Phinney, 1998).
Adapting Psychotherapy

In his review of the literature on conducting psychotherapy in dementia, Cheston (1998) summarises several ways in which therapy may need to be adapted in order to be beneficial and effective for this client group. The four main areas of consideration include adapting the intervention to accommodate for cognitive deficits (Hausman, 1992), providing flexibility regarding therapeutic setting (Jones, 1995), having regular reliable appointments over an extended period of time (Jones, 1995), and attending to the transference and counter-transference relationships and their impact on therapy (Kaplan, 1990).

Dementia Care

Over the years, various psychological approaches and interventions have been recommended for dementia. Until recently, however, there has been little attempt to integrate these into a coherent treatment approach (Kitwood & Bredin, 1992). Reasons for this include a focus on the medical model perspective, with its tendency to consider the disease and its medical consequences, rather than the person and their experience. Kitwood & Bredin (1992) argue that behind this preoccupation lies an avoidance, by psychiatry and clinical psychology alike, of presenting a conceptualisation of the 'person' and their subjective experience. This enables professionals to maintain a psychological distance from these progressive, debilitating conditions which we are helpless to prevent.

When devising a framework for applying intervention in dementia, it is crucial to maintain the focus on changes which are of value to the client and their carers (Woods, 1999). Improvements may only be small, and possibly quite specific, so it is crucial to set treatment targets at a level where change may be noted by those concerned (Woods, 1999). Principles of social role valorisation may also be applied to dementia care (see Stirling, 1996), with emphasis being placed on respecting individuality and promoting self-respect, dignity and choice. Woods & Britton (1985) recommend the use of individual programme planning (IPP) in dementia care, where interventions are integrated into a whole package of care is based around a comprehensive assessment of 'the person's
strengths and needs’ (Woods, 1999). IPP enables the client’s own wishes to be taken into account when selecting interventions.

Conclusion
Over the years, many psychotherapeutic interventions have been devised and employed with clients suffering from dementia. Nevertheless, there has been little attempt to evaluate the efficacy of these approaches, and controlled prospective studies are required before conclusions can be drawn regarding the efficacy of these promising, but as yet, ill-substantiated interventions. There has similarly been little attempt to apply individual approaches within an overall model of dementia care, which places value on the client’s experiences. Central to this model would be an assessment of individual client needs, which would generate treatment goals which were realistic and meaningful for the client. Attention, therefore, needs to be given to these areas before any statements can be made regarding the actual potential for psychotherapeutic work in dementia.
References


Critically evaluate the role of psychological interventions in the management of chronic pain

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Year 3
Introduction

Chronic pain has been defined as “an unpleasant sensory and emotional experience, associated with actual or potential tissue damage, or described in terms of such damage” (International Association for the Study of Pain (IASP), 1979). The transition from acute to chronic pain is generally accepted to occur once the pain has endured beyond the normal expected healing time (Bonica, 1985, cited in Jensen & Karoly, 1991). This is often interpreted as being 6 months post-injury (Tan & Leucht, 1997).

A variety of conditions fall under the rubric of chronic pain (e.g. low back pain, rheumatoid arthritis, migraine). In many cases, the causes of pain may not have been fully explicated (Bonica, 1990, cited in Skevington, 1995). Although there are clear differences between the various conditions, they are often addressed within the psychological literature under the heading ‘chronic pain’. This is perhaps due to the presence of similar psychosocial issues and the relevance of similar types of psychological intervention (Turk, 1996; van Tulder, Assendelft, Koes & Bouter, 1997, cited in Morley et al., 1999). The term chronic pain will be adopted within this essay, although at times, reference will be made to specific pain conditions.

Chronic pain presents a considerable problem for society on a number of levels. Firstly, an estimated 10% of the world’s population are reported to experience chronic pain (Magni, Caldieron, Rigatti-Luchini & Merskey, 1990, cited in Skevington, 1995; Sternbach, 1986). Such prevalence rates pose a major challenge in terms of the demands placed on limited health service resources, the overall costs of medical treatment, and the costs to employers and the government through lost work hours, compensation claims and medical retirement pensions.

Perhaps more importantly, chronic pain also constitutes a significant challenge on an individual level, not only in terms of the pain experienced, but in the additional stressors which often accompany the pain. Living with chronic pain extends beyond the persistence
of a physical symptom (Turk, 1996). Loss of career and leisure activities, financial difficulties, social isolation, limited mobility and low tolerance for activity can all place stress on the individual and can compromise their lives in many ways (Turk, 1996). Indeed, pain may rarely constitute the primary source of stress for an individual.

The prevalence of chronic pain, the heavy demands placed on health service resources, and the tremendous costs to both individuals and society, validate the efforts of clinicians and researchers in their pursuit of cost-effective interventions for this client group. Historically, interventions have been largely surgical and medical. However, the emergence of biopsychosocial models has highlighted the involvement of psychological factors in the experience of chronic pain and suggested the role such factors may play in exacerbating and perpetuating disability. This has created the opportunity for psychological intervention to be incorporated into the care of individuals with chronic pain.

This essay explores the role of psychological intervention in the management of chronic pain, and discusses the efficacy of the main treatment approaches. The relative merits of individual and group therapy, and the role of multidisciplinary pain programmes, will be discussed. In order to set the context for this discussion, the medical and biopsychosocial models of pain will first be presented, raising the issue of treatment goals and the selection of appropriate outcome measures for evaluating interventions.

Biomedical Model
Traditionally, chronic pain has been conceptualised within a biomedical model. Underlying this model is the assumption that pain results from a disease state, which can be identified through the use of objective tests of physical damage and impairment (Turk, 1996). Within this model, a linear relationship is assumed between the degree of damage, or stimulation, and the level of pain experienced. The ultimate aim of medical interventions is to “correct the organic dysfunction or pathology” and thereby remove the pain (Turk, 1996).
There are a number of limitations to this rather simple conceptualisation. Firstly, in many instances, no objective, physical explanation can be found for chronic pain (Compas, Haaga, Keefe, Leitenberg & Williams, 1998). Secondly, the model fails to explain why individuals may experience variable levels of pain, with no underlying change in tissue damage (Compas, Haaga, Keefe et al., 1998). Thirdly, large individual differences are apparent in the pain reports and psychological adjustment of individuals with similar levels of organic pathology or disease activity (Taylor & Curran, 1985, cited in Jensen & Karoly, 1991), resulting in only modest associations between physical pathology and either pain severity, or perceived disability (Magora & Schwartz, 1980, cited in Gatchel & Turk, 1996; Waddell & Main, 1984). This suggests the influence of other factors in mediating the relationship between pathology and disability.

The medical model also proves insufficient in fully explaining the experience of acute pain. Athletes, for example, often continue to the end of a sporting event with little awareness of pain, despite having sustained extensive tissue damage. Similarly, soldiers in battle may report little pain despite having severe injuries. Such findings highlight the need for a more comprehensive model in which to conceptualise pain.

**Biopsychosocial Models**

Recognition of the above limitations has lead to the adoption of a biopsychosocial framework in which to conceptualise pain. The IASP definition of chronic pain, presented earlier, is often favoured within the psychological literature, in that it acknowledges both the subjective nature of the pain experience and the non-linear relationship which often exists between tissue damage and pain severity (Skevington, 1995). Moreover, the definition also allows for the role of psychosocial factor in the experience of chronic pain.

An important issue, with regard to the biopsychosocial framework, is the conceptual distinction between ‘disease’ and ‘illness’. According to Diefenbach & Leventhal (1996), a disease is “characterised by a set of signs and symptoms”, on the basis of which a
diagnosis may be made. Illness, on the other hand, relates to the social definition of illness and does not require all the signs and symptoms of a specified disease to be present (Kleinmann, 1988). The labelling of illness requires a shared agreement between a doctor and others that an individual is sick, thereby incorporating both psychological and social dimensions in the labelling process. The latter, is therefore, of greater relevance to the experience of chronic pain.

**Gate Control Theory of Pain**

One of the earliest biopsychosocial theories was the Gate Control Theory of Pain (Melzack & Wall, 1965, 1989), which suggested that the perception of pain is determined by the balance of various nerve messages reaching the brain. Messages passing between the brain and the site of injury are proposed to pass through gates in the spinal cord. These gates can open or close to control the number of pain messages reaching the brain, thereby influencing the individual’s perception of pain. Biological (e.g. tissue damage, temperature), psychological (mood, self-esteem), and social factors (others focusing on the pain, positive social interaction) are all thought to be involved in opening or closing the gate.

The Gate Control Theory of Pain has received support from both empirical and clinical research (McQuay, Carroll & Moore, 1988), although there have been some antagonists (e.g. Sunderland, 1978). A major contribution of the theory, from a psychological perspective, is that it incorporates a role for psychosocial factors in the experience of chronic pain, thus highlighting the relevance of psychological intervention.

**Role of Psychosocial Factors**

The psychological and social consequences of chronic pain have long been recognised (e.g. loss of confidence, social isolation, loss of social role). Recently, the role of such factors in the development, maintenance and potentiation of chronic pain has also been acknowledged (Weiser & Cedraschi, 1992), which has further supported the need for
psychological intervention. Research in the field of chronic pain is now generally conducted within a multicausal model of chronic pain (e.g. Melzack & Wall, 1982; Wall, 1989). Within such models, the experience of chronic pain is recognised as involving a complex and dynamic interaction of biological, psychological and social factors, which may alter at different stages of the pain process (Weiser & Cedraschi, 1992). For example, the involvement of psychological and social factors is thought to become more pronounced as pain moves from ‘acute’ to ‘chronic’ (Waddell, 1987b). Such findings emphasise the need to conduct a thorough assessment prior to treatment, to formulate the client’s current difficulties and identify appropriate targets for intervention.

**Intervention in Chronic Pain**

Despite increasing recognition of the importance of psychological factors in the experience of chronic pain and research supporting the value of psychological interventions, clinical psychology often represents the last treatment option for clients. This is surprising, given the apparent limitations and often relative ineffectiveness of medical and surgical interventions for many clients with chronic pain (Webb, 1982, cited in Gallon, 1989). One explanation for this may be that referral to psychology is interpreted by many professionals and clients as a failure of physical medicine. Alternatively, there may be an assumption that psychological intervention requires the presence of psychiatric disturbance, which would preclude many chronic pain sufferers (Pither & Nicholas, 1991). Such beliefs and attitudes can be problematic, in that clients may receive a message that their pain is “in their heads” or that they are considered “mad”. As such, it is not surprising that many clients may initially be reluctant to attend a psychology appointment.

**Mode of Intervention**

Psychological interventions for chronic pain may form part of a multidisciplinary programme, or be offered as stand alone interventions (Pither & Nicholas, 1991). The context in which the intervention is conducted will have important implications for the form, content and goals of therapy. Multidisciplinary treatment packages, which offer a
medical component, often aim to influence the pain directly, whilst also addressing
psychosocial factors which may be influencing the client's experience of pain. Minimising
the client's pain as far as possible is obviously an important goal in the early stages of
medical treatment. However, the incorporation of medical interventions into
multidisciplinary pain programmes may encourage the client's search for a 'cure'. The
consequence may be a vicious cycle, where an endless stream of unsuccessful medical
treatments lead to repeated disappointments and increasing desperation for a cure. The
constant supply of medical interventions aimed at "curing" the pain can also foster the
belief that others are responsible for controlling the pain, which may prevent the client
from benefiting from psychological interventions aimed at pain management (Pither &

Alternatively, psychological interventions may be offered in isolation, with the aim being
to enable clients to reach their optimal level of functioning, given their current pain. Such
interventions may be conducted on an individual or group basis, with the latter being most
widely used. However, there is no recognised standard format for such interventions.
Advantages of a group approach include the opportunity to foster social support, to
validate clients' experiences and to offer an opportunity to learn from others.

Multidisciplinary Pain Programmes
Multidisciplinary pain management programmes are probably the most intensive of the
interventions. Many are operated on an inpatient basis and represent the last option for
clients who have received little lasting benefit from other approaches. One limitation of
such programmes is that they provide intervention outside the client's usual environment.
This can create problems for the maintenance of progress, by undermining the client's
sense of independence (Mayer, Gatchel & Kishino et al., 1985, cited in Gallon, 1989) and
limiting generalisability of skills and principles to other settings.
Although programmes often differ quite considerably in the specific goals of treatment and the emphasis placed on different treatment modalities, there are certain fundamental elements. These include physical therapy, occupational therapy, psychology and relaxation training. Such programmes are generally based on a cognitive-behavioural model of pain.

**Treatment Goals**

In contrast to medical models, the concept of cure is neither valid nor useful within a psychological framework. Of greater relevance is the concept of rehabilitation, where the emphasis is on improving quality of life and maximising psychological and physical health, within the physical constraints imposed. In many areas of health psychology, an important goal of intervention is also to improve the efficiency of the client’s utilisation of the health care system and to increase cost-effectiveness (Friedman, Sobel, Myers, Caudill & Benson, 1995).

It has been suggested by some (Compas, Haaga, Keefe et al., 1998), that an important criterion for evaluating psychological intervention for chronic pain is the reduction of the pain itself. Pain reduction is often a target for multidisciplinary pain management programmes, although it is achieved with varying degrees of success. (e.g. Flor, Fydrich & Turk, 1992). However, as a primary goal of intervention, pain reduction is inconsistent with a psychological model of chronic pain. Moreover, for the reasons outlined above, the adoption of such a goal may undermine the basis of the intervention and prevent clients from benefiting from treatment. Adjustment to chronic pain may constitute a more appropriate and realistic goal of psychological intervention (Spinhoven & Linssen, 1991). Moreover, goals such as improved mood, enhanced coping skills, reduction in health care utilisation and enhanced quality of life would surely yield important and substantial benefits for clients, society and the national health service.

Given such an array of potential goals, it is unrealistic to expect any one programme to produce clinically significant improvements on a physical, functional and emotional level
(Slater, Doctor, Pruitt & Hampton Atkinson, 1997). It is recognised within the literature that different types of intervention for chronic pain may effect change in different areas. This creates difficulty for comparing studies, as they may have quite disparate treatment goals (Morley et al., 1999).

**Measuring Outcome of Intervention**

Evaluating the effectiveness of interventions is necessary for monitoring the quality of care being received by clients and in enabling professionals to meet the requirements for evidence-based practice. Moreover, such evaluation is also important for maintaining and advancing the position of psychology as an important and effective component in the treatment of chronic pain. Hence the need for psychological interventions to be both empirically validated and shown to be cost-effective for this client group.

Various outcome measures have been used in the evaluation of psychological interventions for chronic pain. These include subjective ratings of pain, perceived disability, mood, cognitive distortions, coping strategies, pain behaviours, activity levels, improvements in biological and fitness measures (e.g. flexibility, strength, stamina), and finally, the client’s utilisation of health care resources. The lack of relationship between measures of disease activity, or tissue damage, and self reported pain highlights the need to consider the client’s functioning within the context of their daily life (Millard & Jones, 1990). In order to select appropriate measures for assessing and monitoring progress over the course of intervention, it is necessary to clearly state the goals of intervention and identify areas in which change is intended to occur (Kane & Kane, 1981).

One of the problems in measuring outcome is the availability of assessment measures which can detect small, yet clinically meaningful changes, as opposed to statistically significant changes. Such tools are essential for meaningfully measuring change over time (Kopec, Esdaile & Abrahamowicz et al., 1995). Many of the measures also rely on self-report, where the influences of memory bias, social desirability and mood on reporting,
may affect the reliability of the results. Nevertheless, such measures are quick and easy to administer, and are relatively inexpensive (Millard & Jones, 1990).

Psychological Theories and Chronic Pain
A broad spectrum of psychological theories have been applied to the treatment of chronic pain. These have included psychoanalytic (e.g. Engel, 1959), behavioural (Fordyce, 1976; Philips, 1987), cognitive (Turk & Rudy, 1986; Turner & Clancy, 1986) and social theories ((Roy, 1989). Of these, behavioural and cognitive theories have been most influential in the development of psychological interventions for chronic pain, although aspects of social theories may be incorporated. The lack of empirical support for psychoanalytic theories of chronic pain (Gamsa, 1994) has typically precluded their use in interventions. As such, the following discussion will be limited to evaluating the evidence pertaining to cognitive and behavioural interventions.

Behavioural Therapy
Of central importance for intervention in chronic pain is Fordyce’s (1976) theory of operant conditioning. Fordyce proposed that social and environmental factors play a role in the development and maintenance of chronic pain, through the reinforcement of pain behaviours. The development of pain behaviours has also been addressed through reference to Bandura’s (1969) theory of observational learning and modelling.

The aims of behavioural intervention are primarily to improve physical functioning and enhance coping skills. In operant behaviour therapy (OBT), the focus is on the client ‘taking control’ of their pain management (Williams, Nicholas, Richardson et al., 1993). Intervention involves the introduction of differential reinforcement for the client’s behaviours, reinforcing ‘well behaviours’ (e.g. participation in daily activities), whilst reducing reinforcement for ‘pain behaviours’ (e.g. guarding postures). Often relatives and spouses are involved in such interventions, to enhance the generalisation of treatment effects to other settings.
Other common components of Operant Behaviour Therapy (OBT) are graded activity programmes, exercise and gradual reduction of addictive pain medication (Compas, Keefe, Haaga et al., 1998). OBT is thought to be most useful in cases where there is clear involvement of social or environmental reinforcement.

Effectiveness of Behavioural Interventions
Despite some continuing controversy regarding the use of operant methods in the treatment of chronic pain (see Roberts, Sternbach & Polich, 1993), there is now consistent evidence to suggest that such methods are effective in both increasing activity and reducing medication use (Large & Peters, 1991). Outcome studies in both America and Sweden have supported the efficacy of both inpatient and outpatient behavioural interventions (Linton, 1986; Philips, 1987; Turner & Chapman, 1982).

A study by Turner, Clancy, McQuade & Cardenas (1990) compared 4 conditions: behavioural intervention, exercise, behavioural intervention plus exercise and waiting list control condition. The behavioural intervention plus exercise group demonstrated significantly greater improvement on psychosocial outcome measures than the exercise and waiting list conditions. No significant difference was found between the two behavioural interventions. By 6 and 12 month follow-up, all treatment groups remained significantly improved from pre-treatment levels, although there was no significant difference between groups.

OBT has been found to be an effective intervention for chronic pain syndrome and chronic low back pain (Compas, Haaga, Keefe et al., 1998). In one randomised control trial, OBT was compared to an attentional control intervention and to standard medical care (Nicholas, Wilson & Goyen, 1991), with OBT producing significant improvements in psychological functioning and a reduction in pain severity. Two further randomised controlled trials, comparing OBT to a waiting list condition, have reported similar
improvements in psychological functioning (Linton & Gotestam, 1984; Turner, Clancy, McQuade & Cardenas, 1990) and pain reduction (Turner et al., 1990) following OBT.

Finally, Roberts et al. (1993) assessed the outcome of 354 outpatients receiving OBT plus physiotherapy, occupational therapy and biofeedback. Although no control condition was incorporated in the evaluation, the large sample size and minimal drop-out rate recommend the study. Clinically and statistically significant reductions in pain and improvements in physical functioning were reported at 1 month. The reductions in pain were maintained at 2 year follow-up, although there had been some regression towards pre-treatment levels with respect to physical functioning. Regression post-treatment has been reported in other studies (Painter, Seres & Newman, 1980), highlighting the importance of follow-up appointments and brief refresher courses in fostering maintenance.

Cognitive Theories
Concepts from various cognitive theories have been applied to the explanation of the development, maintenance and potentiation of chronic pain (e.g. cognitive style, learned helplessness, coping strategies). Empirical and clinical studies have identified links between a number of cognitive factors (beliefs about pain, control beliefs, catastrophising, helplessness, coping style) and the experience of chronic pain. Due to the correlational nature of many studies, it has been difficult to determine the direction of any cause and effect relationships. However, rather than being unidirectional, it seems likely that such factors are inter-related in complex and reciprocal ways. A good example is the association between depression and chronic pain, where depression has been identified as both a contributor to, and consequence of, chronic pain (Polatin, Kinney, Gatchel, Lillo & Mayer, 1993).

Cognitive factors have been suggested to play an important role in mediating the relationship between chronic pain and disability (Fisher & Johnson, 1998), in addition to
their influence on mood (Beck, 1970). Targeting cognitive factors in intervention may therefore promote improvements in various aspects of functioning. For example, changes in beliefs and coping strategies have been associated with post-programme improvements in physical functioning (Jensen, Turner, Romano & Lawler, 1994). Cognitive factors may also represent a central target of intervention for depression, based on Beck’s (1970) cognitive theory of depression. The main targets for cognitive interventions in chronic pain include coping strategies, cognitive distortions, control beliefs and self-efficacy. Typically, behavioural strategies are also incorporated into such interventions (Tan, 1982, cited in Tan & Leucht, 1997).

**Cognitive Behavioural Intervention (CBT)**

CBT for chronic pain has been suggested to involve three main components. The first is education, involving an introduction to the biopsychosocial model of pain. The second comprises skills training, where clients are guided in the use of various behavioural and cognitive skills for coping with the pain (e.g. progressive muscle relaxation, activity pacing, cognitive restructuring, goal setting). The third involves graded practice of the above skills in increasingly difficult situations (Turk, Meichenbaum & Genest, 1983). Nevertheless, there is often considerable variation in the content and practice of CBT interventions.

**Effectiveness of CBT**

Over the last 30 years, CBT has become increasingly recognised as an empirically supported intervention for the management of chronic pain (Morley, Eccleston & Williams, 1999; Tan & Leucht, 1997). In particular, reviews of CBT for specific types of chronic pain (e.g. Jensen, Turner, Romano & Karoly, 1991; Linton, 1994, cited in Tan & Leucht, 1997) and several meta-analyses (Flor, Fydrich & Turk, 1992; Malone & Strube, 1988, cited in Morley et al., 1999), have supported the efficacy of CBT in improving physical function and mood, reducing pain reports and decreasing observable disability
In terms of specific conditions, five studies have found CBT (incorporating training in relaxation, coping skills and cognitive restructuring) to be efficacious as an intervention for rheumatoid arthritis, when compared with attention control treatment, standard medical treatment or a waiting list control condition (see Compas, Haaga, Keefe et al., 1998). Improvements were reported in all studies on measures of psychological functioning. Three studies also demonstrated reductions in pain (Bradley, Young, Anderson, et al., 1987; Keefe, Caldwell, Williams et al., 1990b, cited in Compas et al., 1998; Parker, Smarr, Buckelew et al., 1995, cited in Compas et al., 1998). Only one study failed to find benefits following CBT intervention (Kraaimaat, Brons, Geenen & Bijlsma, 1995), although this was explained in terms of the participants experiencing an exacerbation of disease processes during the course of intervention.

CBT has also been used for chronic pain syndrome and chronic low back pain. When compared to a waiting list condition, CBT was found to be effective in improving both activity levels and psychological functioning (e.g. depression) (Nicholas et al., 1991; Phillips, 1987; Puder, 1988; Turner, 1982) and in reducing ratings of pain for these client groups (Nicholas et al., 1991; Phillips, 1987; Turner, 1982).

**Meta-analyses**

A number of meta-analyses have also been conducted. Malone & Strube (1988) (cited in Morley et al., 1999) examined both physical and psychological interventions for chronic pain, while Flor, Fydrich & Turk (1992) focused specifically on psychological interventions. The analyses included both controlled and uncontrolled studies. In both analyses, greater effect sizes were generally found for CBT than for medication or standard medical care in terms of mood, behaviour and pain ratings. At long-term follow-up, the CBT group had generally maintained higher levels of functioning than the
comparison groups (Flor et al. 1992). Turner (1996) conducted a meta-analysis of randomised controlled studies addressing the effects of educational, behavioural and cognitive interventions in primary care settings (cited in Morley et al., 1999). Although the analysis yielded similar findings to the previous analyses, the effect for mood was not replicated, perhaps due to the low baseline rates of depression in community samples (Morley, Eccleston & Williams, 1999).

A recent review by Morley, Eccleston & Williams (1999), offered an extremely thorough meta-analysis of randomised controlled trials of cognitive and/or behavioural interventions for chronic pain in adults, excluding interventions for headache. The meta-analysis supported the view that CBT represents an effective intervention for chronic pain, when compared with a waiting list condition. A similar conclusion was drawn regarding both behavioural interventions and biofeedback. In terms of outcome, Morley et al. (1999) reported that CBT “produced significant changes in measures of pain experience, mood/affect, cognitive coping and appraisal (reduction of negative coping and increase in positive coping), pain behaviour and activity level, and social role function” (pp 9).

**OBT vs CBT**

In their meta-analysis, Morley, Eccleston & Williams (1999) concluded that “published randomised controlled trials provide good evidence for the effectiveness of cognitive behaviour therapy and behaviour therapy for chronic pain in adults” (pp 11). In terms of the relative efficacy of these interventions, the analysis indicated that the superiority of CBT was limited to the areas of the client’s experience of pain, use of positive coping strategies and social role functioning.

Other studies, comparing the relative efficacy of OBT and CBT (Nicholas et al., 1991; Turner & Clancy, 1988), have found OBT to produce more immediate effects in terms of medication reduction (Nicholas et al., 1991), psychological and physical functioning (Turner & Clancy, 1988) and significant others ratings functional impairment (Nicholas et
In their comparison of OBT, CBT and a waiting list condition, Turner & Clancy (1988) reported no post-treatment difference between the CBT (involving progressive muscle relaxation, imagery and cognitive restructuring) and the waiting list conditions. However, by 1 year follow-up, the improvements made by the CBT group were found to have equalled those of the OBT group, suggesting that there may be no overall difference in the efficacy of CBT and OBT interventions, but that it may take longer for clients to achieve the full benefits of CBT.

**Maintenance of Benefits**

Despite the positive findings post-intervention, there have been mixed results regarding the long-term maintenance of improvements (Guck, Meilman, Skultety & Dowd, 1986; Guck, Skultety, Meilman & Dowd, 1985; Meilman, Skultety, Guck & Sullivan, 1985). Early studies suggested that although one third of individuals continue to make progress post-treatment, up to one third regress to pre-admission levels (Painter, Seres & Newman, 1980). However, the reliability of such findings has been questioned, due to the methodological weaknesses of the studies involved (Corry, Linssen & Spinhoven, 1992).

More recent studies have suggested that approximately 50% of clients completing multidisciplinary pain programmes are in employment 5 years post-discharge (Deardoff, Rubin & Scott, 1991; Gallon, 1989; Mayer, Gatchel, Mayer, et al., 1987, cited in Gallon, 1989). However, high rates of employment have also been reported among control groups (Mayer et al., 1987). Differences in findings have been attributed to factors such as patients selection criteria, attrition rates and the types of intervention and outcome measures being used (Weiser & Cedraschi, 1992). It is also important to note that the most positive findings have been reported within intensive, multidisciplinary rehabilitation programmes (e.g. Mayer, Gatchel, Kishino, Keeley, Mayer, Capra & Mooney, 1986). The lack of long-term follow-up (beyond 18 months) within many studies prevents the drawing of more definite conclusions regarding the long-term effectiveness of psychological interventions.
Problems with Studies

Evaluation research in chronic pain is complicated by a lack of standardisation in the content and practise of behavioural and cognitive-behavioural interventions (Roberts, 1989; Turner & Clancy, 1988). This is contributed to by the general lack of description provided by authors reporting on their work (Morley et al., 1999). Heterogeneity across studies in the use of control groups further complicates the comparison of findings (Tan, 1982, cited in Tan & Leucht, 1997; Turner & Chapman, 1982). Moreover, it is often difficult to know what interventions a control group may have received during the course of the study (e.g. medication, contact with health professionals, alternative therapies). The lack of component analysis in multi-aspect interventions also creates difficulty in identifying the effective treatment component (Tan, 1982, cited in Tan & Leucht, 1997). In particular, it can be extremely difficult to disentangle the effects of psychological intervention from those of other multidisciplinary interventions (Weiser & Cedraschi, 1992).

Further problems include the general failure to use power analyses, either a priori or post-hoc, resulting in many studies lacking sufficient power (Morley et al., 1999). Meta-analyses have also been complicated by the fact that the majority of studies incorporate numerous outcome measures and have involved multiple treatment arms within the intervention. This precludes the use of a single common measure for calculating effect size and bias may be introduced through the interdependency and inter-correlation of multiple measures. With respect to outcome measures, there is a further problem with programmes selecting different treatment goals and aiming to effect change in different areas. Finally, comparison of findings from British and American pain management programmes, is complicated by differences in client recruitment. This limits the generalisability of findings (Williams, Nicholas, Richardson et al., 1993).
Future Directions
The IASP have recommended that the care of individuals with chronic pain should involve both medically trained and psychologically trained health care professionals (Fields, 1991). However, there is a need to establish a combined approach, which promotes the maximal benefit for clients. There is also a need to establish which treatment components are necessary or sufficient for clinical improvement (Tan & Leucht, 1997). Finally, more randomised prospective studies are required, in order to assess the long-term maintenance of benefits.

Conclusion
Despite the problems discussed, there would appear to be strong and consistent empirical support for the efficacy of both behavioural and cognitive-behavioural interventions for chronic pain. Moreover, the non-invasive nature of such interventions, their cost-efficiency and the limited risk of complications, recommends their use earlier on in the client’s contact with the health service than is typically practised. However, if clients are to maximally benefit from intervention, there is a need for clinical psychology services to be better integrated and supported within the package of medical care being provided for clients. Psychological interventions need to be presented as a means of clients learning to manage their pain on a daily basis, for as long as it endures. Whilst such intervention does not necessarily preclude further medical treatment, the emphasis should be on developing a collaborative approach with the client, aimed at pain management, rather than ‘cure’.
References


Clinical Section
Placement One: Adult Mental Health

Type: Core placement
Clinical Supervisor: Jacqui Seaton
Base: Cranleigh CMHT, South House, South Street, Cranleigh
Trust: Surrey Hampshire Borders Trust
Placement Dates: October 1997 - April 1998

Clinical Experience
Over the course of the placement, experience was gained working with clients of varying ages (21 - 53 years), with a range of presenting problems. These included anxiety, panic attacks, depression, hypochondriasis, obsessive-compulsive disorder, eating disorder, body image concerns, alcohol misuse, work-related stress, psychotic symptoms in the context of childhood sexual abuse, pregnancy-related anxiety and memory problems in the context of long-term psychiatric history. This experience comprised both direct work with clients and observation of the placement supervisor’s clinical work. Assessment, formulation and intervention was largely conducted within a cognitive-behavioural framework, including schema-focused work. Other approaches included motivational interviewing, solution-focused therapy and bereavement work.

The clinical work was primarily conducted within the CMHT, with a neuropsychological assessment being undertaken within a psychiatric rehabilitation setting. There was opportunity to contribute to an activity group for individuals with long-term mental health problems. Weekly referral allocation meetings were attended within the CMHT, in addition to trust wide psychology department meetings. A presentation on informing clients about the potential risks associated with psychological therapy was given in conjunction with another trainee clinical psychologist at a psychology department meeting. Training events on the Care Programme Approach, drug and alcohol misuse and the prevention of suicide and self-harm were attended within the Trust.
Adult Mental Health - Case Report Summary

Mr X, a 36 year old gentleman, was referred to the CMHT by his GP, with a long history of anxiety and panic attacks. He reported a family history of both depression and anxiety and believed his difficulties were hereditary. An assessment interview and Mr X’s scores on the Beck Anxiety (BAI) and the Maudsley Obsessional-Compulsive Inventory (MOC) indicated the presence of high levels of anxiety, 3-4 panic attacks per week, features of obsessive-compulsive disorder and a phobia of heights.

Formulation

Mr X’s difficulties were formulated within a cognitive behavioural model of panic disorder. Childhood experiences, including bullying, parental divorce, and being raised by a parent with psychiatric problems were believed to have been instrumental in the formation of Mr X’s beliefs concerning personal vulnerability. These beliefs created a need for constant vigilance and for actions to reduce vulnerability. Avoidance and compulsive behaviours were identified as constituting maintaining factors for Mr X’s difficulties.

Intervention

The intervention comprised a discussion of the cognitive model of panic, exploration of the origins of Mr X’s unhelpful assumptions, use of the schema-focused questionnaire to explore the core schema involved, discussion of graded exposure principles and techniques and examination of the contributory role of work-related stress.

Outcome

Over the course of therapy, Mr X’s scores on the BAI reduced from 27-29 (severe range) to 16 (mild to moderate range). Mr X reported an improvement in his ability to function at work and was considering alternative forms of employment as a means of further reducing his daily level of stress. He demonstrated a much clearer understanding of the origins of his difficulties in childhood and had begun to acknowledge the role of cognitive factors in his difficulties.
Placement Two - Learning Disabilities

Type: Core placement
Clinical Supervisor: Karen Long
Base: Esher CMHT, Weston Green Road
Trust: Kingston & District Trust
Placement Dates: April 1998 - September 1998

Clinical Experience
Over the course of the placement, experience was gained working with clients of varying ages (19-51 years), with mild to profound learning difficulties. Presenting problems included needle phobia, agoraphobia, separation anxiety, difficulty managing activities of daily living, bereavement, delusions, poor anger management, challenging behaviour and deterioration of self-care skills in the context of Down’s syndrome. This experience comprised both direct work with clients and observation of the placement supervisor’s clinical work. Assessment, formulation and intervention were largely conducted within a behavioural framework, with some cognitive behavioural work. Other approaches included bereavement work and education regarding the recognition and labelling of emotions. A number of assessments of cognitive functioning and adaptive behaviour were undertaken using the LEITER, the WAIS-R, ABS: RC-2 and the HALO.

Clinical work included behavioural observations, consultation with staff, direct client work and liaison with social services regarding allegations of sexual abuse. The work was conducted within a variety of settings, including day centres and client’s homes. A research project investigating the outcome of clients attending a specialist day unit for people with a learning disability was undertaken. A presentation of this project was given to staff within the day unit. Weekly referral allocation meetings were attended within the CMHT, in addition to specialty meetings within the trust. Training events on epilepsy, conducting CBT with people with a learning disability, autism and challenging behaviour were attended.
Learning Disabilities - Case Report Summary

Mr M, a 30 year old man with Down’s syndrome, was referred to the CMHT by staff at his day centre for ‘problem behaviour’. This involved pulling his trousers down during activity sessions. The client had been referred to the CMHT for ‘problem’ behaviours in the past. During a 1-hour observation session, Mr M pulled his trousers down once and put his hand down his trousers a second time. In two subsequent sessions, Mr M did not pull his trousers down, but put his hand down them three and eight times respectively.

Formulation

Mr M’s behaviour was understood within a behavioural framework. A lack of appropriate activity and interaction with Mr M during sessions was hypothesised to leave him under-stimulated. Given Mr M’s lack of verbal communication, the ‘problem’ behaviours were hypothesised to offer an effective means of communicating his needs and receiving stimulation. The immediate staff response to the behaviour was proposed to maintain Mr M’s engagement in it, through a process of positive reinforcement.

Intervention

Case management involved sharing the formulation with staff at the day centre and advising regarding the need for appropriate activities and interaction with Mr M, to provide sufficient levels of stimulation. The need for staff education regarding individual client needs was discussed with the day centre manager. Behavioural guidelines were introduced to support staff in differentially reinforcing communicative behaviours. A referral was made to Speech & Language Therapy for assessment of receptive language.

Outcome

One month post-intervention, staff reported a reduction in the frequency with which Mr M engaged in the ‘problem’ behaviours. Direct observation revealed that he was engaged in activity for a greater proportion of day centre sessions than pre-intervention. Staff were also observed to be interacting with him at regular intervals.
Placement Three - Children & Adolescents

Type: Core placement
Clinical Supervisor: Nick Kirby-Turner
Base: Psychology Department, Princess Royal Hospital, Haywards Heath
Trust: Mid-Sussex NHS Trust

Clinical Experience
Over the course of the placement, experience was gained working with children, adolescents and families with a variety of presenting problems. These included anxiety, urinary incontinence, somatic complaints, behaviour problems, ADHD, psychotic symptoms, poor anger management, stealing, hearing loss, failure to thrive, poor self-management of diabetes, adoption, behaviour problems following head injury, bereavement and developmental delay. Assessment, formulation and intervention were conducted within cognitive behavioural and systemic frameworks. Clinical work was also informed by personal construct theory, attachment theory, motivational interviewing, an understanding of the issues facing blended families and long-term effects of childhood trauma.

Experience was gained working in an outpatient setting, an inpatient psychiatric unit for adolescents and within a family therapy team. A problem-solving group was jointly run with a psychiatric nurse for inpatients within the adolescent unit. Weekly referral allocation meetings and specialty meetings were attended, as were monthly psychology department meetings. A presentation on early-onset schizophrenia was given within a specialty meeting. Visits were made to an inpatient children's psychiatric unit, a playgroup for children with developmental delay and a juvenile court. Training events in family therapy techniques and interventions in ADHD and autism were attended.
Children & Adolescents - Case Report Summary

Mr A, a 17 year old inpatient in the Adolescent Psychiatric Unit, was referred for a psychometric assessment, following a series of psychotic episodes, in the context of academic pressure. The purpose of the assessment was to establish Mr A’s current level of intellectual functioning, to identify the pattern of cognitive strengths and difficulties and to offer recommendations regarding future academic career.

Mr A’s performance on the NART-R and his academic history were compared with performance on tests of current intellectual functioning, and tests of memory, learning and information processing. The results suggested that Mr A’s level of intellectual functioning fell within the ‘average’ range. Specific difficulties with attention, new learning and information processing were noted. Such difficulties were hypothesised to present additional challenges to Mr A’s successful completion of further academic study.

Mr A’s success in previous academic studies was believed to reflect the hard work he had invested. The test results indicated that Mr A’s family and teaching staff had overestimated his level of intellectual ability and had unrealistic expectations of his future academic career. It was hypothesised that in order to meet the standards expected of him, Mr A invested tremendous effort and placed himself under extreme pressure, which contributed to psychotic breakdown.

Mr A, his family and teaching staff in the psychiatric unit were informed of the test results and the associated recommendations. These included exploring alternative academic courses to ‘A’ levels, or reducing the number of subjects being studied and adopting study methods which allowed for his difficulties with attention, new learning and memory. Mr A was referred for psychological input regarding his high personal expectations and their role in precipitating psychotic breakdown.
Placement Four - Older Adults

Type: Core placement
Clinical Supervisor: Ajay Kapoor
Base: Waverley CMHT for the Elderly, Brankscombe House, Godalming,
Trust: Surrey Hampshire Borders
Placement Dates: April 1999 - September 1999

Clinical Experience
Over the course of the placement, experience was gained working with clients of varying ages (59-92 years), with a range of presenting problems. These included agoraphobia, fear of falling, bereavement, depression, obsessive-compulsive disorder, trauma, paranoia, marital conflict, depression and cognitive decline in the context of a history of alcohol misuse, PTSD and stroke. Assessment, formulation and intervention was conducted within cognitive-behavioural and systemic frameworks, with an understanding of models of loss and life cycle stages. A number of neuropsychological assessments were undertaken to assist in differential diagnosis of cognitive deterioration.

Clinical work was largely conducted within clients' homes. Weekly team meetings were attended within the CMHT, including the allocation of referrals and case presentations. Consultation was provided to other professionals within the team regarding psychological aspects of cases and basic neuropsychological principles. Training events on end of life decision making, bereavement counselling and neuropsychological assessment of older adults were attended.
Older Adults - Case Report Summary

Mr D, an 80 year old man, was referred for neuropsychological assessment, with regard to memory and word finding difficulties, in the context of a long history of psychiatric difficulties and alcohol misuse. The referrer, Dr Z, was concerned that the difficulties reflected the onset of dementia. Mr D reported a disturbed sleep pattern and the experience of distressing thoughts concerning inanimate objects directly communicating with him. Mr D dated his difficulties back to the death of his wife, 5 years previously.

Neuropsychological assessment involved the administration of tests to compare Mr D’s premorbid and current levels of intellectual functioning. In addition, tests of memory, new learning, information processing and executive functioning were administered to assess strengths and deficits in these areas of cognitive functioning and to make recommendations regarding future care needs. The Hospital Anxiety & Depression Scale (HADS) was administered to assess Mr D’s mood.

The results suggested the presence of global cognitive deterioration, with likely frontal lobe involvement. A relative strength was Mr D’s recognition memory for words. Areas of difficulty were learning new information, immediate and delayed recall of verbal and visuospatial information, information processing and verbal fluency. The nature and pattern of deterioration was consistent with the clinical presentation typically observed in dementia of the Alzheimer’s type. Mr D’s scores on the HADS fell within the mild range for both anxiety and depression.

The recommendations included repeat testing in 12 months to monitor changes in Mr D’s cognitive functioning and associated needs. Referral was made for an Occupational Therapy assessment, regarding Mr D’s difficulty with self-care tasks. A referral was also made for Clinical Psychology input, due to Mr D’s confusion and distress at the thoughts he was experiencing. Mr D was encouraged to continue with the use of his diary and step-wise cue cards for daily tasks were introduced.
Placement Five - Health Psychology

Type: Specialist placement
Clinical Supervisor: Dr Michelle Sowden
Base: Department of Psychological Medicine, Frimley Park Hospital, Frimley
Trust: Surrey Hampshire Borders
Placement Dates: October 1999 - March 2000

Clinical Experience
Over the course of the placement, experience was gained working with clients of varying ages (23-73 years), with a range of presenting physical health problems and associated psychological difficulties. These included a variety of chronic pain conditions, chronic fatigue syndrome, rheumatoid arthritis, conversion disorder, epilepsy, breast surgery, anxiety, depression, agoraphobia, PTSD, marital difficulties and driving phobia. There was also opportunity to be involved in cases requiring a psychological opinion regarding the appropriateness of surgery. Clinical experience comprised both direct work with clients and observation of the placement supervisor's clinical work. Assessment, formulation and intervention were conducted largely within a cognitive behavioural framework, with understanding of systemic models and reflection on the therapist-client relationship.

Two six week pain management courses were co-facilitated with the placement supervisor. Weekly team meetings were attended and a case presentation was given in this context. There was also opportunity to attend ward rounds with the liaison psychiatry team, to observe a risk assessment in the context of overdose and to observe pain clinic sessions. Meetings were conducted with other health care professionals within the hospital to develop an understanding of the role of a clinical psychologist within a physical health setting. Team away days and trust-wide psychology research group meetings were attended whilst on placement.
Health Psychology - Case Report Summary

Ms P, a 27 year old lady, was referred by the consultant psychiatrist regarding the management of chronic fatigue syndrome. Ms P reported reduced tolerance for activity, social isolation and low mood. Ms P’s score on the Beck Depression Inventory (BDI) (16) placed her within the mildly depressed range, although elevated scores largely concerned slowed physical and cognitive processes. Ms P had previously benefited from a course of CBT, although progress had not been maintained following the termination of therapy.

Formulation

Ms P’s difficulties were initially formulated within a cognitive behavioural model of chronic fatigue syndrome. A vicious cycle of symptoms, prolonged rest, physical deconditioning and exacerbation of symptoms on activity was hypothesised to maintain Ms P in a state of chronic fatigue. The symptoms were also proposed to remove the pressure for Ms P to achieve the high personal standards on which she based her self-worth. Family life events were also deemed important in maintaining her difficulties.

Intervention

The cognitive behavioural model of chronic fatigue and principles of time-contingent activity, were reviewed with Ms P. Core assumptions were challenged within sessions. Given the poor maintenance of gains from previous CBT, and the identification of important family influences in the maintenance of the chronic fatigue, further exploration of these issues was incorporated into the sessions.

Outcome

Ms P made limited progress with the graded activity scheduling and remained entrenched in her view of a disease-basis to her symptoms. The recognition of the importance of family influences led to a re-formulation of the case from a systemic perspective, where Ms P’s chronic fatigue was proposed to reflect family difficulty in negotiating the life cycle stage of children leaving home.
Placement Six - Family Therapy

Type: Specialist placement
Clinical Supervisor: Annette Lumsden
Base: Farnham Road Hospital, Guildford
Trust: Surrey Hampshire Borders
Placement Dates: April 2000 - September 2000

Clinical Experience
Over the course of the placement, experience was gained working with couples and families, with a range of presenting problems. These included eating disorders, childhood physical, emotional and sexual abuse, depression, self-harm, alcohol misuse, gambling, marital conflict, schizophrenia, overdose. This experience comprised both direct work with couples and extensive experience as a co-therapist and working within a reflecting team. An understanding of a variety of systemic approaches to assessment, formulation and intervention was gained, including solution focused therapy, narrative approaches, strategic models of therapy and the Milan approach.

Weekly referral allocation meetings were attended, in addition to a quarterly psychology management meeting and meetings to devise a new structure for the delivery of psychological therapies within the Trust. There was opportunity to discuss the tensions and fit between clinical psychology and social constructionist approaches to family therapy and to consider organisational issues. A systemic research project examining the reasons why families do not take up a referral to family therapy was conducted whilst on placement.
Research Section
Service-Related Research

An Outcome Study of a Specialist Service for People with Learning Disabilities

Year 1
March 1998
Abstract
This paper reports on an outcome study of a specialist day unit for clients with learning disabilities and complex needs. There were two aims of the study. The first involved generating a list of aims and objectives of the unit, in conjunction with the staff team. Three aims and five objectives were identified through this process. The second was to determine the outcomes of clients who had been discharged from the unit in the past 10 years. 45 clients participated in the study. Data were collected by means of a questionnaire, completed by professionals currently involved with the clients. The findings reflected positive outcomes in terms of residential and day placements, level of support received and the infrequency of placement breakdown.
Introduction

Residential Care

During the 1970's, as part of the welfare strategy for the care of priority groups, the government proposed the closure of long-stay hospitals for people with learning disabilities, with the aim of resettlement in the community (1971 White Paper, *Better Services for the Mentally Handicapped*; King's Fund Centre, 1980). In the 1990's, this goal remains far from being realised (Hudson, 1991), fuelling doubts as to whether total de-institutionalisation will ever be achieved. Nevertheless, considerable effort has been directed towards developing community placements for this client group and evaluation studies have been conducted, comparing community provisions with their institutional counterparts (Felce, 1989; Joyce, 1994; Lister Brook & Bowler, 1995; Perry & Felce, 1994, 1995).

Evidence suggests that community placements offer richer, more stimulating environments than the hospitals they have replaced (Mansell & Beasley, 1993). In general, staff:client ratios are higher, with staff spending more time interacting with individual clients (Felce, 1989) and offering more direct assistance (Felce, de Kock, Saxby & Repp, 1986; Mansell & Beasley, 1993). Better outcomes for clients have also been reported (Felce, 1994), although there is considerable room for improvement (Fleming & Stenfert, 1990). Reported benefits include clients spending more time engaged in constructive activity, development of skills, increased use of community facilities and increased social contact (Lowe & de Paiva, 1991). For the majority of clients, community placements are also reported to be cheaper than equivalent institutional care (Beecham, Knapp, McGilloway, Donnelly et al., 1997), although the reverse has been indicated for clients with severe or profound learning disabilities (Ryan, 1994).

Specialist Services

Community placements are noticeably more difficult to find and maintain for clients with challenging behaviour and individuals with a dual diagnosis, or complex medical needs
(Allen & Lowe, 1995). It is generally recognised that such individuals require specialist service provision, but there is dispute as to the form this should take. Two main service models have been proposed. The first involves the development of specialist residential or day service units (Murphy, Holland, Fowler & Reep, 1991), while the second advocates the provision of care within mainstream community services, with additional support from peripatetic teams (Allen & Lowe, 1995).

Empirical research on this issue is lacking (Allen & Lowe, 1995). Anecdotal reports support the efficacy of both specialist units (Keene & James, 1986; Dockrell, Gaskell & Rehman, 1990, cited in Allen & Lowe, 1995) and community models (Allen et al., 1991, cited in Allen & Lowe, 1995), but only a few research studies have been conducted pertaining to specialist units (Hoefkens & Allen, 1990; Murphy et al., 1991) or peripatetic teams (Allen & Lowe, 1995, Donellan, La Vigna, Zambito & Thevdt, 1985). Various problems complicate such research. These include the failure to establish adequate baseline measures prior to intervention (Allen & Lowe, 1995), limited follow-up period (Clare & Murphy, 1993), lack of an adequate control group, inconsistent use of outcome measures and difficulty establishing the cost of service provision (Allen & Lowe, 1995). In general, there is little recognition, or discussion, of such methodological difficulties within reports of these studies.

**Present Study**

The present study aimed to identify the nature of outcomes for clients attending a specialist day service. It was hoped that this would provide the basis for conducting a prospective, long-term follow-up study of subsequent referrals, allowing staff to evaluate the effectiveness of the service and establish the extent to which key aims and objectives were being met.
Day Unit

The Day Unit is a specialist health service resource, offering day placements for clients whose needs cannot be met by mainstream learning disability services. The Unit is staffed by four care workers and an assistant psychologist, under the management of a Clinical Psychologist. Input is provided from the local multidisciplinary team, to facilitate the provision of individual assessment and treatment packages, which meet each client’s needs. Clients typically attend the Unit for a maximum of three days a week, although on occasion, funding is secured for 5 days.

Aims of the Study

There were two phases to the study, each with it’s own aim. These were:-

- **Phase 1:** To identify key aims and objectives of The specialist day unit.
- **Phase 2:** To report on the outcome of clients attending the Unit.

Phase 1

Methodology

As there was no document containing the aims and objectives of the Day Unit, a list was constructed by extracting information from the Unit’s operational policy and 1997/1998 annual reports. A total of 10 statements were generated. These statements were distributed to the Day Unit staff team, including the manager (n=6) (See Appendix 1). Respondents were asked to read the statements and rate each one on a 5 point Likert scale, according to whether or not they held this to be an aim/objective of the Day Unit. A score of 1 represented “definitely not an aim” while a 5 indicated “definitely an aim of the Unit”. Staff were encouraged to add further suggestions to the list, rating them on the same scale. The forms were completed anonymously and returned to the researcher. A final list of agreed aims and objectives was then constructed.
Results

Aims & Objectives of the Day Unit

5 out of 6 members of the staff team completed the Aims & Objectives questionnaire. The results are presented in Table 1. As can be seen, an additional aim, assigned a rating of 5, was suggested by one respondent. With the exception of item 5, all items received a mean rating greater than 4. Item 5 was excluded from the list, due to 4 out of the 5 respondents rating it as either ‘definitely not’ or ‘probably not an aim of the Unit’.

Table 1: Staff Ratings on the Aims & Objectives Questionnaire

<table>
<thead>
<tr>
<th>Aims &amp; Objectives</th>
<th>Mean Rating</th>
<th>Individual Ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. To facilitate the client’s reintegration into mainstream day services for people with learning disabilities, employment or an individual plan which meets the client’s needs.</td>
<td>4.8</td>
<td>5, 4, 5, 5, 5</td>
</tr>
<tr>
<td>2. To ensure a gradual and supported transition back into mainstream services.</td>
<td>4.8</td>
<td>4, 5, 5, 5, 5</td>
</tr>
<tr>
<td>3. To enable the client to live in the community rather than hospital.</td>
<td>4.2</td>
<td>4, 4, 3, 5, 5</td>
</tr>
<tr>
<td>4. To increase independent living skills.</td>
<td>4.6</td>
<td>5, 5, 3, 5, 5</td>
</tr>
<tr>
<td>5. To only recruit clients who meet the specified criteria.</td>
<td>2</td>
<td>1, 5, 1, 2, 1</td>
</tr>
<tr>
<td>6. To discharge clients within 24 months.</td>
<td>4.2</td>
<td>5, 3, 4, 4, 5</td>
</tr>
<tr>
<td>7. To provide individual assessment and treatment of clients’ needs.</td>
<td>5</td>
<td>5, 5, 5, 5, 5</td>
</tr>
<tr>
<td>8. To reduce/eliminate problem behaviour.</td>
<td>5</td>
<td>5, 5, 5, 5, 5</td>
</tr>
<tr>
<td>9. To provide an ongoing review process.</td>
<td>4.4</td>
<td>5, 5, 5, 2, 5</td>
</tr>
<tr>
<td>10. To make recommendations for when a client is discharged.</td>
<td>5</td>
<td>5, 5, 5, 5, 5</td>
</tr>
</tbody>
</table>

Additional Suggestions

11. To prevent future breakdown of residential or day service placement

<table>
<thead>
<tr>
<th>Additional Suggestions</th>
<th>Mean Rating</th>
<th>Individual Ratings</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. To prevent future breakdown of residential or day service placement</td>
<td>5</td>
<td>5</td>
</tr>
</tbody>
</table>

Items were categorised by the author as aims or objectives, based on the definitions offered by Curzon (1997), where aims “are general statements representing ideals or aspirations” and objectives “are statements, often of a quantifiable, operational nature,
indicating events from which mastery of desired activities may be directly inferred”. The final list is presented in Table 2.

Table 2: Agreed Aims & Objectives

<table>
<thead>
<tr>
<th>Aims</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>• To facilitate the client’s re-integration into mainstream day services, employment, or an individual plan which meets the client’s needs.</td>
<td></td>
</tr>
<tr>
<td>• To enable the client to live in the community as opposed to hospital.</td>
<td></td>
</tr>
<tr>
<td>• To prevent breakdown of either day service or residential service placement.</td>
<td></td>
</tr>
<tr>
<td>Objectives</td>
<td></td>
</tr>
<tr>
<td>• To ensure gradual and supported transition back into mainstream services for people with learning disabilities, or employment.</td>
<td></td>
</tr>
<tr>
<td>• To increase independent living skills.</td>
<td></td>
</tr>
<tr>
<td>• To provide individual assessment and treatment of each client’s needs.</td>
<td></td>
</tr>
<tr>
<td>• To reduce/eliminate problem behaviour.</td>
<td></td>
</tr>
<tr>
<td>• To make recommendations for when the client is discharged.</td>
<td></td>
</tr>
<tr>
<td>• To provide an ongoing review process</td>
<td></td>
</tr>
<tr>
<td>• To discharge clients within 24 months</td>
<td></td>
</tr>
</tbody>
</table>

Discussion
Considerable consistency was found regarding the ascription of aims and objectives to the Day Unit, suggesting that staff share an understanding regarding the role of the Unit, despite the lack of explicitly stated aims and objectives. It would seem important for the final list of aims and objectives to be shared with the staff team, allowing items to be operationalised, thereby enabling a clinical audit cycle to begin.

Phase 2: Outcome Study
Methodology
Subjects
All 54 clients who had been discharged from the Day Unit within the last 10 years were included in the outcome study. An additional 4 clients, currently attending the Day Unit despite having exceeded their discharge date, were also included. Of the 58 clients, 3 had died, 8 could not be traced and 2 declined to participate.
Measures
Information regarding the client and their current circumstances was collected using a questionnaire designed specifically for the study (See Appendix 2). This questionnaire was distributed to the manager of the Day Unit and to staff within the multidisciplinary team for comments. Revisions were then made. In addition to demographic information, the questionnaire focused on five key areas. These were:-

- residential placement (where the client currently resides for the majority of the time)
- day placement (services offering day activities for clients)
- employment
- specialist input from multidisciplinary teams
- behaviour problems

The above areas were considered to be most relevant outcome variables, given the aims and objective generated in Phase 1 of the study. Time prevented consideration of additional areas.

Procedure
Clients and their carers were contacted to elicit consent for participation in the study, on an opt-out basis. The two local community learning disability teams were then contacted to identify professionals who were currently working with participating clients. If a client was not currently receiving input from a professional within the teams, the client's care manager, residential placement manager or key worker was determined. One identified professional was contacted by letter for each client, being asked to complete the follow-up questionnaire. Questionnaires were to be returned to the researcher within one month. A telephone follow-up was conducted at 4 weeks, to prompt respondents.

Results
Demographic Information
43 out of 45 questionnaires were returned, constituting a 96% response rate. This represented 74% of the original 58 clients qualifying for the study (3 clients had died, 8
could not be traced and 2 declined to participate). 58.1% (25/43) of the final sample were men. The median age was 34 years, with a range of 23 to 61 years. In terms of learning disability, 31% (13/42) were rated by professionals as being mild, 23.8% (10/42) moderate, 35.7% (15/42) severe and 4.5% (4/42) as profound. 37.2% (16/42) had a diagnosed mental illness, details of which can be found in Table 3. 81.25% (13/16) of these individuals were receiving medication for this illness at the time of the study. 30.2% (13/43) were receiving medication for problem/challenging behaviour.

Table 3: Mental illness diagnoses

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>6</td>
</tr>
<tr>
<td>Depression</td>
<td>3</td>
</tr>
<tr>
<td>Anxiety</td>
<td>2</td>
</tr>
<tr>
<td>Deliberate self-harm</td>
<td>1</td>
</tr>
<tr>
<td>Hypomania</td>
<td>3</td>
</tr>
<tr>
<td>Tourette’s syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Total</td>
<td>16</td>
</tr>
</tbody>
</table>

*Questionnaire Data*

Table 4 provides a breakdown of clients according to the profession responsible for completing their questionnaire.

Table 4: Profession completing the Questionnaire for Clients

<table>
<thead>
<tr>
<th>Professional Group</th>
<th>Percentage of clients (n=43)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Nursing</td>
<td>30.2 (13)</td>
</tr>
<tr>
<td>Social Work/Care Manager</td>
<td>32.6 (14)</td>
</tr>
<tr>
<td>Clinical Psychology</td>
<td>16.3 (7)</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>7.0 (3)</td>
</tr>
<tr>
<td>Day Unit staff</td>
<td>9.3 (4)</td>
</tr>
<tr>
<td>Speech &amp; Language Therapy</td>
<td>2.3 (1)</td>
</tr>
<tr>
<td>Residential Manager</td>
<td>2.3 (1)</td>
</tr>
</tbody>
</table>
Residential Placement

The residential placements of clients are summarised by type in Table 5. As can be seen, approximately half the clients were living in a supported group home, with a further quarter living in the family home. No clients in the sample were living in hospital, although 4 lived in a residential home.

Table 5: Types of Residential Placement

<table>
<thead>
<tr>
<th>Placement Type</th>
<th>Percentage of Clients (n=43)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family home</td>
<td>25.6 (11)</td>
</tr>
<tr>
<td>Own home</td>
<td>7 (3)</td>
</tr>
<tr>
<td>Lives independently with others</td>
<td>2.3 (1)</td>
</tr>
<tr>
<td>Supported group home</td>
<td>53.5 (23)</td>
</tr>
<tr>
<td>Residential home</td>
<td>9.3 (4)</td>
</tr>
<tr>
<td>Health funded assessment unit</td>
<td>2.3 (1)</td>
</tr>
</tbody>
</table>

Table 6 presents a breakdown of the client groups catered for by the residential placements. As can be seen, few clients had placements which catered for individuals with complex needs (i.e. physical disability, or mental illness in addition to a learning disability), despite there being a need for such placements. Only 3 of the 16 clients with a diagnosed mental illness had placements which catered for those with a dual diagnosis, indicating the frequency with which clients are placed in facilities not designed to cater for their needs. 79.3% (23/29) of clients had placements offering a high level of support. The most common finding (68%, 17/25) was for the client’s residential placement to have one member of staff for every 2 to 3 clients.

Table 6: Client Group Catered for by Residential Placements

<table>
<thead>
<tr>
<th>Client Group Catered For</th>
<th>Percentage of Clients (n=29)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Learning disability (LD)</td>
<td>65.5 (19)</td>
</tr>
<tr>
<td>LD &amp; Physical disability</td>
<td>20.7 (6)</td>
</tr>
<tr>
<td>LD &amp; Mental health problems</td>
<td>10.3 (3)</td>
</tr>
<tr>
<td>LD, Physical disability &amp; mental</td>
<td>3.4 (1)</td>
</tr>
<tr>
<td>health problems</td>
<td></td>
</tr>
</tbody>
</table>
Residential Placement Breakdown

80% of clients (n=32/40) in the study had remained in the same residential placement since discharge. An additional 17.5% (7/40) of clients had experienced only one change of placement. The maximum number of changes was four (1 client). In only two cases was change attributable to the client's behaviour. Other reasons for change included client choice (n=2), placement closure (n=1) and a lower level of support being required (n=3). Mann-Whitney U tests revealed that placement breakdown was not significantly more common for clients with a mental illness (Z= -0.823, p= 0.411) or problem behaviour (Z= -1.451, p= 0.147) than for clients without these difficulties. Neither was there an association between time since discharge and placement breakdown, using Spearman's Rho calculation (r = -0.224, p= 0.171).

Day Placement

76.7% (33/43) of clients attended a day placement, with 53.5% (23/43) having one placement and 18.6% (8/43) having two. The median number of placement days was four (30%, 13/43). 24.2% (8/33) of clients attended placements which catered for individuals with physical disabilities and 36.4% (12/33) for those with a dual diagnosis. Only 6 out the 16 clients with a diagnosed mental illness were attending a day placement which catered for this client group. As with residential placements, the most frequent level of support was one member of staff for 2 - 3 clients.

Day Placement Breakdown

45.2% (14/31) of clients had experienced no changes in day placement since discharge, with 25.8% (8/31) having had one change and 22.6% (7/31) having had two changes. The maximum number of changes was four (1/31). Reasons for placement change included breakdown due to client's behaviour (n=3), client's choice (n=3) and placement closure (n=7). Placement breakdown was not significantly more common among clients with a mental illness (Z= -0.93, p= 0.353) or problem behaviour (Z= -1.188, p= 0.235). As with residential placement breakdown, there was no association between time since discharge
and day placement breakdown ($r=0.184$, $p=0.33$). Reasons for not having a day placement included employment ($n=2$), lack of suitable placements ($n=2$) and client choice ($n=4$).

**Employment**

Only 7% ($n=3$) of the sample were employed at the time of the study. Two clients performed manual cleaning jobs, whilst the third assisted at a children’s play group. All three were conducting paid work, but information was not available regarding salary. Duration of employment ranged from 9 to 40 months.

**Multidisciplinary Team Input**

83.7% (36/39) of clients had received input from the community learning disability team since their discharge. (The four clients who had not yet been discharged from the Unit were excluded from this analysis). A summary of the types of input can be found in Table 7, along with input currently being received. 87.2% (34/39) of clients were receiving input from at least one member of the community learning disability team at the time of the study, indicating that the continuing needs of many individuals in this client group.

**Table 7: Professional Input Received by Clients since Discharge**

<table>
<thead>
<tr>
<th>Professional Input</th>
<th>Percentage of Clients ($n=39$)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Received in past</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Speech &amp; Language Therapy</td>
<td>28.2 (11)</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>53.8 (21)</td>
</tr>
<tr>
<td>Clinical Psychology</td>
<td>66.7 (26)</td>
</tr>
<tr>
<td>Community Nursing</td>
<td>56.4 (22)</td>
</tr>
<tr>
<td>Support Worker</td>
<td>7.7 (3)</td>
</tr>
<tr>
<td>Social Worker</td>
<td>66.7 (26)</td>
</tr>
</tbody>
</table>

**Problem Behaviour/Challenging Behaviour**

64.3% (27/42) of clients exhibited at least one problem/challenging behaviour. A breakdown of the types of behaviour can be seen in Table 8. The median number of
behaviours was 1, with a range from 0 to 6. Median frequency was 4-5 times a week, with a range from several times a day to once every 6 months.

Table 8: Problem Behaviours Exhibited by Clients

<table>
<thead>
<tr>
<th>Type of Behaviour</th>
<th>Percentage of Clients (n=42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absconding</td>
<td>9.5 (4)</td>
</tr>
<tr>
<td>Destruction of Property</td>
<td>26.2 (11)</td>
</tr>
<tr>
<td>Violence</td>
<td>45.2 (19)</td>
</tr>
<tr>
<td>Sexual Inappropriateness</td>
<td>16.7 (7)</td>
</tr>
<tr>
<td>Self-Injury</td>
<td>21.4 (9)</td>
</tr>
<tr>
<td>Verbal Aggression</td>
<td>40.5 (17)</td>
</tr>
</tbody>
</table>

Discussion

The response rate for the study was very high, suggesting that the final sample was probably representative of clients attending the Unit. It is reassuring to note that only two clients and two professionals declined to participate. Nevertheless, it is important to recognise that the sample attending The specialist day unit may not be representative of clients attending similar units, perhaps due to differences in inclusion criteria, or the purpose of the Unit. Such differences would obviously limit the generalisability of the findings.

Several important findings arose from the study. Firstly, over half the clients were living in small, staffed group homes, with the majority receiving a high level of support. This was verified by both ratings of support and the high staff:client ratios. This finding is reassuring, given recent reports of the benefits associated with such placements (Joyce, 1994; Mansell, 1995; Mansell & Beasley, 1993), and the Unit’s aim of enabling the client to live in the community. A quarter of clients were, however, continuing to live in the family home. For some clients and their families, this may represent a satisfactory outcome, but for many it will be neither appropriate, nor desirable, for maximising quality of life and addressing the client’s specific needs.
The need for more appropriate, specialised community placements for clients with complex needs has been reported in previous studies (Allen & Lowe, 1995). This study’s finding that less than one quarter of clients with a diagnosed mental illness had residential placements which catered for individuals with a dual diagnosis, indicates the frequency with which clients are placed in facilities not designed to cater for their specific needs.

A second important finding was that 80% of clients had experienced only one residential placement since discharge from the Unit. This indicates that for the majority of clients, the Unit’s aim of preventing placement breakdown, is being met. Moreover, given previous research which suggests that placement breakdown is a typical experience for this client group (Intagliata & Willer, 1982; Sutter, 1980), this is a commendable result. It is also important to note, that although the follow-up period for some clients may only have been several months, time since discharge was not found to be related to placement breakdown. Nevertheless, based on the data available, it is impossible to establish the extent to which clients had experienced placement breakdown prior to, or during, their placement at the Day Unit.

The majority of clients in the study were attending a day placement at least three days a week. This is again a positive finding. Only three clients were currently in employment, which may suggest either a lack of opportunities, or the unrealistic nature of such a goal for this client group. The majority of clients had experienced only one, or no change in day placement, since discharge. In only three cases was this attributable to the client’s behaviour. Moreover, clients with problem behaviour were found to be at no greater risk of placement breakdown than their counterparts. This is not consistent with previous findings (Hemming, 1982). One possible explanation for the lack of a statistically significant relationship is the small sample size in the present study.

Given the pervasiveness of placement breakdown among this client group, and the proposed importance of the client’s behaviour in provoking this (Intagliata & Willer,
1982), these findings are important. One explanation is that the findings reflect improvements in the clients' behaviour following attendance at the Day Unit. Alternatively, clients may move to day services better equipped to cope with their behaviour following discharge. The contribution of the environment to placement breakdown has also been discussed in the literature (Intagliata & Willer, 1982).

The finding that the majority of clients required additional multidisciplinary team input subsequent to discharge, with most continuing to receive input, highlights the enduring needs of this client group. The necessity for continuing specialist input is perhaps not surprising, given the complex needs and limited coping resources of such clients. In addition to various life events, these individuals often experience frequent staff changes, a lack of stimulation, limited social relationships and lack social roles within the community. Until improvements are made within mainstream services for people with learning disabilities, in terms of resources and specialised staff training, the professional skills within the multidisciplinary team will continue to be demanded by this client group. As such, specialist services should be realistic in terms of their goals and expectations.

A high incidence of problem/challenging behaviours was found within the current sample, probably attributable to the type of service under consideration. This is consistent with previous research, indicating that clients with challenging behaviour necessitate specialist services, due to the inability of mainstream services to meet their needs (Allen & Lowe, 1995). The challenging behaviours exhibited by clients attending the Day Unit tended to be of high frequency and of a moderate to severe level, which may help explain why professional input continued to be required by clients following discharge. Therefore, although attendance at the Day Unit appears to protect against placement breakdown, this is perhaps only with continued professional input.
Critique of Research

There were a number of limitations to the current study. Firstly, only members of the Day Unit staff completed the Aims & Objectives questionnaire. By including members of the associated community team for people with learning disabilities in this part of the study, a wider range of ideas could have been sampled. In addition, respondents could have been asked to rank the aims and objectives in order of importance.

There was a high response rate to the outcome questionnaire, but the missing clients could have been traced to ensure the representativeness of the findings. Also, the outcome data collected was descriptive in nature, and the study would have undoubtedly benefited from the use of standardised assessment measures such as the Adaptive Behaviour Scale (Nihira, Foster, Shellhaas & Leland, 1974), both pre- and post- attendance. As with previous research in this area, no control group was available for the present study. Unfortunately, these aspects could not be accommodated within the confines of the present study. Finally, there were several items on the questionnaire which respondents reported difficulty answering (e.g. level of learning disability; staff client ratio for placements). This may have led to inaccuracies in the data collected. Furthermore, the questionnaire failed to elicit details of specific syndromes (e.g. autism), additional categories of challenging behaviour (e.g. obsessions/compulsions) and information pertaining to care management. Alterations to the wording and content of the questionnaire may have improved the quality of the data collected.

Future Research

This study has paved the way for a number of further projects. These are as follows:-

1. To operationalise the aims and objectives of the Day Unit and monitor the extent to which these are being met for clients. This could not be incorporated in the present study due to the absence of pre-admission baseline data, against which to compare the client's current circumstances.
2. To establish the extent to which referring agencies and trust managers share an understanding of the Day Unit aims and objectives. This would obviously have implications for the appropriateness of referrals, satisfaction with the service and future funding.

3. To adapt the current questionnaire to collect pre-admission, discharge and follow-up data on clients, to enable a clinical audit cycle to begin. This will inform staff on the effectiveness of the service being offered, allowing practice to be improved.
References


Appendix 1: Aims & Objectives Questionnaire

AIMS & OBJECTIVES OF THE DAY UNIT
This is a survey about the aims and objectives of the Day Unit. I am interested in finding out what you, as a member of the Day Unit team, believe to be the purpose of the Day Unit, and what you feel are the most important aims and objectives. Please do not put your name on the form, so that responses may be kept anonymous.

The table below contains a list of possible aims and objectives. Please read each statement and then indicate whether or not you think this is an aim/objective of the Day Unit by placing a number from 1 - 5 in the box on the right, based on the following rating scale:

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitely not</td>
<td>Not really</td>
<td>Possibly</td>
<td>Probably</td>
<td>Definitely an</td>
</tr>
<tr>
<td>an aim of the Day Unit</td>
<td>an aim</td>
<td>an aim</td>
<td>an aim</td>
<td>aim of the Day Unit</td>
</tr>
</tbody>
</table>

There may be many some additional aims/objectives you can think of. Please add any extra ones to the end of the list and give them a rating from 1 - 5, as you did for the other statements.

<table>
<thead>
<tr>
<th>AIMS &amp; OBJECTIVES</th>
<th>RATING (1 - 5)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Facilitate the client's reintegration into mainstream day services, employment or individual plan which meets the clients needs</td>
<td></td>
</tr>
<tr>
<td>2. Gradual and supported transition back into mainstream services</td>
<td></td>
</tr>
<tr>
<td>3. Enable client to live in the community</td>
<td></td>
</tr>
<tr>
<td>4. Increase independent living skills</td>
<td></td>
</tr>
<tr>
<td>5. Only recruit clients who meet the criteria for group 1 and 2</td>
<td></td>
</tr>
<tr>
<td>6. Discharge within 24 months</td>
<td></td>
</tr>
<tr>
<td>7. Provide individual assessment and treatment of each client's needs</td>
<td></td>
</tr>
<tr>
<td>8. Reduction/elimination of problem behaviour</td>
<td></td>
</tr>
<tr>
<td>9. Provide ongoing review process</td>
<td></td>
</tr>
<tr>
<td>10. Make recommendations for when client is discharged</td>
<td></td>
</tr>
</tbody>
</table>

Additional suggestions
Appendix 2 - Outcome Questionnaire

DAY UNIT FOLLOW-UP QUESTIONNAIRE

Name of client: .................................................................
Date Discharged from Day Unit: ........................................
Name of person completing questionnaire: ........................
Profession of person completing questionnaire: .................

Demographic Information (* Please delete as applicable)

1. Client’s Date of Birth: - ............................................
2. *Level of learning disability: - MILD/ MODERATE/ SEVERE/ PROFOUND
3. *Does the client have a diagnosed mental illness? YES/ NO
   If YES: -
   Please state diagnosis: ......................................................
   How long has the client suffered from this mental illness? ...
   *Are they currently receiving treatment for this mental illness? YES/NO
   If YES, please state what treatment they are receiving: ....
   How long has the client been receiving this treatment? ...
4. *Is the client currently being prescribed any medication? YES/NO
   If YES: -
   Please indicate which, (if any), of the following problems the client is currently receiving medication for.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Medication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Epilepsy</td>
<td></td>
</tr>
<tr>
<td>Mental illness</td>
<td></td>
</tr>
<tr>
<td>Behaviour problems/challenging behaviour</td>
<td></td>
</tr>
<tr>
<td>General health problems</td>
<td></td>
</tr>
</tbody>
</table>
Residential Placement

5. Please place a tick in the right hand column to indicate the client’s current place of residence.

<table>
<thead>
<tr>
<th>Placement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family home</td>
</tr>
<tr>
<td>Own home</td>
</tr>
<tr>
<td>Lives with other clients independently</td>
</tr>
<tr>
<td>Group home</td>
</tr>
<tr>
<td>Hospital</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

If *other* has been ticked, please specify: ............................................................

6. Please indicate the type of accommodation in which the client is currently living.

<table>
<thead>
<tr>
<th>Type of Accommodation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Private</td>
</tr>
<tr>
<td>Voluntary</td>
</tr>
<tr>
<td>Social Services</td>
</tr>
<tr>
<td>Health</td>
</tr>
</tbody>
</table>

7. If the client is living in local health authority, social services or private/voluntary sector accommodation, please indicate which client group(s) the placement caters for? You may tick more than one box if appropriate.

<table>
<thead>
<tr>
<th>Client Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with learning disability</td>
</tr>
<tr>
<td>People with mental health problems</td>
</tr>
<tr>
<td>People with physical disability</td>
</tr>
<tr>
<td>Elderly</td>
</tr>
<tr>
<td>Other</td>
</tr>
</tbody>
</table>

If *other* has been ticked, please specify: ............................................................

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

............................................................
8. If relevant, please indicate the usual staff: client ratio in the residential placement.

......... staff for ........ clients

9. If the client lives in a group home, please specify the number of clients the home caters for:


10. Please indicate the level of support offered by the client’s current residential placement, using the definitions below for guidance.

<table>
<thead>
<tr>
<th>Level of Support</th>
</tr>
</thead>
<tbody>
<tr>
<td>No support</td>
</tr>
<tr>
<td>Minimal support</td>
</tr>
<tr>
<td>Low support</td>
</tr>
<tr>
<td>Moderate support</td>
</tr>
<tr>
<td>High level of support</td>
</tr>
</tbody>
</table>

**Minimal support** - Staff not routinely available. Infrequent visits from support staff.

**Low support** - Staff not routinely available, but regular visits from support staff.

**Moderate support** - At least 1 staff member available for most of the time. Staff time available for supervision and assistance for tasks such as cooking, but not for routine tasks e.g. cleaning, bed making.

**High level support** - At least 1 staff member in the residence at all times. Other members of staff available at peak times of activity.

11. How long has the client been in their current placement (to nearest month)?


12. How many residential placements has the client had since being discharged from The specialist day unit?


13. If the client has had more than one residential placement, please state the reason for this change (e.g. client required more support/ client wished to move etc.)


14. *Does the client currently have additional respite care? YES/ NO

If YES:-
Please indicate how often i.e. how many days a week/ a month/ a year:-

15. *If the client is not living at home, or independently, do they visit the family home on a weekend? YES/NO

If YES:-
Please state approximately how many days a month/year the client visits the family home

Day Placement

16. *Does the client currently attend a day placement? YES/NO

If YES:-
Where does the client attend? (If the client has more than 1 day placement, please give details for each one).

Placement 1:- ...................................................................................................................
Placement 2:- ..................................................................................................................
Placement 3:- ...................................................................................................................

If NO:-
Please explain why this is the case, then proceed to the Employment section :-

17. What client group(s) does this placement cater for? (Please give details for each placement and tick as many boxes as are relevant).

<table>
<thead>
<tr>
<th>Client Group</th>
<th>Placement 1</th>
<th>Placement 2</th>
<th>Placement 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild learning disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate learning disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe/profound learning disability</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>People with mental illness</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
18. Please indicate the approximate staff: client ratio at the client's main day placement.

............. staff for .......... clients

19. How many days a week does the client attend a day placement? ........................................

20. How many changes in day placement has the client had since being discharged from the Day Unit?

If the client has had changes in day placement, please explain why these have occurred.

Employment

21. *Is the client currently employed in either a voluntary or paid capacity?  

YES/NO

If NO:-
Please go on to the Specialist Input Section.

If YES:-
What type of work does the client currently do?

*Is this VOLUNTARY/PAID?

How many days a week does the client work?..............................................................

22. *Has the client had any paid employment prior to this post? YES/NO

23. How long has the client been working in total?......................................................

Specialist Input

24. *Has the client needed any further specialist input (e.g. multidisciplinary team) since being discharged from the Day Unit? YES/NO
If YES:-
Please indicate which of the following professional input has been provided since discharge, by placing a tick in the relevant boxes.

<table>
<thead>
<tr>
<th>Professional input</th>
<th>Received input?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech &amp; Language Therapy</td>
<td></td>
</tr>
<tr>
<td>Psychiatry</td>
<td></td>
</tr>
<tr>
<td>Clinical Psychology</td>
<td></td>
</tr>
<tr>
<td>Community Nursing</td>
<td></td>
</tr>
<tr>
<td>1:1 worker</td>
<td></td>
</tr>
<tr>
<td>Social Work</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

If you have ticked other, please specify the professional input which has been provided:

25. Please indicate which of the following professionals are currently involved with the client.

<table>
<thead>
<tr>
<th>Professional Input</th>
<th>Currently involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Speech &amp; Language Therapy</td>
<td></td>
</tr>
<tr>
<td>Clinical Psychology</td>
<td></td>
</tr>
<tr>
<td>Psychiatry</td>
<td></td>
</tr>
<tr>
<td>Community Nursing</td>
<td></td>
</tr>
<tr>
<td>Social Work</td>
<td></td>
</tr>
<tr>
<td>Support Worker</td>
<td></td>
</tr>
<tr>
<td>Disability Officer</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

If you have ticked other, please specify the service being received.
Behaviour Problems

26. Please indicate which (if any) of the following behaviours the client exhibits:

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Exhibited?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-injury</td>
<td></td>
</tr>
<tr>
<td>Physical aggression towards others</td>
<td></td>
</tr>
<tr>
<td>Destruction of property</td>
<td></td>
</tr>
<tr>
<td>Verbal aggression</td>
<td></td>
</tr>
<tr>
<td>Absconding</td>
<td></td>
</tr>
<tr>
<td>Sexually inappropriate behaviours</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>

If other has been ticked, please specify ........................................................................

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

27. Please give an estimate of how frequent and severe the main problems are, by listing them as headings in the table below and ticking the relevant boxes for severity and frequency.

<table>
<thead>
<tr>
<th>Frequency</th>
<th>1.</th>
<th>2.</th>
<th>3.</th>
<th>4.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Several times a day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>About once a day</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4-5 times a week</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-3 times a week</td>
<td></td>
<td></td>
<td></td>
<td></td>
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Liz Chorlton  
Clinical Psychologist in Training

Dr Karen Long  
Chartered Clinical Psychologist
Literature Review

Children's representations of illness

Year 2
August 1999
Introduction

Interest in children’s conceptualisation of illness has flourished over the last 20 years and a sizeable body of literature has now emerged. Studies in this area have traditionally been founded upon Piaget’s (1930) theory of cognitive development and have aimed to demonstrate that children’s concepts of illness reflect the developmental progression proposed for concepts of physical phenomena (cited in Bibace & Walsh, 1980). However, criticisms of this approach, methodological limitations and inconsistent findings, have highlighted the need for alternative theoretical and methodological approaches. One suggestion has been to extend Leventhal’s (1970) self-regulation model of adult illness representations to child populations. A number of studies have already utilised this framework in studying children’s conceptualisation of illness. However, the literature remains in its infancy.

This review addresses our current understanding of how children conceptualise illness. Research relating to each of the above approaches is reviewed, with discussion of salient findings and their clinical implications. Directions for future research are also indicated. The review begins with a brief summary of the historical origins of this area, to set the context for the discussion.

Historical Context

Interest in children’s conceptualisation of illness was initially the domain of clinicians in the paediatrics field, who were concerned with the meaning children attach to illness episodes (e.g. Langford, 1948). Of particular interest, were children’s beliefs regarding the causes of their illness (Langford, 1948; Richter, 1943, cited in Eiser, 1985), and specifically, the assumption that illness would be viewed by children as a punishment for misdeeds. Children’s beliefs about illness and the meaning they attached to their experience were deemed important in determining their psychological and emotional responses to illness (Langford, 1948).
Early research in this area tended to focus on the specific beliefs children hold about health and illness (Brodie, 1974, Palmer & Lewis, 1975, cited in Eiser, 1985). Several authors utilised aspects of Rosenstock's (1974) Health Belief Model (HBM), such as perceived vulnerability, (Dielman, Leech, Becker, Rosenstock, Horvath & Radius, 1980; Gochman, 1970, cited in Lau & Klepper, 1988) to guide their investigation. The HBM presents a catalogue of factors (e.g. perceived susceptibility, perceived vulnerability) believed to influence the probability of an individual engaging in health-related behaviours. Studies utilising this model confirmed that children over the age of seven years do possess beliefs about illness, and that these beliefs exhibit some consistency between, and within, individuals (Gochman, 1970, 1972, cited in Lau & Klepper, 1988). However, numerous criticisms have been made of the HBM (Diefenbach & Leventhal, 1996). In particular, the model is atheoretical and fails to explain both the relationship between individual factors and the cognitive or emotional mechanisms through which health beliefs may activate health-related behaviours.

Sociological Perspective

From a sociological perspective, early research by Campbell (1975) explored children's development of attitudes and social roles relating to illness. This work was based on the premise that definitions of illness are socially and culturally constructed (Mishler, Amarasingham, Hauser, Liem, Osherson & Waxler, 1981). Campbell proposed that children 'learn' their attitudes and beliefs about illness from adults within their social or cultural setting. Assimilation to adult attitudes and beliefs was believed to arise with increasing age. Campbell (1975) termed this increasing convergence 'patterned similarity'. He also hypothesised that qualitative differences would be found between children of different ages (i.e. developmental changes).

In a preliminary study with an acute paediatric population, Campbell (1975) demonstrated greater sophistication in children's illness definitions with increasing age and supported the notion of patterned similarity. The qualitative data reflected similarity across children in
their definitions of illness, but age differences were apparent in the conceptual sophistication of these definitions. Within the study, age was assumed to constitute a crude measure of cognitive development, allowing Campbell to conclude that developmental changes were apparent in the illness definitions.

The notion of a developmental progression in children's concepts of illness has been widely explored within the psychological literature. In contrast to Campbell's assumption, chronological age is generally not considered to be an accurate predictor of cognitive developmental stage (Bibace & Walsh, 1979). Studies relying on age as a measure of cognitive development have often failed to find as strong a relationship between developmental stage and children's illness concepts (Bibace & Walsh, 1979).

Contemporary Research
In the last 20 years, two main theoretical frameworks have been applied to studying how children conceptualise illness. Paterson, Moss-Morris & Butler (1999) describe these as the 'developmental' and 'functional' perspectives. The majority of early studies were grounded in the developmental perspective. This approach has focused on delineating how children's concepts of illness evolve over the course of cognitive development. This framework has also been employed in studying concepts such as death (Koocher, 1973) and smoking (Meltzer, Bibace & Walsh, 1984). In recent years, studies have applied a 'functional' approach to their investigation, examining how illness experience and socio-cultural factors may influence concepts of illness. Given it's historical precedence, the developmental literature will be discussed first.

Cognitive-Developmental Framework
Piaget's Theory of Cognitive Development
Cognitive-developmental research has predominantly been guided by Piaget's theory of developmental stages (Piaget, 1952). This theory is founded on the assumptions that children's concepts of physical phenomena (e.g. space, time) follow an ordered and
Piaget (1930) delineated four stages of cognitive development (cited in Bibace & Walsh, 1980), labelled as:

(a) sensorimotor (birth to 2 years),
(b) pre-operational (2-6 years),
(c) concrete-operational (7-11 years) and
(d) formal-operational (12 years and beyond).

As children progress through these stages, they are held to make increasing distinction between themselves and others (Bibace & Walsh, 1980). Later stages reflect increasing conceptual understanding and a move from global, undifferentiated ideas to abstract reasoning (Bird & Podmore, 1990). Piaget viewed these stages as denoting the logic available to the child (Gelman & Baillargeon, 1983), and in determining the child’s construction of reality (Shaffer, 1989).

Piaget proposed that the child’s reasoning in the pre-operational stage is dominated by personal experience. Egocentricity, circular reasoning and an inability to take another’s point of view are key characteristics. In the concrete-operational stage, a major development is proposed to occur in the child’s ability to differentiate between the self and others and between internal and external aspects of their experience (Laurendeau & Pinard, 1962, cited in Bibace & Walsh, 1980). Despite a limited capacity for logical thought, reasoning remains tied to the concrete experiences of the child. In the formal-operational stage, the capacity for abstract thought is held to emerge, with children developing a conceptual understanding of phenomena beyond their concrete experience (Piaget, 1952).
Research
Numerous studies have adopted a cognitive-developmental framework in their investigation of children’s understanding of illness (e.g. Berry, Hayford, Ross, Pachman & Lavigne, 1993; Bibace & Walsh, 1980; Brewster, 1982; Perrin & Gerrity, 1981). Such research has been based on the assumption that children’s reasoning about illness parallels the developmental sequence proposed for concepts of physical phenomena. In the main, studies have focused on healthy children’s understanding of specific illnesses (Bird & Podmore, 1990). A number of findings, consistent with Piagetian theory, have repeatedly been reported.

Concerning the pre-operational stage, children have been found to offer global and non-specific explanations for illness (Natapoff, 1978; Perrin & Gerrity, 1979, cited in Eiser, 1985), influenced by immediate physical or temporal relationships (Bibace & Walsh, 1980; Kister & Patterson, 1980; Perrin & Gerrity, 1981). Difficulty differentiating between the symptoms and causes of illness, and a reliance on external cues, have also been reported (Burbach & Peterson, 1986). Early studies suggested that children in this stage often blame themselves for illness, viewing symptoms (Brewster, 1982; Brodie, 1974, cited in Eiser, 1985; Cook, 1975, cited in Eiser, 1985; Langford, 1948) and medical treatment (Steward & Steward, 1981) as punishments for misdeeds. Other causal explanations include magic (Eiser, 1985), phenomenism (where a co-occurring object/event is perceived to be the cause of an illness, despite spatial and/or temporal distance) (Bibace & Walsh, 1980) and contagion (Bibace & Walsh, 1981).

In the concrete-operational stage, greater differentiation has been noted in children’s concepts of illness, in terms of both internal-external and self-other divisions (Laurendeau & Pinard, 1962, cited in Bibace & Walsh, 1980). Reported causal explanations include contamination and internalisation (where illness is recognised as being internal, but is assigned an external cause) (Bibace & Walsh, 1981).
An understanding of physiological and psychological causes of illness have been reported in the formal-operational stage (Bibace & Walsh, 1980). Notions of individual vulnerability to illness, and an awareness of the interaction between individual and environmental factors in triggering illness episodes, have been noted (Brewster, 1982). Older children have also been reported to employ more categories in their definitions of health and illness (Caradang, Folkins, Hines & Steward, 1979, cited in Eiser, 1985; Natapoff, 1978, cited in Eiser, 1985), to demonstrate greater ability to generalise from basic principles and to possess a more structured understanding of the causes and processes of illness (Perrin & Gerrity, 1979, cited in Eiser, 1985).

One widely cited study, based on Piagetian theory, is that of Bibace & Walsh (1980). In this study, children aged 4, 7 and 11 years were interviewed using direct questions about specific illnesses (e.g. What is a heart attack?) and their causes. Responses were coded according to Piaget's stages of cognitive development, with subdivisions being made within each category. The results reflected a developmental progression, with specific causal explanations predominating in each stage of development.

Among the 4 year olds, contagion was the most commonly cited explanation (54%). Only 34% of children mentioned contamination. Among the 7 year olds, contamination was discussed by 63% of children, with only 29% referring to internalisation. In contrast, 54% of 11 year olds discussed internalisation, with 34% mentioning physiological explanations. The study also found children’s perception of personal control over illness to increase in later stages of development. Bibace & Walsh (1981) concluded that these findings were consistent with Piaget’s theory of developmental stages.

A similar study, by Perrin & Gerrity (1981), yielded consistent findings. However, children’s concepts of illness were generally found to be less developed than their concepts of physical phenomena. This would appear to challenge the assumption of a general stage theory of cognitive development, upon which the above research is based.
Indeed, findings from the cognitive developmental research have often been inconsistent, as this review will now demonstrate.

Recent Research
Siegal (1988) suggested that previous studies had underestimated children's understanding of contagion and contamination (e.g. Bibace & Walsh, 1981; Kister & Patterson, 1980). This study involved asking children short, closed questions about video exerts or short stories concerning contamination and contagion as possible causes for illness. Siegal attributed his findings to the use this less threatening assessment method, which explored children's understanding of familiar ailments and minimised the potential for misunderstanding.

Siegal, Patty & Eiser (1990) failed to support the hypothesis that immanent justice constitutes a common causal explanation among 4-5 year olds. They concluded that young children possess a basic understanding of causal relationships which enables them to make logical inferences, based on the unobservable properties of objects (Gelman, Collman & Maccoby, 1986; Shultz, 1982). Consistent with Siegal (1988), the authors contended that children only employ immanent justice explanations if they are unclear about the illness being described, or if other causal explanations are not readily available. Siegal (1988) further proposed that immanent justice lies at the base of a hierarchy of causal explanations available to children, with rule selection being determined by contextual factors (e.g. parsimony) (see Shultz, Fisher, Pratt & Ruff, 1986).

Criticisms of Research
Despite the widespread application of Piaget's theory in exploring children's conceptualisation of illness, numerous criticisms have been made regarding both theory and research methodology. Firstly, studies have been criticised for their reliance on interview methods. Bibace & Walsh (1980) justified their use of Piaget's "clinical method" on it's application in previous research (Bernstein & Cowan, 1975, cited in Bibace &
Walsh, 1980). However, the method’s reliance on expressive and receptive language skills may preclude access to subtler aspects of the child’s understanding. Siegal et al. (1990) argued that children may “misunderstand the procedural requirements of the interview” (p.160). The traditional emphasis on assessing what children do not understand may also introduce confusion (Eiser & Kopel, 1997). Hence, the child’s responses may not reflect their actual understanding.

Direct questioning naturally imposes structure on the child’s responses (Eiser & Kopel, 1997), perhaps highlighting attributes which are not typically salient. Siegal et al. (1990) argued that questioning children about illness causality in the context of discussing the consequences of misdeeds, may cue them into immanent justice explanations. The use of verbal questioning may also restrict, or skew, responses, producing greater homogeneity in the data and increasing the likelihood of hypothesis confirmation (Eiser, 1985). Such bias raises questions regarding the reliability and validity of the resulting conclusions.

Scoring

Problems have also been encountered in scoring children’s responses. Myers-Vando, Steward, Folkins & Hines (1979) contended that the scoring for illness concepts has often been less complex than that for conservation tasks (used to assess developmental stage), yielding a lower ceiling effect for the former. Moreover, in fitting responses to predetermined categories, complexity of data is lost and the level of analysis reduced. Discrepancies in assigning causal explanations to a developmental stage have also complicated matters (Hergenrather & Rabinowitz, 1991).

Further methodological problems have included small sample sizes (Eiser, 1985), unclear measurement of variables, inadequate demographic information and failure to adequately address reliability and validity issues (Burbach & Peterson, 1986; Moss-Morris & Paterson, 1995). Additional research is needed to address such factors (Eiser, 1985).
Socio-cultural factors

A major theoretical criticism of the cognitive-developmental approach, is its failure to address the roles of personal experience and socio-cultural factors in the development of illness concepts (Paterson, et al., 1999). Social factors have been reported to influence the development of concepts within physical domains (Perret-Clermont, 1980), but few studies have explored social influences on illness concepts (Mechanic, 1964; Pratt, 1973). The influence of culture has similarly been neglected in the cognitive-developmental literature, despite studies reporting cultural differences in the structure of adult illness representations (Tan & Bishop, 1996) and in treatment choice (Quah & Bishop, 1996).

Illness Experience

Piaget (1952) proposed that cognitive development would be influenced by a child’s experience with a phenomenon and their associated emotional response. In relation to illness, he argued that children’s understanding would be enhanced by personal experience. Although early studies reported chronically ill children to have more advanced conceptualisations of illness than their healthy peers (Williams, 1978a,b, cited in Paterson et al., 1999), subsequent research has failed to support this relationship. Studies have typically reported either less advanced conceptualisations among chronically ill children (Cook, 1975, cited in Eiser, 1985; Eiser, Town & Tripp, 1988; Shangena, Snadler & Perrin, 1988), or no significant difference (Brewster, 1982; Myers-Vando et al., 1979; Young, McMurray, Rothery & Emery, 1987). Bibace & Walsh (1981) proposed that illness may involve emotional consequences which serve to inhibit or regress the child’s conceptual understanding.

Domain-specific Development

Performance on standard Piagetian tasks has typically been used to gauge the child’s developmental stage. However, intercorrelation between Piagetian tasks is poor and they seemingly fail to provide reliable measures of cognitive-developmental stage (Gelman & Baillargeon, 1983). Limited work also suggests that concepts of physical phenomena may
actually develop prior to those of health and illness (Perrin & Gerrity, 1979, cited in Eiser, 1985).

Shifts in cognitive development are believed to guide the internal organisation of domain knowledge. However, within domains, a differential level of understanding may exist for specific concepts (Carey, 1985; Gelman & Baillargeon, 1983; Nelson, 1986), depending on the child’s experiences. Hence, although cognitive development may reflect a natural progression, this may not involve distinct stages which are sequentially invariant and dependent on chronological age (see Flavell, 1985). These findings represent a challenge to Piaget’s universal theory of cognitive development and highlight the need for alternative frameworks in which to conceptualise children’s understanding of illness (Burbach & Peterson, 1986; Eiser, 1989). One proposal has been to focus on the structure of domain-specific knowledge (Carey, 1985; Gelman & Baillargeon, 1983) and to explore children’s implicit models of illness.

**Illness Representations Framework**

There is evidence to suggest that, in a similar way to adults, children’s emotional and behavioural responses to health threats are guided by their implicit models of illness (Goldman, Whitney-Saltiel, Granger & Rodin, 1991). In children with diabetes, for example, a relationship has been reported between the belief that diabetes is disruptive (the consequences) and poor metabolic control (Johnson, 1982, cited in Whitney-Saltiel, 1991). Similarly, both healthy and sick children who perceive illness as a punishment for misdeeds (the cause) have been reported to experience more guilt and negative emotion (Kister & Patterson, 1980). Such findings, along with adult research on illness representations, have encouraged researchers to adopt an illness representations framework with children.
Self-regulation Model

The concept of illness representations derives from Leventhal’s (1970) self-regulation/information processing model of health-related behaviour. Here, the individual’s health and illness beliefs are held to be a major determinant of their health-related behaviour (Leventhal, Diefenbach & Leventhal, 1992). The model is dynamic and interactive, in that health-related behaviours are viewed as the product of multiple factors, existing on multiple levels and having reciprocal causal relationships” (Bishop, 1995, pp 33).

Leventhal’s model (1970) incorporates a two level, parallel processing system. This consists of a cognitive level, dealing with the perceived reality of a health threat and an emotional level, concerned with the associated emotional responses. The model proposes that when faced with a health threat, the individual strives to generate meaning from their experience by integrating incoming information with existing cognitive structures for the object or event (Bishop, 1995). In this respect, the individual is perceived as an active problem solver (Bishop,1995; Diefenbach & Leventhal, 1996), seeking to derive meaning to inform subsequent action (Leventhal, Diefenbach & Leventhal, 1992). As can be seen, the model addresses some of the major limitations of the HBM.

Nature of Illness Representations

The term representation is used widely in the literature, but is rarely defined. In it’s most general sense, the term refers to a cognitive construct, used by the individual, to organise their understanding of an object or event. Moscovici (1984, p. 26), in discussing social representations, offers a functional definition. He states that “the act of re-presentation is a means of transferring what disturbs us, what threatens our universe, from the outside to the inside, from far off to near by”.

Theoretical concepts such as schemata, prototypes and concepts are also discussed in the literature, with no clear definition and apparent interchangeability. Little attempt has been
made to delineate conceptual similarities or differences (Paterson et al., 1999). In particular, the terms representation and schema are often interchanged. This is, perhaps, not surprising given the general definition of schemata as the ‘organised knowledge that a person has about given types of stimuli’ (Bishop, 1995, pp 34). Reference to cognitive psychology is required to clarify this issue and there is a need for researchers to be clear and precise in their use of terminology.

Similarly, ‘illness’ and ‘disease’ representations are referred to in the literature with apparent interchangeability. However, Diefenbach & Leventhal (1996) remind us of the conceptual distinction between these phenomena. A disease is “characterised by a set of signs and symptoms” on the basis of which a diagnosis may be made. Illness, on the other hand, involves social definition, requiring a shared recognition by the doctor, and others, that the individual is sick. Illness, therefore, incorporates psychological and social dimensions in the labelling process. Moreover, being ill does not require the presence of all the signs and symptoms of a specified disease (Kleinman, 1988).

**Clinical Importance**

Individual differences in adults’ representations of illness have suggested the need to address how these representations develop (Leventhal, Meyer & Nerenz, 1980; Leventhal, Nerenz & Steele, 1984). Illness representations are thought to be influenced by factors such as personal experience with illness, information derived from interactions with the health care system, and the socio-cultural context (Schiaffino, Shawaryn & Blum, 1998). Childhood represents a logical starting point for investigating how illness representations develop and the influence such factors may have.

Understanding how children conceptualise illness is also important for planning health education programs (Eiser, 1985). Health promotion with children is a valuable endeavour, as beliefs and behavioural patterns developed in childhood tend to endure into adulthood (Maddux, Roberts, Sleddin & Wright, 1986). Eiser & Koppel (1997) discussed
the importance of developing healthy behaviours in childhood as a major way of reducing morbidity in adulthood. Understanding children’s representations of illness also has clinical implications for work in paediatric settings, in terms of providing appropriate information to children. This can reduce distress and promote children’s involvement in treatment decision making (Eiser, 1990).

Structure of Representations

Studies exploring the internal structure of illness representations have typically adopted one of two approaches. The first has involved identifying the common components of illness representations (e.g. cause), whilst the second has addressed factors, or dimensions, along which these components may be organised (e.g. perceived vulnerability). Within the literature, the term dimension has been used to refer to both of the above, generating confusion as to what is being discussed. In this review, the term will be used to denote the structuring factors within components.

Components

Initial work by Leventhal and colleagues, with seriously or chronically ill individuals (Leventhal, et al., 1980; Leventhal, Nerenz & Strauss, 1982; Leventhal et al., 1984), generated four components, considered to be “the basic building blocks” of illness representations. These were:

(a) Identity - referring to bodily symptoms and their associated illness label.
(b) Cause - concerning beliefs about how the illness was contracted.
(c) Timeline - comprising predictions regarding the course and duration of the illness.
(d) Consequences - concerning perceptions of the immediate and long-term sequelae of the illness and it’s ultimate outcome.

Lau & Hartman (1983) identified these four components in a healthy sample, along with a ‘cure’ component, concerning recovery from illness. They proposed that Leventhal and
colleagues failed to find this component, because recovery may not be expected by those with a serious or chronic illness. Further studies have replicated Lau & Hartman's findings, using similar (Lau, Bernard & Harman, 1989) and different methodologies (Bishop, Briede, Cavazos et al., 1987).

**Factors**

Factor analytic studies have investigated possible dimensions along which the above components may be evaluated. Various solutions have been proposed. The following are cited by Bishop (1995). Jenkins (1966) identified a three factor solution, labelling the dimensions as personal involvement, social desirability and human mastery. Lau & Hartman (1983) yielded three factors from their analysis of the cause and cure components. These factors were labelled locus of control, stability and controllability. Turk, Rudy & Salovey (1986) conducted exploratory and confirmatory factor analyses, yielding a four factor solution, comprising seriousness, personal responsibility, controllability and changeability.

Although the findings from the two approaches appear to be conflicting, Bishop (1995) argued that they may "examine different, but complementary, aspects of the same phenomena" (Bishop, 1995, p.44). In fact, the two approaches differ in the basic assumptions underlying the studies (e.g. addressing content versus criteria for evaluating such content) and in the type of methodologies and analysis being applied (e.g. content analysis of free illness descriptions versus quantitative analysis of scale ratings).

**Children's Illness Representations**

The above work has been conducted solely with adult populations. It is therefore unclear whether the findings may be generalised to children's representations. In their study of children's understanding of illness, Bird & Podmore (1990) applied the illness representations framework. They interviewed children of two ages (5 and 9 years) regarding the identity, cause, consequences and prevention of four different 'illnesses':
cold, heart attack, broken arm and chicken pox. They found that older children generated more prevention strategies for heart attack and broken arm than younger children, with no significant differences for a cold or chicken pox. Older children also reported more observable and non-observable signs and symptoms for some illnesses, but there were differences across illness categories and between signs or symptoms. Younger children demonstrated some confusion between strategies for prevention and those for cure. The above differences were partially attributed to experience with illness. However, the finding that most younger children had experienced colds, but failed to use this experience when answering the questions about colds, suggested that the relationship is not straightforward.

The study failed to support cognitive-developmental research (Bibace & Walsh, 1980) in that younger children did not offer immanent justice explanations or overextend the notion of contagion. Moreover, younger children were able to use both internal and external factors in their explanations of illness. Bird & Podmore (1990) proposed that children's understanding of illness may be determined more by access to relevant information than by their cognitive-developmental stage.

Charman & Chandiramani (1995) employed a similar interview schedule to Bird & Podmore (1990), to investigate the structure of children's understanding of depression and chicken pox. Here, older children were reported to offer more comprehensive and mature conceptualisations for both depression and chicken pox. However, children in all age groups (5, 7 and 9 years) could name objective signs and observable and non-observable symptoms of both depression and chicken pox, with a significant age difference only with respect to non-observable symptoms of depression. These findings contrast with the cognitive-developmental literature and also more recent studies (Bird & Podmore, 1990), in that young children were able to describe non-observable symptoms of illness (e.g. psychological states). In addition, their responses were not egocentric and they did not overextended the notion of contamination.
These findings support previous research, emphasising the competencies of young children (Donaldson, 1978, cited in Siegal et al., 1990). In applying Nelson’s (1986) “script theory” and Carey’s (1985) theory of conceptual change to children’s understanding of illness, Eiser (1989) emphasised the view of children as active theoreticians, who are able to use available information to construct theories of illness and disease. In Charman & Chandiramani’s (1995) study, even the five year olds demonstrated basic, intact knowledge about illness. Differences in reasoning about depression and chicken pox were consistent with domain specific models of development and theories of conceptual change.

Carey (1985) proposed that cognitive development entails both the acquisition of knowledge and changes in the organisation of schemata. As children have less experience with depression, their theories would be expected to be less developed than those for familiar illnesses. The clinical implications of these findings is that children’s understanding in one area should not be assumed to parallel that in other areas.

**Organisation of Children’s Representations**

A study by Goldman et al. (1991) explored the structure of children’s illness representations, using a pre-school sample (4-5 years). Adopting ‘a priori’ hypotheses from theoretical models and empirical findings from the adult literature (e.g. Bishop et al., 1987; Leventhal et al., 1980), they offered preliminary evidence to suggest that children’s representations incorporate the five characteristic attributes of adult’s representations. They speculated that children may possess representations which are similar in structure to those of adults, but less mature and informed. No relationship was found between the five attributes, in terms of the level of reasoning or complexity of response. Although the lack of a relationship may be attributable to a small sample size, the findings support the contention that different levels of reasoning may exist for specific concepts within a domain (Carey, 1985; Gelman & Baillargeon, 1983). In this study, for example, children appeared to possess a more developed understanding of illness cure than cause.
A major criticism of the study was that children were cued into each of the five illness attributes by direct questioning. Although children may be able to consider these attributes with regard to illness, they may not actually constitute salient features of their representations. Hence, the need for research which does not employ a priori hypotheses regarding the latent variables underlying children’s illness representations.

Methodological Limitations
There have been a number of problems with the studies conducted within the illness representations framework. Despite criticisms of the cognitive-developmental framework, many studies have continued to use Piaget’s developmental stages as the basis for coding responses (e.g. Bird & Podmore, 1990). The limitations of this approach were discussed earlier. Many studies have also continued to employ verbal methods of assessment, which are constrained by the child’s comprehension and their expressive language abilities (Charman & Chandiramani, 1995).

Researchers have also tended to select illnesses by their use in previous studies (Bird & Podmore, 1990). Although these may constitute common childhood experiences (e.g. cold, chicken pox), they may not represent the most salient and meaningful items for children. Moreover, participants may be unfamiliar with the terms being used (e.g. depression, Charman & Chandiramani, 1995). Burt & Oaksford (1999) have criticised the use of ‘armchair induction’ methods, advocating the use of qualitative methods (e.g. grounded theory, Glaser & Strauss, 1967, cited in Burt & Oaksford, 1999) for generating hypotheses.

Despite the recognised importance of social and cultural factors in the development of children’s illness representations (Eiser & Kopel, 1997), these factors have been largely ignored in existing research. Studies have typically recruited Caucasian, middle class samples, limiting the generalisability of findings.
Summary & Future Research

This review has examined the research on children's conceptualisations of illness. The majority of studies have been conducted within a cognitive-developmental framework. Criticisms of this approach have generated doubt as to the reliability and validity of the conclusions drawn by these studies. Hence the adoption of alternative approaches, including an illness representations framework. At present, data suggest that children's representations of illness increase in complexity and maturity as cognitive abilities develop, although the timing and process of development does not appear to be fixed. Maturational factors alone fail to explain individual differences in illness representations, highlighting the need to investigate additional factors which may influence their acquisition and development. In particular, the roles played by social and cultural influences and direct illness experience require delineation.

There is a recognised need for the use of qualitative research methods, which could yield richer and more complex information pertaining to the development of illness representations. Clarification of what children understand by the term 'illness' is also required, in addition to work on the underlying attributes or dimensions which form the structure of children's illness representations. Finally, there is a need for researchers to be clear in their use and definition of terms such as concepts, schemata and representations and to highlight conceptual differences between them.
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Major Research Project

A qualitative study exploring children's illness representations:
A developmental and cultural perspective

Year 3
August 2000
Abstract

The present study comprised a qualitative exploration of the salient components of children's illness representations. The relative influences of cognitive development and ethnic background on children's representations were examined. Leventhal's self-regulation model of illness representations (Leventhal, 1970) provided the theoretical framework for the investigation.

40 school children were recruited for the study. Two age groups (8-9 and 10-11 years) and two ethnic groups (white British and black African/Caribbean) were included. Participants were asked to complete two structured card sorts and a maximum of two free sorts, with 24 illnesses. The structured sorts related to children's self-rated knowledge of, and experience with, the illnesses. In the free sort condition, children selected their own criteria for sorting the cards and were asked to verbally explain their reasons for grouping illnesses together. Data were analysed using non-parametric statistics, multidimensional scaling analysis and content analysis.

Important similarities were identified across children with respect to the salient components of their illness representations. The most common basis for grouping illnesses together was that of illness identity, and in particular, the symptoms of illness. Groupings were also formed on the basis of the causes and consequences of illness, although these were mentioned less frequently, and by fewer children, than identity. The findings suggest that 'identity', 'cause' and 'consequences' constitute the most salient features of children's illness representations between the ages of 8-11 years. Regarding cultural differences, children of black African/Caribbean ethnicity were more likely to refer to 'illness cause' and 'personal vulnerability to illness' than their white British peers. This would suggest that important differences may exist in the saliency of individual illness components for children from the two ethnic backgrounds.
The findings from the study have clinical implications for work in paediatric and health promotion settings. Health-related interventions with children need to consider that between the ages of 8 and 11 years, children are most concerned with the symptoms of illness, with some focus being on causes and consequences. As such, communication which emphasises these aspects is most likely to be of relevance to children. Differences in the saliency of components for children of white British and black African/Caribbean ethnicity highlight the need for culturally tailored interventions.
Introduction

Understanding how children conceptualise illness is important for health-related work with both clinical and non-clinical child populations. In paediatric settings, such information can assist professionals in communicating with children regarding their illness and the treatment they require. Effective and appropriate communication has consistently been emphasised within the literature, as a means of reducing distress, promoting self-management behaviours and facilitating children's participation in treatment decision-making (Eiser, 1984; Eiser, 1990; Potter & Roberts, 1984). The current lack of theoretical and empirical guidance concerning what information to provide, has been attributed to our limited understanding of the actual thoughts and concerns of sick children (Eiser, 1984). Much of the information available for health-care professionals is based on research conducted during the 1970's, which has since received much criticism (e.g. Burbach & Peterson, 1986). As such, there is a need for further research in this area to advance our understanding and to provide guidance for health care professionals communicating with children about illness.

In discussing illness with sick children, there has been a tendency for health professionals to focus on biological explanations of the condition involved. It has been suggested, however, that such explanations may appear irrelevant to children and may neglect aspects of illness which are more salient for them (Whaley, 1999). Solomon (1986) suggested that being reassured as to the normality of their experience may constitute a more pressing concern for children. She suggested that explanations which address this concern, by describing the child's experience as it is, may be most preferable for children.

The negative consequences (e.g. non-adherence to treatment protocols) of a mismatch between the illness models of patient and health-care professional have been discussed with respect to adult populations (Kleinman, Eisenberg & Good, 1978). Similar consequences could be expected to result from a mismatch between the illness models of children and paediatric staff. As such, there is a need to extend our understanding of how
children conceptualise illness and to identify the aspects which are most salient for them (Whaley, 1999).

Understanding how children conceptualise illness is also important for the development and implementation of health promotion programmes in schools (Eiser, 1985). The acquisition of healthy behaviours in childhood has been recommended as a major way of reducing adult morbidity (Maddux, Roberts, Sledden & Wright, 1986). In order for such programmes to be effective, they need to be developmentally appropriate in language and content (Eiser, 1985), but also personally relevant to children (Whaley, 1999). Whaley (1999) has emphasised the importance of providing personally relevant information for children, to increase the likelihood that the information will be processed and elaborated upon (Johnson & Eagly, 1989; 1990). However, the provision of such information is dependent on knowing which features of illness are most salient for children.

**Definition of ‘Illness’**

Before going on to discuss the literature concerning children’s concepts of illness, it is important to define what we mean by the term ‘illness’. Within the literature, there has been a tendency to neglect the conceptual distinction between the terms ‘illness’ and ‘disease’ and to use the words interchangeably. However, Diefenbach & Leventhal (1996) highlight important differences between the two, with respect to the domains in which they operate, and the basis on which they are defined.

The term ‘disease’ operates predominately within the medical domain, and refers to a condition characterised by “a set of physical signs and symptoms” (Diefenbach & Leventhal, 1996, pp 13). In contrast, ‘illness’ is suggested to operate within the social domain, being defined by an agreement between the doctor and family that the individual is sick (Diefenbach & Leventhal, 1991). Being ill, therefore, is not dependent on the presence of disease (Kleinman, 1988). The term ‘illness’ has been used throughout this document for consistency, despite some of the phenomena fitting the criteria for disease.
Historical Background
To illustrate the rationale for the present study, a brief review of the research on children’s concepts of illness will be provided. This will included discussion of the theoretical models which have been applied, methodological limitations of the studies and questions which remain unaddressed.

Research on how children conceptualise illness has traditionally been approached from a developmental perspective, founded upon Piaget’s (1930) theory of cognitive development. Piaget proposed that children’s concepts of physical phenomena (e.g. space, time) evolve according to an ordered and invariant developmental sequence of stages (Piaget, 1970). Progression through the developmental stages was proposed to promote increasing conceptual understanding, greater distinction between self-other and internal-external divides and a move from global, undifferentiated ideas to abstract reasoning (Bird & Podmore, 1990).

Cognitive developmental studies have attempted to show that children’s concepts of illness develop according to the sequence proposed for concepts of physical phenomena (Piaget, 1952). A number of findings, consistent with Piaget’s theory of developmental stages, have repeatedly been reported, supporting the conclusion that children’s concepts of illness follow the developmental stage model outlined by Piaget (Bibace & Walsh, 1980; Perrin & Gerrity, 1979). However, recent studies have failed to support the proposition of distinct and invariant universal stages in children’s concepts of illness (Siegal, 1988; Siegal, Patty & Eiser, 1990). Moreover, criticisms have been made of both the theoretical framework (see Gelman & Baillargeon, 1983, Nelson, 1986) and research methodologies employed in the cognitive developmental studies (see Burbach & Peterson, 1986), prompting a search for alternative frameworks (e.g. script theory, Nelson, 1986) in which to view the findings.
Criticisms of Research

A thorough review of the cognitive developmental literature and its limitations is beyond the scope of the present study. A detailed account and critique of the research and its theoretical framework is provided in the literature review on children's representations of illness (Chorlton, 1999), contained within the present volume. In order to set the context for the present study, three principal areas of difficulty are briefly discussed. These concern the use of interview methods of assessment, failure to account for individual differences in children's illness concepts and a lack of support for general stage theories of cognitive development.

Assessment Methods

A major criticism of the cognitive developmental research is the reliance on interview methods of data collection. Such methods are argued to limit or bias the responses of participants through the constraints imposed by immature expressive and receptive language skills and through the potential for direct questioning to introduce or encourage particular response sets (Eiser, 1985; Eiser & Kopel, 1997; Paterson, Moss-Morris & Butler, 1999; Siegal et al, 1990). These concerns have highlighted the need to develop alternative methodologies for studying children's concepts of illness (Burbach & Peterson, 1986; Eiser, 1989; Siegal et al., 1990), which are less reliant on language abilities (Eiser & Kopel, 1997).

Illness Experience

A second criticism of Piagetian-based research has been the failure to fully account for individual differences in the sophistication of children's illness concepts in terms of cognitive development (Paterson et al., 1999). This finding has caused some researchers to investigate the role played by illness experience. A number of studies have demonstrated a relationship between a child's experience of a particular illness and the sophistication of their concepts for that illness (Crisp, Ungerer & Goodnow, 1996; Paterson et al., 1999). Such findings highlight the importance of factors other than cognitive development in the
evolution of children's illness concepts. Factors which need further investigation are illness experience and socio-cultural factors.

**Socio-cultural Factors**

The influence of social and cultural factors has been largely neglected within the cognitive developmental literature (Paterson, et al., 1999). Within the physical domain, social factors have been found to influence the development of children's concepts (Perret-Clermont, 1980). However, few studies have explored their influence with respect to illness (Mechanic, 1964; Pratt, 1973). Similarly, the majority of research has conducted with Caucasian children, despite the fact that children from other ethnic backgrounds may be at increased risk of contracting certain diseases (e.g. AIDS, sickle cell anaemia) (Eiser & Kopel, 1997). Failure to understand how children from different cultures conceptualise illness may compromise efforts to support children and their families in dealing with health threats (Eiser & Kopel, 1997), and impede access to, or utilisation of, health care services.

**Domain-specific Development**

Finally, a number of problems have been identified with the measurement of cognitive developmental stage. The standard practice within studies has been to estimate developmental stage on the basis of a child's performance on standard Piagetian tasks (e.g. conservation, perspective taking) (Hergenrather & Rabinowitz, 1991). However, intercorrelation between the Piagetian tasks tends to be poor, suggesting that individually, they constitute unreliable measures of cognitive development (Gelman & Baillargeon, 1983). Research has also suggested that concepts of physical phenomena may develop prior to those of health and illness (cf Perrin & Gerrity, 1979), hence questioning the use of such methods and challenging the premise on which universal theories of cognitive development are based.

Domain-specific theories of cognitive development offer an alternative framework in which the above findings can be viewed. Such theories accept that children's concepts of
phenomena reflect a natural progression over the course of development, with shifts in
cognitive development guiding the organisation of knowledge within domains. However,
they dismiss the notion of distinct developmental stages of conceptual understanding,
which are dependent on chronological age (see Flavell, 1985). The theories propose that
children may possess different levels of understanding for specific concepts within a
domain (Carey, 1985; Gelman & Baillargeon, 1983; Nelson, 1986), dependent on their
experience in that area. Nelson's (1986) script theory offers an explanation of how illness-
related experience may influence the development of children's conceptualisation of
illness.

Recent research
Criticisms of the cognitive developmental approach, methodological limitations and
inconsistent findings, have highlighted the need for alternative theoretical and
methodological approaches in this area. Domain-specific theories recommend a focus on
the structure of domain-specific knowledge (Carey, 1985; Gelman & Baillargeon, 1983)
and the exploration of children's implicit models of illness. The suggestion to apply
Leventhal's (1970) self-regulation model of adult illness representations to child
populations is consistent with this proposal. However, few studies have actually adopted
this framework for studying children's concepts of illness.

Self-regulation Model
Leventhal's self-regulation model of health-related behaviour is discussed in detail in the
review on children's illness representations (Chorlton, 1999). A brief description is
presented here to set the context for the present study. Leventhal's model proposes a two
level parallel processing system, concerned with the management of cognitive and
emotional information pertaining to a perceived health threat. Central to the model is the
notion of illness representations, which enable the individual to compare and integrate
incoming information with previous experience, to generate meaning and to determine
appropriate action. Various definitions have been offered of illness representations, Within
the present study, however, the term is used in it's broadest sense, to refer to 'a cognitive construct', used by the individual, to organise their understanding of an object or event (Diefenbach & Leventhal, 1996).

**Illness Representations**

Illness representations are proposed to be influenced by factors such as personal experience with illness, information derived from interactions with the health care system, and the socio-cultural context (Schiaffino, Shawaryn & Blum, 1998). As such, the model offers the opportunity to account for the individual differences observed in adults’ and children’s concepts of illness. It also emphasises the importance of socio-cultural factors, which has been neglected within the cognitive developmental literature.

**Structure of Representations**

Much of the research on illness representations has focused on identifying the common features of their structure. Five principal components, described as “the basic building blocks” of illness representations, have repeatedly been found (Bishop, Briede, Cavazos, Grotzinger & McMahon, 1987; Lau, Bernard & Hartman, 1989; Lau & Hartman, 1983), in healthy adult populations and in individuals with acute or chronic disease (Bishop, 1991; Lau et al., 1989; Leventhal & Diefenbach, 1991). These components are:

(a) *Identity* - referring to bodily symptoms and their associated illness label.
(b) *Cause* - concerning beliefs about how the illness was contracted.
(c) *Timeline* - comprising predictions regarding the course and duration of the illness.
(d) *Consequences* - concerning perceptions of the immediate and long-term sequelae of the illness and it’s ultimate outcome.
(e) *Cure* - concerning recovery from illness.

In addition to the above, factor analytic studies have suggested several dimensions which may be contained within the above components. These include the following: personal
involvement, social desirability and human mastery reported by Jenkins (1966); seriousness, personal responsibility, controllability, changeability found by Turk, Rudy & Salovey (1986); and locus of control, stability and controllability discovered by Lau & Hartman (1983). For further discussion of the relationship between the components and dimensions of illness representations, see Chorlton (1999).

In relation to the above, Hampson and colleagues (Hampson, Glasgow & Toobert, 1990; Hampson, Glasgow & Zeiss, 1994) have reported the presence of a ‘seriousness’ component in the personal illness models of individuals with chronic illness. Their findings suggest that this construct may reflect a composite of Leventhal’s timeline and consequences components. They concluded that Leventhal’s five components may not actually reflect separate and independent constructs and that the five component structure may not constitute the optimum representation of personal models of illness (Hampson, 1997). Their findings suggested that a more accurate illness representations structure for arthritis may comprise three components (intensity, cause and treatment effectiveness) (Hampson, 1997). These findings represent a challenge to the widespread acceptance and application of Leventhal’s five factor structure in previous studies.

**Children’s Illness Representations**

Studies which have applied the illness representations framework to children have tended to adopt the five component model and have explored children’s understanding within each component. Preliminary findings from two studies involving primary school children have failed to support the cognitive developmental research and have suggested that children may possess different levels of understanding for specific concepts within a domain (Bird & Podmore, 1990; Charman & Chandiramani, 1995). A study by Goldman and colleagues (Goldman, Whitney-Saltiel, Granger & Rodin, 1991) found no relationship between children’s levels of reasoning regarding individual illness components, again suggesting that different levels of reasoning may exist for specific concepts within a domain (Carey, 1985; Gelman & Baillargeon, 1983).
One explanation for these findings is that children's understanding of illness may be more determined by access to illness information (e.g. through personal experience of illness, episodic memory processes) than by cognitive developmental stage (Bird & Podmore, 1990). Such findings are consistent with domain-specific theories of cognitive development and Nelson's script theory (Nelson, 1986). They also highlight the active role children play in integrating available information to construct theories of illness (Eiser, 1989).

Methodological Problems

Relevance of 'a priori' assumptions

Preliminary evidence would appear to suggest that the illness representations framework offers a promising alternative to the cognitive developmental approach for studying children's concepts of illness. However, methodological limitations of previous research and gaps within the literature necessitate that changes be made to investigation in this area. The first difficulty is that previous studies have tended to apply 'a priori' hypotheses from Leventhal's model in developing interview questions to assess children's understanding of illness (e.g. Goldman et al., 1991). This approach has been criticised for cueing children into each of the five illness components, rather than focusing on aspects which are salient for them. Studies which do not apply 'a priori' hypotheses regarding the latent variables underlying children's illness representations are required. Burt & Oaksford (1999) recommend the use of qualitative methods (e.g. grounded theory, Glaser & Strauss, 1967) to generate hypotheses, guarding against the use of 'armchair induction'.

Interview methods of assessment

A second problem with the research has been the continued reliance on interview methods of assessment. As discussed earlier, such methods are constrained by the child's expressive and receptive language abilities (Charman & Chandiramani, 1995) and by the tendency to cue children into certain response sets. The need to employ alternative methods of assessment is widely recognised (e.g. Eiser, 1989). A method which has been used with
adult populations, that may have relevance for research with children, is the card sort procedure (Hampson, Glasgow & Zeiss, 1996).

Card sort methods of assessment
Card sort procedures have been little used in research with child populations. A review of the literature from the past 15 years yielded one study which had employed a card sort task to examine children’s perceptions of themselves in comparison with their siblings (Graham-Berman, 1991). Two further studies had employed a dimensional change (colour-shape) card sort to examine the influence of rule use on behaviour in pre-school children (age 3-4 years) (Zelazo, Frye & Rapus, 1996) and adults with learning disabilities (Zelazo, Burack, Benedetto & Frye, 1996). Card sort procedures have also been employed clinically with adults with a learning disability (El-Leithy & Webb, 1998). The limited use of card sort procedures in research with children offered the opportunity to test the viability of the approach in the present study.

Socio-cultural influences
Despite the finding of cultural differences in the illness representations of adults (Tan & Bishop, 1996), the influence of cultural factors has continued to be neglected in research with children (Eiser & Kopel, 1997). The recruitment of participants from Caucasian, middle class populations has limited the generalisability of findings and has failed to address these potentially important influences on the illness experience of children. As such, the influence of these factors needs to be addressed in future studies.

Relevance of illnesses for children
Finally, in selecting the illnesses to be considered in a study, researchers appear to have relied on items which have been used in previous studies (Bird & Podmore, 1990). Although these illnesses may constitute common childhood experiences (e.g. cold, chicken pox), they may not constitute the most salient and meaningful items for children. Moreover, participants may be unfamiliar with the labels being used, hence limiting their
ability to communicate the extent of their knowledge (e.g. depression, Charman & Chandiramani, 1995).

Research Questions
The literature on children’s representations of illness has yet to adequately address a number of key questions. Firstly, what are the principal components of children’s illness representations? Research in this area would help determine whether or not the five components of Leventhal’s model are applicable to child populations. Secondly, which features of illness are most salient for children? Such information would enable professionals to provide health-related communication which is of relevance to children. Thirdly, do factors such as cognitive development and socio-cultural background influence which components are most salient for children? If so, there is a need for interventions to be individually tailored, to be developmentally and culturally appropriate.

Present Study
The present study represented an attempt to apply qualitative research methods to the exploration of children’s representations of illness. The aim was to investigate the above questions with respect to the salient features of children’s illness representations. Developmental differences were examined to allow comparison with the cognitive developmental research and domain specific theories of development. The role of cultural factors, in the form of ethnic background, was investigated as research has indicated the influence of culture on adult illness representations. The limited scope of the present study prevented a full investigation of the roles played by social factors and illness experience.

Attempts were made to overcome some of the methodological criticisms of previous research. A card sort methodology was applied to avoid the problems associated with interview methods of assessment. The study, therefore, comprised a test of the viability of card sort procedures for studying children’s conceptual understanding. Finally, the illnesses selected for use in the study were generated through focus groups with children
of the relevant age and ethnicity to participants. This represented an attempt to ensure the relevance and meaningfulness of the items for children and to avoid imposing adult views and terminology on children.
Method

Participants
Participants were recruited from the year 4 (age 8-9 years) and year 6 (age 10-11 years) classes of two outer London primary schools. Together, these schools were deemed to reflect a cross-section of socio-economic status and ethnic background. Consent was obtained from the headteachers regarding the participation of the school in the study. Parental consent for children's participation was obtained through an opt-in procedure.

Exclusion Criteria
Children were excluded from the study if:-

- they suffered from a chronic illness requiring frequent hospitalisation, or hospital based treatment;
- they had been at the school for less than 1 year;
- they had insufficient receptive English language to fully understand the requirements of the interview, including the vocabulary used in the test materials (a raw score of 51 on the BPVS-II, age equivalence of 5 years, was used as the cut-off point);
- the child was recognised as having as having special learning needs.

Demographic Information
40 participants were recruited from the 110 children in the four target classes. This sample size was selected due to the exploratory nature of the study and the feasibility of conducting individual interviews with each participant within the constraints of the study. 20 children were recruited from the year 4 classes and 20 from the year 6 classes. 10 children from each year were of white British/Irish ethnicity and 10 of black African/Caribbean ethnicity. 22 children were recruited from School A and 18 from School B. The difference between schools was due to the small number of children of black African/Caribbean ethnicity in one year 6 class.
Representativeness of the Sample
The male:female ratio for participants was 3:5, compared to an overall ratio of 2:3 for the four classes. Chi-square analysis revealed that this difference was not significant ($\chi^2 = 0.067$, $p = 0.796$). 22.5% of participants received free school lunches, compared to an overall figure of 30% for the four classes. Chi-square analysis revealed that this difference was not significant ($\chi^2 = 0.722$, $p = 0.396$).

To draw firm conclusions regarding the representativeness of the sample, further comparison on the variables of personal and family illness history, experiences of hospitalisation and family composition, would have been necessary. Such comparison was not possible in the present study, since consent for access to school records had not been obtained from the parents of non-participants. Moreover, the qualitative nature of the study was thought to mitigate the need for establishing representativeness.

Ethnicity of Participants
The ethnicity of participants was determined through reference to demographic information held at the schools. This information comprised parental reports of the child's ethnicity. Within the white British group, 17 children were identified as being English, Welsh or Scottish and three as Irish. Within the black African/Caribbean group, 12 children were identified as being Black African, seven as Black Caribbean and one as Black Other.

The mean ages for the white British and black African/Caribbean children in year 4 were 8.66 (s.d. = 0.313) and 8.56 years (s.d. = 0.286) respectively. In year 6, the mean ages were 10.68 (s.d. = 0.218) and 10.65 years (0.242) respectively. An ANOVA revealed no significant effect for ethnic group with respect to chronological age ($F = 0.622$, 1df, $p = 0.436$). Chi-square tests revealed no significant ethnic group differences for sex ratio ($\chi^2 = 0.107$, $p = 0.744$) and incidence of single parent families ($\chi^2 = 0.533$, $p = 0.465$). A two-
tailed Fisher's exact test yielded no significant ethnic group difference for receipt of free school lunches (\( p = 1.00 \)).

**School Year**

The mean chronological age for year 4 children was 8.61 years (s.d. = 0.30) and for year 6 children was 10.67 years (s.d. = 0.22). As expected, an ANOVA yielded a significant effect for school year (\( F = 591.97, 1 \) d.f., \( p = 0.000 \)). Chi-square tests revealed no significant year effect for sex ratio (\( \chi^2 = 0.107, p = 0.744 \)) or incidence of single parent families (\( \chi^2 = 0.533, p = 0.465 \)). A Fisher's exact test yielded no significant year difference for receipt of free school lunches (\( p = 1.00 \)).

**Group comparability**

As no significant year or ethnic group differences were found for the above demographic variables, the four groups of children could be compared in subsequent analyses, with confidence that demographic differences were not responsible for any significant findings.

**Measures**

1. **Demographic Information**

Participants were asked a set of questions to elicit information concerning family background and personal, or family experience of hospitalisation, due to illness (Appendix 1). Information regarding socio-economic status, ethnicity and reading age was obtained from records held at the school.

2. **Card Sort**

A card sort task was devised to examine participants' views on the differences and similarities between 24 illnesses and to explore the basis on which comparisons were made. The items used in the study were generated through focus groups with children of the relevant age. This method was employed to ensure that the illnesses would be meaningful for the participants in the study and that the appropriate terminology was used. Focus group participants were selected from school B and from an additional school...
outside of the London area. Pupils from school B who participated in the focus groups were excluded from participating in the main study.

**Focus Groups**

Four focus groups were conducted, each comprising 8-10 children. A range of ethnic backgrounds, socio-economic status and cognitive ability were represented. Within the groups, children were asked to name as many ‘illnesses, diseases, or things which could make people feel sick, hurt or unwell’, as they could think of. Notes were taken by a field researcher and the discussions were tape-recorded, to prevent items being missed.

Following the focus groups, a list was generated of all the illnesses which had been mentioned. Items which had been discussed by children from at least three of the four focus groups were selected for use in the study. This yielded a total of 25 illnesses (see Appendix 2). However, the decision was made to remove ‘leprosy’ from the study, due to the rarity of this condition in Britain. Moreover, the item appeared to have been made more salient for children in two focus groups, due to it being discussed in their humanities lesson the previous week. To verify the relevance of the final 24 illnesses for participants in the study, the card sort was piloted with four children. This is discussed later.

**Structured Card Sort**

The card sort task comprised two components. The first required participants to complete two structured card sorts, according to criteria specified by the researcher. These sorts concerned the participant’s knowledge of, and experience with, the illnesses. Concerning knowledge, participants were asked to sort the illnesses under the headings “I know a lot about it”, “I know a bit about it”, “I have heard of it, but don’t know anything about it” and “I have never heard of it before”.

This task examined participants’ perceptions of their knowledge, rather than the accuracy of their understanding, or the information they possessed. The emphasis was on self-rating
for several reasons. Firstly, assessing the accuracy, or content, of children’s knowledge would require a detailed interview with participants regarding individual illnesses. This was beyond the scope of the present study. Secondly, the study represented an attempt to move away from interview methods of assessment. Finally, a self-rating approach was believed to be more compatible with an exploratory study investigating children’s thoughts and beliefs about illness.

The second structured sort related to participants’ personal experience of the illnesses. Children were asked to place the illnesses under the headings “I have had this myself”, “I have not had this myself, but someone in my family has had it”, “No one in my family has had it, but a friend has had it” and “I don’t know anyone who has had it”. This assessed children’s perceptions of their experience, rather than their actual experience, since contact with an illness was not thought to necessarily equate with the saliency of that experience for the child, and the integration of the experience into episodic memory. Moreover, the nature of the present enquiry precluded the collection of information concerning the actual illness history of participants and their families.

Free Card Sort

The second component of the card sort was a free sort condition, where participants selected their own criteria for sorting the illnesses. The purpose of this task was to identify the criteria, or illness features, that participants used to sort the items. The task also allowed exploration of the perceived similarities and differences between the illnesses. Any items which the child had placed in the “I have never heard of it” category for the structured sort for knowledge were excluded from the free sort, as the child was presumed to lack the necessary information to compare this illness with others in the sort.

Multiple sorting procedures are a recommended method for the “flexible exploration of conceptual systems at the individual or group level” (Canter, Brown & Groat, 1985). They are of particular value in identifying the categories used by individuals to order their understanding of a phenomenon, or to compare particular instances according to similarities and differences. Of relevance to the present study, and the examination of
developmental and cultural differences, is the applicability of multiple sorting procedures for analysing between group differences.

Reliability
Given the dearth of literature on the use of card sort procedures in research, issues concerning the reliability of these methods have yet to be addressed (Canter, Brown & Groat, 1985). Canter et al (1985) have suggested that for stable individuals, repeated administration of a card sort task across two, or three occasions, would probably yield reliable responses, unless the procedure itself enhanced participants’ understanding of the conceptual system under investigation. In the present study, the card sort procedure was not expected to influence participants’ conceptual systems for illness. Given the above factors, the study was not extended to exploring the reliability of the card sort procedure.

3. Estimating Cognitive Development
The British Picture Vocabulary Scale (2nd Edition) (BPVS-II) (Whetton, 1997), a measure of receptive (hearing) vocabulary for English language, was administered to provide an estimate of cognitive development. Scores on this test were compared with the participant’s performance on a reading age test, conducted by class teachers in July 1999 (3 months prior to data collection) to examine the degree of correspondence. The BPVS-II involves the presentation of four simple black and white pictures in conjunction with a spoken stimulus word. Participants are requested to point to, or say the number of, the picture which matches the stimulus word. The value of the BPVS-II, as an assessment tool for both clinical and research purposes, is widely recognised (Whetton, 1997). The corrected split-half reliability for the BPVS-II is 0.86, with a test-retest reliability of 0.75. The test is considered to possess content and construct validity and reflects an improvement from the original BPVS, in that the risk of floor and ceiling effects is reduced, and the test requires shorter administration time (Whetton, 1997).
Standardised scores, percentile ranks and age equivalent scores for the test can be calculated from an individual's overall test score, using the norms provided. Separate norms are available for children where English is the second language. In the present study, the performance of black African/Caribbean participants on the BPVS-II was not found to differ significantly from white British participants. As such, the same norms were used for both groups.

**Pilot Work**

The card sorts were piloted with four children prior to the commencement of the study. The aim of the pilot work was to verify the relevance of the illness items for children of 8-11 years and to ensure that children across the range of cognitive ability could follow the procedural requirements of the interview. It was also important to establish that children could successfully differentiate between illnesses in the free sort condition and could offer some explanation of their reasons for grouping cards together. A summary of the pilot data is presented in Table 1.

<table>
<thead>
<tr>
<th>Child</th>
<th>Age</th>
<th>Ethnicity</th>
<th>BPVS-II estimated age</th>
<th>No. of items never heard of</th>
<th>No. of free sorts</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>7 years 10 months</td>
<td>white British</td>
<td>10.11</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td>2</td>
<td>10 years 11 months</td>
<td>white British</td>
<td>10.01</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>3</td>
<td>7 years 11 months</td>
<td>Indian</td>
<td>9.08</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>4</td>
<td>8 years</td>
<td>white British</td>
<td>7.09</td>
<td>7</td>
<td>1</td>
</tr>
</tbody>
</table>

All four children in the pilot study were able to complete the structured card sorts and at least one free sort. The number of free sorts ranged from one to three. Children reported having never heard of between one and seven of the illnesses. The only item which all four children reported having never heard of was meningitis. Given the recent concerns regarding meningitis, and the various education efforts which have been undertaken within schools and through the media, this item was retained in the main study. The remaining
illnesses were also retained, since their exclusion would have restricted the number of items to be sorted, and reduced the potential for measuring individual differences. Based on the average number of sorts completed in the free sort condition, and the time taken to complete each one, a maximum limit of two free sorts was adopted for the main study.

**Procedure**

The procedures for the present study were approved by the University of Surrey Ethics Committee and were agreed in consultation with headteachers from the two primary schools.

**Recruitment**

Recruitment letters, with an accompanying consent form, were sent to the parents of all children in the four target classes. The letter outlined the purpose and nature of the study, the tasks to be completed by participants and issues of confidentiality (see Appendix 3). The letter was sent to all parents, covering a wide range of ethnic backgrounds, to ensure that the final procedure and test materials could be further piloted, prior to data collection. Parents were asked to indicate their decision regarding their child’s participation in the study by signing and returning the consent form to the researcher, using the envelope provided. In the case of insufficient response rates, a follow-up letter or a phone call from the headteacher was employed.

All children for whom consent was received participated in the pilot work or the main study. Children who did not fall within the targeted ethnic groups were asked to complete the card sort task and to answer the questions regarding demographic information. This was to establish the meaningfulness of the illness items for children within these schools and from this geographical area. The pilot work was also to ensure that individual differences could be detected by the free sort condition.
Interview

The interviews with participants followed a standard format of demographic questions, BPVS-II assessment, structured card sorts, and free card sorts. The assessment was conducted in the same order for each participant, since BPVS performance related to inclusion in the study.

Instructions for the card sort tasks are presented in Appendix 4. In the structured sorts, the names of individual illnesses were read aloud to children, to ensure accurate perception of the items. In the free sort condition, items were read aloud to participants on request. Following each sort, the illnesses in each group were read aloud to participants, to verify that they were satisfied with the sort. Illnesses could be reallocated to different groups at this stage, if the child expressed a desire to do so. In the free sort condition, participants were asked to explain their reasons for grouping items together.

Debriefing

Following the interview, participants were asked to consider the relative value of different courses of action in response to illness (see Appendix 5). This task was included to highlight the potential for personal agency in relation to recovery from illness. Participants were asked whether they had any questions or concerns regarding the study, or the tasks they had completed. They were thanked for their participation. Letters were also sent to the parents of children who took part in the pilot work and the main study, thanking them for their consent and outlining the tasks their child had completed (see Appendix 6).

Data Analysis

Quantitative Analysis

Non-parametric statistics were used to analyse the demographic and structured card sort data. The decision to use non-parametric, rather than parametric tests, was made on the basis of the small sample size and the presence of ordinal and nominal levels of measurement for the majority of variables under consideration. Despite debate within the
literature concerning the use of parametric tests with ordinal level data (see Fife-Shaw, 1995), a conservative approach was adopted, as recommended by Stine (1989) (cited in Breakwell, Hammond & Fife-Shaw, 1995). It is important to note that non-parametric statistical methods are considered to be only marginally less powerful than parametric methods (Everitt & Wykes, 1999).

**Group Differences**

Mann-Whitney tests were conducted to examine between-group differences for ordinal level variables. Chi-square tests were conducted to examine year and ethnic group differences for nominal demographic variables and for children’s reported knowledge and experience of the illnesses in the card sort. When expected cell frequencies for the chi-square analysis fell below five, Fisher’s exact tests were used. Median values were calculated as the measure of central tendency, due to the difficulty in assuming a normal distribution with small sample sizes.

Due to the exploratory nature of the present study, Bonferroni corrections were not applied to reduce the probability of obtaining Type I errors. As such, any significant findings should be interpreted with caution and be subject to empirical replication.

**Qualitative Analysis**

**Multidimensional Scaling Analysis**

Multidimensional scaling analysis was conducted to examine developmental and cultural differences in the grouping of illnesses in the free sort condition. Multidimensional scaling analysis is a computer-based technique which provides a visual representation of the relationships between variables, based on their groupings in the card sort. The programme generates a two-dimensional plot, in which the proximity of items reflects the degree of similarity in their profiles. The similarities and differences perceived between illnesses by the four groups were examined through comparison of the group plots.
Content Analysis

Content analysis was conducted on participants’ verbal explanations for illness groupings in the free sort condition. This form of analysis allows conclusions to be drawn regarding the most salient themes being discussed. Content analysis involves systematically counting the occurrence of specified categories within the data set, to yield a quantitative description of textual material (see Weber, 1990). The method is largely numerical, although inferences are substantive, rather than statistical (Tesch, 1990). According to Woodrum (1984, 1) “content analysis remains an under-utilised research method with great potential for studying beliefs, organisations, attitudes and human relationships”.

Participant’s statements concerning the grouping of two or more illnesses were the chosen unit of analysis for the present study. This decision was made due to the focus on the overall dimension, or illness component, being used by participants to compare illnesses. The first stage of the content analysis involved the researcher sorting through the statements of each participant. Statements were grouped together on the basis of the overall theme being discussed. The second stage involved the generation of a meaningful label for each group of statements, to reflect that overall theme.

The process of categorising textual information introduces concerns regarding the reliability of the categorisation process being used. Qualitative researchers recognise the importance of categories being applied in a standardised manner, such that the same categorisation could be made by a second researcher (i.e. inter-coder reliability) (Neuman, 1999). In the present study, a second researcher sorted the participants’ original statements using to the category labels of the first researcher. The second researcher was free to add any additional categories and to change any category labels. The category allocations of the two researchers were compared and the percentage of agreement was established. The agreement rate for the present study was 70.93%. Differences of opinion regarding the categorisation of items and category labels were resolved through discussion between the researchers.
Results

Cognitive Development

Reading Age

With regard to the estimation of cognitive development, the mean reading ages for children in year 4 and year 6 were 8.51 years (s.d. = 1.607) and 10.05 years (s.d. = 1.958) respectively. As expected, this difference was significant on a Mann-Whitney test (Z = -2.509, p = 0.012), suggesting the presence of a developmental progression in reading ability. Mann-Whitney analysis by ethnic group revealed a significant developmental trend for the black African/Caribbean children, with year 6 children possessing significantly higher reading ages than year 4 children (Z = -2.168, p = 0.030). Unexpectedly, there was no significant trend for the white British group (Z = -1.099, p = 0.272). As can be seen from Table 2, this may have been due to the elevated mean reading age for the year 4, white British children.

The mean reading age for the year 4, white British children was higher than their mean chronological age, although the difference was not significant on a Wilcoxon signed rank test. The mean reading ages for the three remaining groups were lower than the mean chronological ages. The difference was significant for the year 4, black African/Caribbean group (Z = -1.960, p = 0.05) and approaching significance for the year 6, white British group (Z = -1.784, p = 0.0745).

<table>
<thead>
<tr>
<th>Group</th>
<th>Mean chronological age in years (s.d.)</th>
<th>Mean reading age in years (s.d.)</th>
<th>Mean BPVS score (s.d.)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Year 4</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>white British</td>
<td>8.659 (0.313)</td>
<td>9.130 (1.634)</td>
<td>101.4 (12.35)</td>
</tr>
<tr>
<td>black African/Caribbean</td>
<td>8.559 (0.286)</td>
<td>7.735 (1.268)</td>
<td>93.7 (10.53)</td>
</tr>
<tr>
<td>Year 6</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>white British</td>
<td>10.683 (0.218)</td>
<td>9.894 (1.333)</td>
<td>97.1 (12.86)</td>
</tr>
<tr>
<td>black African/Caribbean</td>
<td>10.650 (0.242)</td>
<td>10.222 (2.561)</td>
<td>92.9 (21.80)</td>
</tr>
</tbody>
</table>
A significant positive association was found between chronological age and reading age using Spearman’s rho (r = 0.483, p = 0.002). When examined by year, this association was supported for the year 4 children (r = 0.539, p = 0.021), but not the year 6 children (r = 0.03, p = 0.903). Examination by ethnic group yielded associations which were approaching significance for both the white British (r = 0.435, p = 0.055) and black African/Caribbean children (r = 0.477, p = 0.053). These findings suggest that although a relationship may exist between chronological age and reading age for many children, the two measures are not necessarily commensurate with each other.

**BPVS**

Mean standard scores on the BPVS were 97.55 (s.d. = 12.894) for year 4 and 95.00 (s.d. = 16.8) for year 6. This difference was not significant on a Mann-Whitney test (Z = -0.14, p = 0.892), indicating the absence of a developmental trend. Table 2 presents a breakdown of the mean standard scores by year and ethnic group, and suggests a trend for higher scores among the white British children than the black African/Caribbean children. However, this difference was not significant for either year 4 (Z = -1.32, p = 0.186) or year 6 children (Z = -0.379, p = 0.705). This was expected, given that all participants had been born and raised within Britain. A Spearman’s rho correlation indicated that the association between chronological age and BPVS standard score was not significant (r = 0.061, p = 0.707).

**BPVS & Reading Age**

A highly significant positive correlation was observed between reading age and standard score on the BPVS, using Spearman’s rho (r = 0.6465, p = 0.00). This relationship was observed for year 4 (r = 0.757, p = 0.00) and year 6 (r = 0.796, p = 0.00) and for the white British (r = 0.532, p = 0.016) and black African/Caribbean groups (r = 0.683, p = 0.002).

**Children’s experience of illness**

**Hospital Stay**

77.5% (31/40) of participants reported having experienced an overnight stay in hospital. 77.5% (31/40) also reported that a family member had experienced an overnight hospital stay. Two tailed Fisher’s exact tests yielded no significant year differences for personal (
there were no significant ethnic group differences for personal (χ², p = 1.00) or family experience of hospital stays (χ², p = 0.405).

**Chronic Illness**

30% (12/40) of participants reported personal experience of asthma. No child reported personal experience of any other chronic illness included in the card sort.

**Group Differences**

Chi-square tests were conducted to examine between group differences in children’s reported experience of the illnesses in the card sort. The four response categories from the structured card sort were collapsed in order to compare the number of children who had reported personal experience of the illness (“I have had this myself”) with those who had reported either indirect experience or no experience (“someone in my family has had it”, “a friend has had it”, or “I don’t know anyone who has had it”). Within the literature, personal experience of an illness has been found to be associated with increasingly sophisticated concepts of that illness (Paterson et al., 1999).

Given the low incidence of meningitis, it was predicted that most children would report neither direct nor indirect experience of this illness. As such, between group tests for meningitis experience involved comparing the number of children who had gained some experience of meningitis (either direct or indirect) with those who had gained no experience. Table 3 presents a summary of the significant findings.

As can be seen from the table, significant year differences were observed for children’s reported experience of flu and meningitis. Children from year 4 were more likely to report personal experience of flu and less likely to report knowing someone who had experienced meningitis, than their year 6 counterparts.
Ethnic Group Differences

Significant ethnic group differences were observed for children’s self-rated experience of chicken pox and sunburn. White British children were more likely to report personal experience of these illnesses than black African/Caribbean children.

Table 3: Significant group differences in children’s reported experience of illness

<table>
<thead>
<tr>
<th>Illness</th>
<th>Number of children reporting personal experience of the illness</th>
<th>Significant results</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White British (n=20)</td>
<td>Black African (n=20)</td>
</tr>
<tr>
<td>Chicken pox</td>
<td>18</td>
<td>9</td>
</tr>
<tr>
<td>Sunburn</td>
<td>13</td>
<td>4</td>
</tr>
<tr>
<td>Year 4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Flu</td>
<td>19</td>
<td>6</td>
</tr>
<tr>
<td>Verruca</td>
<td>16</td>
<td>*9</td>
</tr>
<tr>
<td>Meningitis</td>
<td>*16</td>
<td>*9</td>
</tr>
</tbody>
</table>

(* Figures here represent the number of children who reported not knowing anyone who had experienced meningitis, as only one child reported personal experience of meningitis)

Perceived Knowledge about Illness

Regarding knowledge of the illnesses, there were a number of items which at least a quarter of participants reported having never heard of before. 57.5% (23/40) said they had never heard of migraine and 52.5% (21/40) had never heard of diabetes. The figures for verruca and eczema were 40% (16/40) and 27.5% (11/40) respectively. Children in the study would, therefore, appear to perceive themselves as less knowledgeable about these four illnesses than others under investigation.

In terms of children’s experience with the above illnesses, 75% (30/40) of participants reported not knowing anyone who had experienced migraine and 80% (32/40) not knowing anyone who had diabetes. The figures for verruca and eczema were 52.5% and 50% respectively. These findings would seem to suggest a children’s knowledge of an illness is influenced by their experience with that illness.

However, the above relationship was not replicated for other illnesses in the study. Many children reported no personal, family or peer experience of cancer (65%, 26/40) or food...
poisoning (62.5%, 25/40), yet assigned themselves a high level of knowledge about these illnesses. As such, personal experience does not fully account for children’s reported knowledge of illnesses in the present study.

Group Differences

Fisher’s exact tests were conducted to examine between group differences in children’s self-rated knowledge of individual illnesses. The four response categories from the structured card sort were collapsed to compare the number of children who reported knowing something about an illness (“I know a lot” or “I know a bit”) with those who reported not knowing anything about the illness (“I have heard of it, but don’t know anything about it” or “I have never heard of it before”). Significant findings are presented in Table 4.

No significant year effects were found with respect to children’s reported knowledge of individual illnesses. Regarding ethnic group differences, the results for eczema and mosquito bites were nearing significance. Children in the black African/Caribbean group tended to assign themselves a higher level of knowledge about these illnesses than their white British peers.

Table 4: Significant between group differences in children’s reported knowledge of illness

<table>
<thead>
<tr>
<th>Illness</th>
<th>Number of children knowing “a lot” about the illness</th>
<th>Significant effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>White British (n=20)</td>
<td>Black African (n=20)</td>
</tr>
<tr>
<td>Mosquito bite</td>
<td>5</td>
<td>15</td>
</tr>
<tr>
<td>Eczema</td>
<td>4</td>
<td>8</td>
</tr>
</tbody>
</table>
Content Analysis

A total of 313 illness groups of 2 or more items were formed by children in the free sort condition. Children’s statements concerning their reasons for placing illnesses together were collated and analysed using content analysis. The statements were categorised according to the overall theme being used by the child in their response. Initial analysis yielded 14 categories into which the statements were grouped. Table A in Appendix 7 provides a breakdown of the number of statements placed in each category by the initial rater.

A second rater, who was blind to the original card sort data, sorted the statements according to the original categories. The rater was free to add any further categories and to re-label existing ones. This analysis yielded an additional category to the original 14. Table B in Appendix 7 provides a breakdown of the number of statements placed in each category by the second rater. The number of statements placed in the same category by both raters is also provided in Table B.

The percentage agreement between raters for the 313 statements was 70.93%. Inter-rater discrepancies in the allocation of items to categories were debated and a final category agreed upon by both raters. Table 5 presents the final breakdown of statements into content analysis categories, after all inter-rater discrepancies had been resolved. This table provides a summary of the distribution of responses and the number of participants referring to each theme. In the process of resolving inter-rater discrepancies two additional categories were created. These were labelled ‘multiple clause response’ and ‘personal/family experience of illness’. Three subcategories, which had originally been placed under the heading ‘Identity’ (nature, symptoms, location), were collapsed to form a global category of ‘Identity’. This was because many responses contained ideas relating to two or more of the identity aspects, although the overarching theme was that of illness identity.
Table 5: Final categorisation of children's explanations for illness groups after resolving inter-rater discrepancies

<table>
<thead>
<tr>
<th>Category Label</th>
<th>Number of Responses (%)</th>
<th>Number of Children mentioning theme (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Uncategorised</td>
<td>3 (1)</td>
<td>3</td>
</tr>
<tr>
<td>Child did not know</td>
<td>24 (7.7)</td>
<td>13</td>
</tr>
<tr>
<td>Answer did not make literal sense</td>
<td>2 (0.6)</td>
<td>2</td>
</tr>
<tr>
<td>Statement of similarity with no explanation</td>
<td>20 (6.4)</td>
<td>16</td>
</tr>
<tr>
<td>Perceived severity</td>
<td>10 (3.2)</td>
<td>7</td>
</tr>
<tr>
<td>Cause</td>
<td>29 (9.3)</td>
<td>19</td>
</tr>
<tr>
<td>Identity</td>
<td>128 (40.9)</td>
<td>37</td>
</tr>
<tr>
<td>Personal vulnerability</td>
<td>17 (5.4)</td>
<td>7</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>10 (3.2)</td>
<td>6</td>
</tr>
<tr>
<td>One illness influencing another</td>
<td>10 (3.2)</td>
<td>6</td>
</tr>
<tr>
<td>Consequences</td>
<td>26 (8.3)</td>
<td>16</td>
</tr>
<tr>
<td>Timeline</td>
<td>5 (1.6)</td>
<td>4</td>
</tr>
<tr>
<td>Cure</td>
<td>4 (1.3)</td>
<td>3</td>
</tr>
<tr>
<td>Personal/Family Experience</td>
<td>3 (0.9)</td>
<td>3</td>
</tr>
<tr>
<td>Multiple clause response</td>
<td>22 (7)</td>
<td>17</td>
</tr>
</tbody>
</table>
As can be seen from the first four categories in Table 5, 49 responses provided insufficient data from which to deduce the conceptual basis on which children were grouping illnesses together.

22 responses were categorised under the heading 'multiple clause response'. These responses all contained reference to two or more illness themes and had originally been placed into different categories by the two raters. It was unclear whether these responses reflected a combination of the individual illness themes, or whether the child was using an alternative, overarching theme, not immediately apparent to the researcher. Clinical experience and observations made during the study suggested that the likelihood of the former explanation. However, the qualitative nature of the present investigation, and an unwillingness to further impose an adult structure on children's responses, led to an additional category being created to contain these items. Due to the uncertainty regarding the predominant theme being discussed, these items were excluded from the main analysis. A breakdown of the multiple clause responses according to individual themes is presented in the appendix (Table C, Appendix 7).

As can be seen from Table 5, the most common basis for grouping illnesses together was illness identity. 37 out of the 40 participants (92.5%) used illness identity as an organising theme within their responses, indicating that this constituted a highly salient feature of illness for these children. Illness identity was found to include three components, to which participants referred. These were the nature of the illness (e.g. “both are diseases”), the symptoms associated with the illness (e.g. “you can get coughs from them”) and the location of symptoms within the body (e.g. “both are in your stomach”). The symptoms of illness were referred to most frequently by participants, with only nine responses relating to the nature of an illness and 18 concerning the location of symptoms.

The cause of illness was the next most common theme in participant’s responses. However, cause was referred to much less frequently, and by fewer children, than illness
identity. This would suggest that cause constituted a less salient feature of illness for participants than identity. The consequences of illness were discussed in a similar number of responses to cause and were referred to by a similar number of children. This would suggest that the consequences and causes of illness were of similar salience for participants in this study.

The notion of personal vulnerability to illness was the next most common theme in participant’s responses. This theme was used much less frequently than either cause or consequences, suggesting that it constituted a less salient feature of illness for participants. Perceived severity, comorbidity, and the idea of one illness influencing (the course or occurrence of) another each formed the focus of 10 responses (3.2%), which would suggest that these aspects of illness were less salient features of illness for participants than identity, cause or consequences. The themes of cure, timeline and personal/family experience of illness were used relatively rarely by children in the study, suggesting that these represented the least salient aspects of illness for participants.

**Group Comparison of Illness Themes**

**Salience of Themes**

Of the 313 statements concerning children’s reasons for grouping illnesses together, the following number were made by children from each of the four groups: 91 by the year 4, white British group; 71 by the year 4, black African/Caribbean group; 75 by the year 6, white British group; and 76 by the year 6, black African/Caribbean group. Between group comparisons were conducted on the number of children who referred to an identified illness theme in at least one of their responses (see Table D, Appendix 7).

**Developmental Differences**

Table 6 presents a breakdown by year of the number of children who referred to each theme in at least one of their responses. As can be seen from this table, there were important commonalities and differences to years to note between the years. Firstly, the
majority of children from each year referred to illness identity within at least one of their responses. This would suggest that illness identity comprises a salient feature of illness for children between the ages of 8 to 11 years. One child from year 4 and two from year 6 did not use illness identity to structure any of their responses, which may indicate the absence of an identity component within their illness representations. Alternatively, identity may constitute a less salient feature of illness for these children.

The consequences of illness were referred to by 9 children from year 4 and 7 from year 6, suggesting that this is as salient a feature of illness for children of 8-9 years as those of 10-11 years. A further commonality between the years was second commonality was that less than 3 children from each year referred to the timeline and cure components in their responses. As such, timeline and cure would not appear to constitute salient features of children’s illness representations between the ages of 8-11 years.

7 out of the 20 year 4 participants referred to illness cause in their grouping of illnesses. This was in contrast to 12 children from the year 6 group. This would suggest that cause constituted a more salient feature of illness for year 6 children (age 10-11 years) than year 4 children (age 8-9 years). Although there were some small differences in the number of children from each year referring to the remaining themes, these was not believed to be large enough to be of note.
Table 6: Comparison by year of the number of children who used each theme to structure their responses

<table>
<thead>
<tr>
<th>Category Label</th>
<th>number of year 4 children</th>
<th>number of year 6 children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived severity</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Cause</td>
<td>7</td>
<td>12</td>
</tr>
<tr>
<td>Identity</td>
<td>19</td>
<td>18</td>
</tr>
<tr>
<td>Personal vulnerability</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>One illness influencing another</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Consequences</td>
<td>9</td>
<td>7</td>
</tr>
<tr>
<td>Timeline</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Cure</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Personal/family experience</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

Ethnic group differences

Table 7 presents a breakdown by ethnic group of the number of children who referred to each theme in at least one of their responses. There were several findings of note. Firstly, the majority of children from each ethnic group used illness identity to structure at least one of their responses. This indicated that illness identity comprised a salient feature of illness for children of both white British and black African/Caribbean ethnic background. Three black African/Caribbean children did not refer to illness identity in any of their responses. This may reflect an absence of an identity component within their illness representations. Alternatively, identity may form a less salient feature of illness for these children.
Table 7: Comparison by ethnic group of the number of children who used each theme to structure their responses

<table>
<thead>
<tr>
<th>Category Label</th>
<th>number of white British children</th>
<th>number of black African/Caribbean children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived severity</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Cause</td>
<td>4</td>
<td>14</td>
</tr>
<tr>
<td>Identity</td>
<td>20</td>
<td>17</td>
</tr>
<tr>
<td>Personal vulnerability</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>One illness influencing another</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Consequences</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Timeline</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>Cure</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Personal/family experience</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

14 out of the 20 black African/Caribbean children used the theme of illness cause to structure at least one of their responses. This would suggest that cause constituted a salient feature of illness for many black African/Caribbean participants. Only four (n=20) white British children referred to cause in their responses. This difference was significant on a chi-square test \( \chi^2 = 8.12, p = 0.0043 \), suggesting that cause constituted a more salient feature of illness for black African/Caribbean children than white British children.

A third finding of interest concerned children's reference to curing illness. Three children from the white British group used this theme to structure at least one of their responses in the card sort, compared to no children from the black African/Caribbean group. Although the difference is not large, it is interesting that no child from the black African/Caribbean group referred to this concept. The findings would suggest that illness cure did not constitute a salient feature of illness for participants in the study.

Quantitative Analysis of Free Sort Data

There was no significant effect for year or ethnic group in the number of card sorts completed in the free sort condition. Chi-square values were 0.902 (p = 0.342) for year and
and 2.506 (p= 0.113) for ethnic group. Regarding the latter, the trend was for the more white British participants to complete two sorts than black African/Caribbean participants.

**Number of cards excluded from the sorts**

Any illness cards placed in the “I have never heard of it” category on the structured sort for knowledge were excluded from the free sort condition. The median number of cards excluded was 2, with a range of 0 to 8. There was no significant effect for year (Z= -1.055, p=0.291) or ethnic group (Z= -0.672, p= 0.502) in the number of cards excluded.

**Number of groups used in the sorts**

The number of groups used in the free sort condition was examined for year and ethnic group differences, using Mann-Whitney tests. Both values were included for children who completed two sorts. There was no significant effect for year (Z= -0.366, p= 0.715) or ethnic group (Z = -0.027, p= 0.978).

**Maximum number of cards grouped together**

Mann-Whitney tests revealed no significant effect for year (Z= -0.218, p= 0.828) or ethnic group (Z= -0.544, p= 0.587) in the maximum number of cards being placed in one group by a participant in the free sort condition. As before, both values were included for children who had completed two sorts.

**Single card groups**

Mann-Whitney tests revealed no significant effect for year (Z= -0.901, p= 0.368) or ethnic group (Z= -0.799, p= 0.785) in the number of illnesses placed in their own group (i.e. not grouped with other illnesses) in the free sort condition. Both values were included for children who completed two free sorts.
Multidimensional Scaling Analysis (MSA)

Individual illness Plots

Year 4, black African/Caribbean illness plot
There were clear similarities between the two illness plots produced by multidimensional scaling analysis of the year 4 groups’ free sort data. The distance between individual clusters was comparable and the size of individual clusters was similar, although their composition was different. The illness plot for the year 4, black African/Caribbean children was clearly divided into five distinct illness clusters, as can be seen from Plot 1. Two clusters each contained two illnesses. These were hayfever and nosebleed, bee sting and mosquito bite. The remaining clusters contained three (cut, chicken pox and flu), four (stomach ache, toothache, headache and earache) and 13 illnesses (cancer, diabetes, eczema, migraine, headlice, meningitis, asthma, diarrhoea, broken leg, tonsillitis, food poisoning, verruca, sunburn).

Year 4, white British illness plot
The year 4, white British plot was also clearly divided into five distinct clusters, with one isolated illness (nosebleed) standing alone (see Plot 2). Three clusters contained two illnesses. These were bee sting and mosquito bite, broken leg and cut, cancer and meningitis. The remaining clusters contained five (asthma, tonsillitis, food poisoning, headache, diarrhoea) and 12 illnesses (diabetes, eczema, hayfever, flu, stomach ache, toothache, chicken pox, migraine, headlice, sunburn, verruca, earache).
Plot 1: MSA plot for the year 4, black African/Caribbean group

Key:
1 - asthma 7 - stomach-ache 13 - tonsillitis 19 - sunburn
2 - cancer 8 - toothache 14 - migraine 20 - nosebleed
3 - eczema 9 - headache 15 - food poisoning 21 - cut
4 - meningitis 10 - chicken pox 16 - diabetes 22 - mosquito bite
5 - hayfever 11 - bee sting 17 - earache 23 - head lice
6 - flu 12 - broken leg 18 - verruca 24 - diarrhoea
Plot 2: MSA plot for the year 4, white British group

Key:
1 - asthma  7 - stomach-ache  13 - tonsillitis  19 - sunburn
2 - cancer  8 - toothache  14 - migraine  20 - nosebleed
3 - eczema  9 - headache  15 - food poisoning  21 - cut
4 - meningitis  10 - chicken pox  16 - diabetes  22 - mosquito bite
5 - hayfever  11 - bee sting  17 - earache  23 - head lice
6 - flu  12 - broken leg  18 - verruca  24 - diarrhoea
Year 6, black African/Caribbean illness plot

The illness plots for the year 6 groups differed considerably in the size and arrangement of clusters. As can be seen from Plot 3, the year 6, black African/Caribbean plot differed from the three remaining plots, in that it contained only three illness clusters. Two clusters each contained two illnesses. These were cancer and meningitis, tonsillitis and diabetes. The remaining cluster contained 15 items (headache, earache, stomach ache, toothache, food poisoning, diarrhoea, nosebleed, cut, broken leg, sunburn, headlice, bee sting, mosquito bite, migraine, verruca). Five illnesses appeared in isolation on the plot. These were asthma, eczema, hayfever, flu and chicken pox. Their position on the plot suggested that the year 6, black African/Caribbean children perceived each of these illnesses to be different from the other illnesses in the card sort. In particular, hayfever and flu were positioned on the opposite side of the plot to the remaining illnesses, suggesting that these two items were perceived as being very different from the remaining items.

Year 6, white British illness plot

The plot for the year 6, white British children comprised seven illness clusters, with four illnesses standing alone (see Plot 4). Clusters were generally more compact than on the previous plots, suggesting that this group perceived greater similarity between items within a cluster than other groups. The two largest clusters on the plot each contained five illnesses (eczema, meningitis, hayfever, diabetes, tonsillitis) (headache, earache, stomach ache, toothache, migraine). The five remaining clusters each contained two illnesses. These were chicken pox and flu, headlice and sunburn, bee sting and broken leg, diarrhoea and food poisoning, asthma and cancer.

Nosebleed, verruca, cut and mosquito bite all appeared alone on the plot. Their proximity to illness clusters, however, suggested that although these illnesses were perceived as being dissimilar to the others, they were not considered to be too different.
Plot 3: MSA plot for the year 6, black African/Caribbean group

Key:
1 - asthma
2 - cancer
3 - eczema
4 - meningitis
5 - hayfever
6 - flu
7 - stomach-ache
8 - toothache
9 - headache
10 - chicken pox
11 - bee sting
12 - broken leg
13 - tonsillitis
14 - migraine
15 - food poisoning
16 - diabetes
17 - earache
18 - verruca
19 - sunburn
20 - nosebleed
21 - cut
22 - mosquito bite
23 - head lice
24 - diarrhoea
Plot 4: MSA plot for the year 6, white British group

Key:
1 - asthma 7 - stomach-ache 13 - tonsillitis 19 - sunburn
2 - cancer 8 - toothache 14 - migraine 20 - nosebleed
3 - eczema 9 - headache 15 - food poisoning 21 - cut
4 - meningitis 10 - chicken pox 16 - diabetes 22 - mosquito bite
5 - hayfever 11 - bee sting 17 - earache 23 - head lice
6 - flu 12 - broken leg 18 - verruca 24 - diarrhoea
Comparison Between Groups

Comparison of the four plots indicated that illnesses were divided into more distinct clusters by the year 4 groups than year 6 groups. There were fewer lone illnesses on the year 4 plots, suggesting that children in this year were more likely to perceive similarity between illnesses, and/or less likely to perceive uniqueness, than the year 6 children. These findings suggest a developmental change in children's conceptualisation of illness between year 4 (8-9 years) and year 6 (10-11 years).

No ethnic group differences were apparent on the year 4 plots. However, considerable differences were noted on the year 6 plots concerning the number of clusters being formed and their respective size. Illnesses on the year 6, white British plot were separated into a larger number of clusters than on the black African/Caribbean plot. Moreover, the largest cluster on the white British plot contained 5 items, compared to 15 items on the black African/Caribbean plot. The latter was similar in size to the largest clusters on the two year 4 plots. These differences suggest that the year 6, white British children made greater conceptual differentiation, and/or were less able to perceive similarity between illnesses, than the three remaining groups of participants.

Principal Illness Clusters

A number of illnesses were repeatedly found to cluster together on the above plots, suggesting that these illness items were consistently perceived as being similar. On some occasions these items formed separate clusters and on other occasions the items were closely positioned within a larger illness cluster. These illness groupings are presented below.

Cancer and meningitis

Cancer and meningitis formed a separate and distinct cluster on the illness plots for the year 4, white British children and the year 6, black African/Caribbean children. This
would suggest that participants in these groups perceived these items to be highly similar to each other and dissimilar from other illnesses in the card sort.

**Bee sting and Mosquito Bite**

Bee sting and mosquito bite formed a separate and distinct cluster on both year 4 plots. This cluster was located at a distance from the remaining illnesses on the plot, suggesting that the year 4 children perceived bee sting and mosquito bite to be highly similar to each other, yet clearly different from the remaining illnesses in the card sort. Bee sting and mosquito bite were also located near each other on the year 6, black African/Caribbean plot, although they formed part of the larger cluster. This would suggest that these children perceived bee sting and mosquito bite to be similar to each other, but also similar to the other illnesses in the cluster.

Bee sting and mosquito bite were distant from each other on the year 6, white British plots, suggesting that these children perceived bee sting and mosquito bite to be different from each other and to each share similarity with other illnesses in the card sort.

**Chicken pox and Flu**

Chicken pox and flu formed a distinct cluster on the year 6, white British plot. This pairing was also found on the year 4, black African/Caribbean plot, with cut being included in the cluster. Chicken pox and flu were also found in proximity on the year 4, white British plot, but formed part of a larger cluster. This would suggest that all three groups perceived similarity between chicken pox and flu, although children in the latter two groups did not perceive the illnesses as being distinct from others in the card sort.

**Headache, Earache, Toothache, Stomach ache and Migraine**

Headache, earache, toothache and stomach ache formed a separate and distinct cluster on the year 4, black African/Caribbean plot and the year 6, white British plot, suggesting that these items were perceived as being highly similar to each other. These items were
also found in proximity on the year 6, black African/Caribbean plot and the year 4, white British plot, although they were located within larger clusters. This would suggest that the illnesses were perceived as being highly similar to each other, yet similarity was also perceived with other illnesses.

Migraine was found in combination with the four illnesses on the two white British plots, suggesting that children perceived similarity between migraine and these illnesses. On the two black African/Caribbean plots, migraine was located at a distance from the four illnesses, suggesting that the black African/Caribbean children perceived migraine to be quite different from the four items and more similar to other illnesses.

**Food Poisoning and Diarrhoea**
Food poisoning and diarrhoea were located near each other on all four illness plots, suggesting that these two items were consistently perceived as being similar. However, the items only formed a separate and distinct cluster on the year 6, white British plot. On the remaining three plots, the illnesses formed part of a much larger cluster, suggesting that similarity was perceived between these items and others in the cluster.

**Headlice & Sunburn**
Headlice and sunburn formed a separate and distinct cluster on the year 6, white British plot. These items were also in proximity on the year 4, white British plot and the year 6, black African/Caribbean plot, although they formed part of a larger cluster. This would suggest that these items were perceived as being similar to each other by these three groups of children. However, only the year 6, white British children would appear to have perceived the items as being unique from others in the study.

**Broken leg and Cut**
Broken leg and cut formed a separate and distinct cluster on the year 4, white British plot, with the nearest illness being nosebleed. The cluster fell at the edge of the plot, at a
distance from the other clusters, which would suggest that these items were considered to be similar to each other, but quite different to other illnesses in the card sort.

Broken leg and cut were located in proximity on the two year 6 illness plots, although other illnesses were also present. This would suggest that while similarity was perceived between these items, they were not viewed as being distinct from other illnesses in the card sort. Cut and broken leg were some distance apart and in separate clusters on the year 4, black African/Caribbean plot, suggesting that these children perceived the two items to be different from each other.

_Asthma and Tonsillitis_

Asthma and tonsillitis were found in proximity on all four illness plots, although they did not form a separate and distinct cluster. This would suggest that although children perceived similarity between the items, each was perceived to be similar to other illnesses in the card sort.

**Summary of Main Findings**

Certain illnesses were found in proximity on all four plots, suggesting that the items were consistently perceived as being similar to each other. The common clusters were as follows: headache, toothache, stomach ache and earache; asthma and tonsillitis; food poisoning and diarrhoea. The earlier finding, that identity formed the most salient feature of illness for all children in the study, may explain these groupings.

**Year Differences**

Regarding year differences, bee sting and mosquito bite were identified as being separate and distinct from other illnesses in the card sort by year 4 children, but not year 6 children. The year 4 children also appeared to perceive greater similarity between eczema and migraine than year 6 children, as evidenced by greater proximity on the plot.
Ethnic Group Differences

There was an ethnic group difference in the pairing of migraine with other illnesses in the card sort. Both white British groups appeared to perceive similarity between migraine and headache, toothache, stomach ache and earache. In contrast, the black African/Caribbean groups perceived migraine as being different from these items.

Nosebleed was perceived as being different from other items in the card sort by the white British children. However, the black African/Caribbean children clustered nosebleed together with other illnesses, indicating that this item was perceived as being similar to other items in the sort.

Year 6, white British group

A number of illness were perceived as being similar by all four groups of children, but only constituted separate and distinct clusters on the year 6, white British plot. These clusters were: food poisoning and diarrhoea; headlice and sunburn; chicken pox and flu. Similarly, on all but the year 6, white British plot, bee sting and mosquito bite were found in close proximity, suggesting that the year 6, white British children were the only ones who perceived these items as being dissimilar from each other. Similarly, verruca stood alone on the year 6, white British plot, but was found within the main cluster on all three remaining plots. This would indicate that only the year 6, white British children perceived a clear difference between verruca and other illnesses in the sort. These findings would suggest that as a group, the year 6, white British children made greater conceptual distinction, and/or saw less similarity between illnesses than other groups of participants.
Discussion

The findings from the present study are discussed below, commencing with a section on estimating children’s cognitive developmental level. The developmental and ethnic group differences in children’s reported knowledge and experience of illness are then discussed, before addressing the research questions outlined earlier. The findings are interpreted in the light of relevant literature on children’s concepts of illness, adult illness representations and theories of cognitive development. Clinical implications of the findings and the methodological limitations of the study are then addressed.

Cognitive development

Reading Age

In the present study, the examination of cognitive developmental differences in children’s concepts of illness was complicated by a number of unexpected findings. Firstly, the developmental trend for reading age, which was observed in the black African/Caribbean groups, was not apparent in the white British groups. This appeared to be due to an elevated mean reading age in the year 4, white British group. One explanation for this finding was that the year 4, white British participants were selected from a much larger population than the three remaining groups. In this group, sufficient children were recruited through the first parent recruitment letter. For the three remaining groups, the insufficient number of participants necessitated that a second recruitment letter be sent to parents who had not replied. As such, bias may have been introduced into the results through differences in the recruitment process.

An alternative explanation was that the elevated mean reading age reflected a cohort effect for the year 4 children. The absence of an observed effect in the year 4, black African/Caribbean group may have been attributable to the diversion of efforts into developing literacy in more than one language.

BPVS -II

The second unexpected finding was the absence of a developmental trend for BPVS-II performance. This suggested that participants from the two years were comparable
with respect to receptive language ability and did not represent developmentally separate samples. The decision to recruit participants from year 4 and year 6 was based on the need for children to be old enough to understand the procedural requirements of the card sort task, yet to be members of the same school. Recruiting the two year groups from different schools would have introduced the potential for further confounding variables. In selecting participants who were separated by a whole school year, it was hoped to secure developmentally separate samples with respect to cognitive ability. However, the findings suggest that the year difference may have been insufficient to achieve this.

No significant ethnic group differences were observed for BPVS scores, although there was a trend for the white British children to have higher scores than their black African/Caribbean peers. This finding would suggest that children of ethnic minority background who are raised within the British school system are not at a significant disadvantage in terms of their receptive language ability for English.

Estimating cognitive development
A highly significant correlation was found between reading age and BPVS performance, suggesting that participant’s scores on the two measures were highly related. However, the two measures were not commensurate with each other, as evidenced by the discrepant findings with respect to developmental trend. One explanation for these inconsistencies is that the tests of reading and receptive language tap different abilities and domain specific knowledge. Discrepant scores on the two tests would, therefore, be consistent with domain-specific theories of cognitive development (e.g. Gelman & Baillargeon, 1983; Nelson, 1986), which propose that children may possess different levels of reasoning and understanding for different domains and for specific concepts within a domain.

An alternative explanation is that the measures of reading age and receptive language tap the same global ability, but differ with respect to the level of sensitivity in their measurement. As such, the BPVS-II may have failed to reveal subtle developmental differences in receptive language ability which were detected on the reading age test.
Given the above findings, the decision was made to use school year in the analysis of developmental changes in children's concepts of illness. It was recognised that any changes associated with year, or chronological age, could not be presumed to reflect underlying changes in cognitive development. This is consistent with the conclusion from previous studies (e.g. Pidgeon, 1985), that chronological age does not provide an accurate estimate of cognitive development (Burbach & Peterson, 1986). Year was selected as the basis for the analysis since it provides a more obvious identifying characteristic for professionals involved in discussing illness with children. Conclusions drawn on the basis of age provide information which is of more obvious clinical value than that based on cognitive development.

**Year differences and the conceptualisation of illness**

With regard to the above dilemma, the MSA illness plots for the four groups of participants suggested a developmental progression in children's ability to conceptually distinguish between illnesses. Children in year 6 appeared to make greater conceptual distinction between individual illnesses, and were less focused on shared similarities than the year 4 children. For the year 6 children, this developmental progression appeared to be influenced by ethnic background, as the year 6, white British plot reflected greater differentiation between illnesses and less perception of similarity, than the black African/Caribbean plot.

The developmental changes on the year 4 and year 6 white British plots were not accompanied by changes in reading age or BPVS-II scores. The more subtle developmental changes on the black African/Caribbean plots were accompanied by developmental changes in reading ability, but not BPVS-II scores. These findings would again appear to be consistent with domain specific theories of conceptual change, in that developmental progression in children's conceptual understanding of illness was not necessarily accompanied by changes in receptive language ability or reading age. This raises important questions regarding the appropriateness and value of applying single measures to the estimation of cognitive development. Moreover, there is a need to develop new approaches to investigating the influence of cognitive
development on children’s concepts of illness, which are consistent with the assumptions of domain-specific theories.

**Experience and knowledge concerning illness**

The present study explored children’s self-reported knowledge and experience of 24 illnesses. With regard to knowledge, the results indicated that there were a number of illnesses which participants across both years and ethnic groups consistently rated as being unfamiliar to them. These included migraine, diabetes, verruca and eczema. This lack of familiarity appeared to be related to a lack of experience, since many participants reported not knowing anyone who had experienced these illnesses. However, most participants also reported little personal, family or peer experience of cancer and food poisoning, yet perceived themselves as having considerable knowledge about these illnesses. This would suggest that although personal experience (through self, family, friends) may influence children’s self-reported levels of knowledge about specific illnesses, other factors are also involved. It is possible that factors such as the profile of an illness within a society or cultural group, discussion of illnesses with peers or family members, health education within schools or information obtained through the media, may affect children’s rating of their knowledge about a particular illness.

An alternative explanation is that participants may have been unfamiliar with the illness label being used in the study, whilst being familiar with the symptoms or nature of that illness. As such, illnesses with which participants were familiar, may have been categorised as unfamiliar. However, this explanation was challenged by the fact that the illness labels were generated by focus groups with children of the same age and ethnic background as participants.

**Between group differences**

A number of year and ethnic group differences were found with respect to participant’s knowledge and experience of specific illnesses. These may have important implications for professionals working with children in paediatric settings.
or conducting health promotion programmes in schools. The differences are discussed below.

**Developmental differences**

Children from the two years differed significantly in their reported experience of flu and meningitis. Year 4 children reported greater personal experience of flu than year 6 children, but this difference was not accompanied by reports of greater knowledge. One explanation for this finding is that the reports of greater experience among year 4 children may have been confounded by poorer conceptual understanding of the differences between flu and a cold. This is consistent with the findings from the MSA plots, that year 6 children appeared to make greater conceptual distinction between illnesses than year 4 children, and were less focused on similarities. The year 6, white British plot suggested that this group of children made the greatest conceptual distinction between illnesses.

Script theory (Nelson, 1986) suggests that when asked about events they have experienced, younger children mention fewer structural variations between episodes of a recurring event than older children (Fivush, Kuebli & Clubb, 1992). Fivush et al. (1992) assumed that this difference was associated with the children of different ages being in different stages of script development (Goodman, 1981). Hudson, Fivush & Kuebli (1992) proposed that younger children are concerned with confirming the scripts they have derived for events. This process necessitates a focus on the commonalities across episodes. In contrast, older children, due to greater cognitive development, are presumed to be capable of establishing a script after only limited exposure to an event, allowing them to focus on variations between episodes.

A greater number of children from year 6 than year 4 reported knowing someone who had experienced meningitis. This difference was unexpected, due to the low incidence rates of meningitis within the general population. The finding was attributed to the fact that the year 6 children from one school were aware of a fellow pupil having died from meningitis some years earlier. The year 4 children from this school were much less aware of this fact. The above findings are consistent with research demonstrating the
role of experience with specific illnesses in enhancing children’s understanding of that illness (Paterson et al., 1999).

**Ethnic Group Differences**

The white British children in the study reported greater personal experience of sunburn and chicken pox than their black African/Caribbean peers. The difference for sunburn could be attributable to the darker skin and higher melanin levels of the black African/Caribbean children. This may directly reduce the black African/Caribbean children’s experience of sunburn, both personally and through their families. However, perceived experience of sunburn may also be indirectly limited through a reduced need for discussion concerning the use of protective suncream, or through sunburn being less visible on darker skin.

Concerning chicken pox, it was not known whether black African/Caribbean children were at lower risk of experiencing these illnesses than their white British peers, or whether the difference in experience reflected cultural variation in assigning illness labels to symptoms. Unexpectedly, children from the two ethnic groups did not differ significantly in their reported knowledge of the above illnesses. This again suggested that factors other than personal experience with the illness contribute to children’s perceptions of their knowledge about that illness.

The black African/Caribbean participants reported significantly higher levels of knowledge for mosquito bites and eczema than the white British participants. Ethnic group differences were not observed in children’s reported experience of these illnesses, again suggesting that factors other than illness experience influence children’s perception of their knowledge concerning an illness. Regarding mosquito bites, for example, it is possible that black African/Caribbean children are more exposed to discussion about this item than white British children, through increased incidence rates in the family’s country of origin.
Research Questions

The next section will consider each of the original research questions in the order in which they were presented. Reference will be made to the quantitative analysis of the free sort data, findings from the MSA illness plots and the content analysis as required.

1. The principal components of children’s illness representations

The first research question concerned identifying the principal components of children’s illness representations. Content analysis of the participant’s free sort responses revealed that the five illness components (timeline, identity, cause, consequences and cure) associated with adult illness representations (e.g. Leventhal et al., 1980) were present as themes within children’s responses. However, not all children referred to each of the five components. One possible explanation for this is that children’s conceptual understanding of the various components may emerge at different points in cognitive development. As such, children’s limited reference to the timeline and cure themes may reflect a relative absence of these components in the illness representation structure.

An alternative explanation is that by 8 years of age, children already possess the basic illness representations structure necessary to process information concerning the five components of Leventhal’s model. Differences in the number of children who referred to each component may reflect variations in the saliency of each component for children. This explanation is consistent with the findings of Goldman et al. (1991), who used direct questioning to verify pre-school children’s (age 4-6 years) ability to conceptualise illness in terms of the five components.

A number of factors may influence the saliency of illness components for children. Firstly, conceptual understanding of the different components may develop at different rates, such that children possess a more complex and interactive understanding of some components earlier than others. This proposal is consistent with the contention of domain specific theories, that children may exhibit different levels of reasoning for specific concepts within a domain (Carey, 1985; Gelman & Baillargeon, 1983).
Secondly, as suggested by the previous findings, saliency may be affected by children’s individual experiences with a particular illness (Paterson et al., 1999). Thirdly, the saliency of an illness component for children may be influenced by the nature of the illness-related information which is available (e.g. media campaigns, family discussion of illness). This may be influenced by factors such as socio-cultural background.

The above explanation is consistent with Goldman et al.’s (1991) suggestion that children’s illness representations may simply be less mature and less well informed than those of adults (Goldman et al., 1991). However, the explanation challenges the basic presumption of Piaget’s theory of developmental stages, that children’s concepts of illness, and the logic they employ, are different from those of adults.

Additional components
In addition to Leventhal’s five components, five additional illness themes were identified through the content analysis. These were labelled ‘perceived severity’, ‘personal vulnerability’, ‘comorbidity’ (of symptoms or illnesses), ‘one illness influencing (the occurrence or course of) another’ and ‘personal/family experience of illness’. Children’s completion of the structured sort for illness experience prior to the free sort condition was believed to have cued participants into the latter category.

In their work on the illness representations of adults with chronic illness, Hampson and colleagues (Hampson, 1997) identified a component labelled ‘seriousness’, which appeared to represent a composite of the consequences and timeline components. The construct of ‘seriousness’ has also been identified by factor analytic studies of the underlying dimensions of adult illness representations (Turk, Rudy & Salovey, 1986). The ‘perceived severity’ component in the present study was, perhaps, comparable to Hampson’s ‘seriousness’ component. This would explain the relative infrequency with which children referred directly to the timeline component of illness. The perceived severity of an illness, along with an individual’s perception of personal vulnerability, are also factors proposed by the health belief model (HBM) (Rosenstock, 1974) to contribute to adults’ intentions to engage in health behaviour.
As such, they are recognised as being important influences in the processing of illness information.

**Multiple clause responses**

In addition to the illness categories outlined above, a category labelled ‘*multiple clause response*’ was created in the content analysis, to contain items where the child’s response appeared to refer to more than one illness component (e.g. symptoms and timeline). It was uncertain whether these responses reflected the child’s reference to two separate illness components, or whether they were referring to an underlying theme not immediately apparent to the researcher. One possibility is that children were referring to concepts which reflect composite measures of Leventhal’s components, as in Hampson’s (1997) seriousness (comprising timeline and consequence) and intensity (comprising seriousness and symptoms) composites. Further research is necessary to investigate this possibility.

An alternative explanation is that children lacked the necessary verbal skills to adequately explain their intentions to the researcher. The limitations imposed by children’s expressive language ability have been well documented in relation to interview methods of assessment (e.g. Eiser, 1985; Paterson et al., 1999). A final possibility is that children failed to fully understand the procedural requirements of the free sort task and sorted cards according to a number of different criteria within an individual sort. These findings question the viability of card sort procedures for participants in the study. Further research is necessary to establish the viability of card sort procedures with children in this age range.

**Summary**

The findings from the present study suggest that identity, cause and consequences are the most prominent aspects of illness for children between 8-11 years, with cure and timeline being far less prominent. The findings may indicate that most children between the ages of 8-11 years have yet to develop an awareness of the cure and timeline aspects of illness. Alternatively, children may be aware of such aspects, yet choose to focus on more salient components in their responses. It is possible that if
children had been directly questioned about each component, as in the study by Goldman et al. (1991), a greater number would have been able to discuss them.

The identification of the themes of personal vulnerability, perceived severity, comorbidity, and the influence of one illness on another, which were more prevalent in children’s responses than timeline and cure, challenges the assumption that the five component model of adult illness representations forms the optimum structure for children of this age. This assumption has similarly been challenged with respect to chronically ill adult populations (Hampson, 1997).

Further research is required to investigate the structure of children’s illness representations and to establish how Leventhal’s five components relate to concepts such as the seriousness of an illness (Hampson, 1997) and perceived vulnerability (Rosenstock, 1974), which have been identified in other research. There is a need to investigate when and how the individual illness components emerge over the course of the child’s cognitive development, to establish whether a lack of emphasis on specific components reflects an absence of the component in their illness representations, relatively underdeveloped conceptual understanding, or differences in their saliency for children.

2. Saliency of illness components
The second research question concerned the identification of the most salient components of illness for children. In the present study, differences were observed in the frequency with which children referred to the various illness components in their responses on the free sort task. Important differences were also apparent in the number of children who made reference to each component.

Identity
Illness identity, and in particular the symptoms of illness, formed the focus of the majority of children’s explanations for grouping illnesses together. As such, identity appeared to constitute the most salient component of illness for children between the ages of 8 and 11 years. It is possible that the finding of common illness groups (across
the four MSA plots reflected this shared use of the illness identity component in sorting of the cards. In particular, it was speculated that the groupings of headache, earache, stomach-ache and toothache, food poisoning and diarrhoea, broken leg and cut, and headlice and sunburn were based on perceived similarities in identity.

The saliency of illness identity for children of this age may reflect a focus on concrete aspects of personal internal or external experience, rather than on more abstract or complex features. This would be consistent with Piaget’s (1952) suggestion that children’s conceptual understanding within this age range remains tied to their concrete experiences. The process whereby children learn language, with the emphasis on naming visually salient objects and features, may reinforce identity as a significant component of illness for children.

**Causes & Consequences**

A considerable number of children referred to the causes and consequences of illness in their responses. However, these components were much less prevalent in children’s responses than illness identity. It was speculated that certain common illness groupings on the MSA plots reflected the participants’ concern with the causes or consequences of illness. For example, the perceived similarity between cancer and meningitis may have been based on the consequences of the illness, whereas the similarity between chicken pox and flu may have been based on the causes of the illnesses.

The components of timeline and cure were mentioned infrequently by children, suggesting that while some children of this age may possess an awareness of these components, they are unlikely to be as salient for children as illness identity. With regard to the additional components identified in the present study, all but ‘personal/family experience of illness’ were mentioned in more responses, and by a greater number of children, than the timeline and cure components of Leventhal’s model. This suggests that the former constitute more salient features of illness for children between the ages of 8 and 11 years than timeline or cure.
3. Developmental and cultural differences in the saliency of illness components

The final research question related to developmental and cultural differences in the saliency of illness components for children. Answering the question regarding cognitive developmental differences was precluded by the absence of a significant difference between the years with respect to performance on the BPVS-II. As such, any developmental differences between the year groups cannot necessarily be attributed to increasing cognitive ability.

The absence of significant between group differences on the quantitative analysis of the free card sort data, suggested that neither year nor ethnic group influenced children's ability to follow the procedural requirements of the task. This finding enabled between group comparisons to be made without the risk of confounding variables. However, it is important to note that the small number of participants in the study may have contributed to the non-significant effects. Hence, the conclusions need to be interpreted with caution.

Developmental differences

Regarding developmental differences, an important finding was that the identity of illness was referred to by almost all children in both the year 4 and the year 6 groups. The number of children referring to identity was considerably higher for both years than for any other component. This would indicate that identity is the most salient component of illness for children between the ages of 8-11 years.

The findings demonstrated noticeable differences between the year groups with respect to the number of children referring to the causes and consequences of illness. Fewer children from year 4 referred to the causes of illness than in year 6, which would suggest that cause is a more salient feature of illness for children of 10-11 years than those of 8-9 years of age. The finding that bee sting and mosquito bite formed a separate and distinct cluster on the year 4 illness plots, but not the year 6 plots may be explained by the focus on different aspects of illness. The above findings are not consistent with Piaget's theory (Piaget, 1930), since both year groups would be predicted to be in the same stage of cognitive development.
Only a few children from each year referred to components other than identity, cause and consequences. This would suggest that although children may possess an awareness of such components, they are not particularly salient even for children of 11 years of age.

**Ethnic group differences**

Examination of ethnic group differences in the saliency of illness components for children formed an important part of the present study, since the influence of culture on children’s illness representations has previously been neglected in the literature. There were two main finding from the present study. The first was that illness identity was the component most referred to by children from both ethnic groups. The number of children referring to identity was higher than for other components for both the white British and black African/Caribbean groups.

The second finding was that children in the black African/Caribbean group were much more likely to discuss the causes of illness in their responses than their white British peers. Moreover, in the black African/Caribbean group, cause was referred to by only a few less children than identity. This finding is of importance for professionals involved in discussing illness with children, in that different illness features appear to have greater relevance for children from different cultural groups. Further research is necessary to replicate the current findings and to explore differences in the saliency of illness components for children from other ethnic backgrounds.

It is possible that the above differences may reflect a greater emphasis on cause within black African/Caribbean culture than white British culture. As such, the black African/Caribbean children may develop a concept of cause earlier in childhood than white British children. Alternatively, all children of 8 years of age may possess a concept of illness cause, but this aspect may be more salient for children of black African/Caribbean background than their white British peers, due to factors such as cultural belief systems concerning illness.
Clinical Implications

The findings from the present study have a number of important clinical implications for professionals communicating with children about illness. Firstly, younger children (age 8-9 years) tend to make less conceptual distinction between illnesses than older children (age 10-11 years), and are more focused on establishing the commonalities between events. As such, younger children may be at increased risk of confusing benign everyday illness with more serious conditions which share similar features. Younger children may, therefore, require greater assistance to differentiate between illnesses they may encounter, in order to reduce unnecessary anxiety and distress. Older children, who are more able to differentiate between illnesses and to note idiosyncratic features, are less likely to experience such confusion and may require less help to understand the features of a given illness.

The finding that identity formed the most salient aspect of illness for children of 8-11 years also has important implications for communicating with children about illness. Whaley (1999) suggested that in explaining illness to children, an assertion regarding the normalcy of the event may prove more important than a biological explanation of aetiology. He described this as stating what the child's experience is (e.g. “you have a cold”). The findings from the present study are consistent with this, in that explanations which concern the symptoms, location and nature of the illness would be of most concern to children of this age.

Regarding intervention with children of different ages and cultural background, the findings indicate that identity forms the most salient feature of illness for children from 8-11 years of age and from both white British and black African/Caribbean backgrounds. However, older children (age 10-11 years) and those of black African/Caribbean ethnicity, may be more concerned with the causes of illness than younger children and those of white British ethnicity. Hence, it may be both appropriate and valuable to offer some statement regarding the causes of illness to the former groups. These findings highlight the need to tailor interventions according to the developmental and cultural needs of the child.
Limitations of study

Estimating cognitive development

Despite the value of the present study, there were a number of limitations which need to be considered. Firstly, the absence of a developmental trend in receptive language ability, and the discrepant findings for reading age, raised questions regarding the use of these measures as global estimates of cognitive development. The estimation of cognitive development has been cited as a difficulty of previous studies (e.g. Eiser, 1985; Paterson et al., 1999), with the use of chronological age (e.g. Burbach & Peterson) and performance on Piagetian tasks (e.g. conservation) being challenged as inadequate. However, the support for domain-specific theories of cognitive development from this and other studies (Goldman et al., 1991) raises questions regarding the appropriateness of single indicators of cognitive ability. Underlying domain-specific theories is the premise that children may possess different levels of understanding and conceptual ability for different domains and for different aspects within a domain. This challenges the notion of deriving a single measure of cognitive development and raises questions regarding the design of future studies.

A second limitation of the study was the failure to secure developmentally distinct samples through recruiting participants from year 4 and year 6. The need to recruit participants from the same school and to ensure that all children were able to complete the card sort task, offered little alternative to this problem in the present schools. An alternative approach would have been to identify middle school populations (9-13 year), or to have recruited an older sample from the junior schools.

Illness items

A further limitation concerned the nature of the illnesses selected for use in the study. Given the emphasis on studying children's understanding of illness, it was deemed important to include illnesses which would be of relevance to children. However, the items generated by the focus groups contained a mixture of what would medically be classified as diseases (e.g. cancer) and symptoms (e.g. headache). This mix created problems in the content analysis, in that it was difficult to distinguish whether children
were treating certain items (e.g. headache) as illnesses or symptoms. This distinction ultimately determined the category in which the response was placed.

The use of disease labels in the present study was consistent with adult research on illness prototypes (Bishop, 1995). The illness prototypes model is based on the premise that individuals develop idealised representations, or prototypes, for particular diseases, which include the symptoms and other attributes generally associated with that disease. The inclusion of symptoms in the present study was in contrast to this approach, as the focus was directed away from disease labels and onto the individual features of illness (i.e. symptoms). As discussed above, the different focus of the two approaches may affect how the cards are sorted. As such, future studies need to be clear in their choice of approach and in selecting the appropriate items to be sorted.

A further difficulty in this area was that despite the illnesses being generated by children in the focus groups, there were a number of items which many participants reported having never heard of. Although these items were removed from the participant’s free card sort, items which they had heard of, but knew nothing about, were still included. As such, children may have been asked to make decisions about illnesses they knew relatively little about. Also, certain items were excluded from the free sort more frequently than others, increasing the likelihood of bias being introduced into the illness plots. The decision was made to retain the less well known items in the analysis, since their exclusion would have compromised the explorative nature of the study. However, future research may benefit from selecting items with which all participants are familiar.

Card sort
A third area of difficulty was the presence of ambiguity in children’s responses concerning their grouping of illnesses in the free sort condition. The generation of a category labelled ‘multiple clause response’ highlighted the ambiguity concerning the overall theme being discussed by children. The card sort procedure requires that participants use a single criteria for allocating all items within an individual sort. Although children demonstrated their ability to do this in the structured sort, it was
unclear whether children met this requirement in the free sort condition. Given the explorative nature of the study and the reluctance to impose an adult interpretation on the responses of participants, the data were analysed as intended. However, the findings raise questions regarding the viability of a free card sort procedure for children of 8-11 years of age. Research is needed to consider this issue.

A number of children were unable to explain their responses in the free sort condition. Several responses also provided insufficient information for them to be classified according to the illness themes. As with previous studies, children’s responses appeared to be limited by their expressive language ability, thus restricting the amount of information available. Although the loss was not substantial, this may have introduced some bias into the data set. The present study would have been strengthened by the inclusion of an assessment of expressive, as well as receptive language ability, to investigate the above effect.
**Future Research**

The findings from the present study indicate the need for further research in a number of areas. These are presented below.

(1) The present study highlighted the value of alternative theoretical frameworks for considering children's concepts of illness. In particular, it demonstrated the relevance of Leventhal's illness representations model for studying child populations, and emphasised the important contributions of domain-specific theories of cognitive development and Nelson's script theory (1986). The application of such approaches to this area has already been recommended within the literature (see Eiser, 1989). In the light of the theoretical criticisms and lack of empirical support for the Piagetian approach to studying children's concepts of illness, the adoption of such approaches offers a promising avenue for advancing our understanding in this area.

(2) Given the qualitative and exploratory nature of this study, there is a need for the present findings to be replicated in further empirical work. This would involve randomised studies, with larger sample sizes, and the recruitment of participants from a wider age range, so as to secure developmentally separate samples. It would also be of value to include children from a wider range of ethnic backgrounds, to further investigate the influence of ethnicity on children's concepts of illness.

(3) Studies are required to further investigate the optimum model of children's illness representations and to explicate the relationship between Leventhal's five illness components and the components identified in other research (e.g. perceived severity of illness). Such work needs to consider that composite measures of Leventhal's individual components, such as Hampson's seriousness and intensity components, may offer a more optimal representation of children's concepts of illness.

(4) There is a need to investigate the emergence and development of individual illness components within children's representations. Issues include the age, or phase of cognitive development when children become aware of each component and how
factors such as cognitive ability, ethnic background, illness experience and exposure to illness-related information (e.g. through the media, or through cultural group) may influence the development of individual components.

(5) There is a need to further explore the viability of card sort procedures for children of this age (8-11 years). In particular, studies need to verify whether or not children of 8 to 11 years of age are capable of selecting and applying a single rule for allocating cards within a free sort procedure.

(6) Finally, there is a need to reconsider the current approach to investigating the influence of cognitive development on children’s concepts of illness. The inconsistencies in the present study, and the support for domain-specific theories of cognitive development, challenge the notion of a universal level of cognitive ability. Work is needed to establish guidelines for investigating the influence of cognitive development within a domain-specific cognitive developmental framework.
Conclusions

The following conclusions were drawn from the findings of the present study. Firstly, children of 8-11 years of age spontaneously apply the five components of adult illness representations when asked to consider the similarities and differences between illnesses. Identity, and in particular, symptoms, appear to form the most salient feature of illness for children in this age range, with the causes and consequences of illness also being salient for some children. Cause appears to be a more salient feature of illness for children of 10 and 11 years of age than those of 8 and 9 years. It also appears to be a more salient feature of illness for children of black African/Caribbean ethnicity than those of white British ethnicity. Cure and timeline do not appear to be salient features of illness for the majority of children of this age, irrespective of ethnic background.

In addition to Leventhal’s components, some children of 8-11 years spontaneously consider illness in terms of perceived severity, personal vulnerability, comorbidity of symptoms and illnesses and the idea of one illness influencing the course of another. These components appear to be more salient for children than Leventhal’s cure or timeline components. It is unclear whether the lack of saliency of particular components reflects the absence of these components in the illness representations of children in this age range, differences in the degree of conceptual development of components, or differences in the relevance of components for children.

In general, children of 10 and 11 years of age appear to make greater conceptual distinction between illnesses and are less focused on commonalities, than children of 8 and 9 years. This is consistent with Nelson’s script theory. Greater ability to differentiate between illness did not appear to be associated with cognitive developmental changes in other domains. This is consistent with domain-specific theories of cognitive development and represents a challenge to universal stage theories, such as Piaget’s (1930).
The findings suggest that when communicating with children about illness, emphasis should be placed on the identity of the illness and in offering a statement of the normality of the child’s experience. Such information would appear to be of most concern to children and is consistent with their own focus with respect to illness. Some explanation of the causes of illness may also be meaningful and appropriate for older children and those of black African/Caribbean ethnicity, since many of these children appear to spontaneously consider illness in these terms. Given the limited salience of the timeline and cure aspects of illness for children of this age, communication concerning these aspects of illness is likely to be less relevant.

Children’s knowledge of particular illnesses appears to be influenced by their personal experience with that illness. However, other factors are also involved. These may include the illness-related information children receive through the media, the relative prevalence of illnesses within different cultures and cultural beliefs about illness.
References


Appendices

1. Demographic interview questions

2. Illness items used in the study

3. Recruitment letter for parents and consent form regarding children’s participation in the study

4. Instructions for the card sort tasks

5. Items concerning actions in response to illness

6. Thank you letter to parents

7. Results from the data analysis

   Table A: Content analysis category allocation by first researcher

   Table B: Content analysis category allocation by second rater

   Table C: Breakdown of multiple clause responses
Appendix 1: Demographic interview questions

1. Does your mother/father go out to work? Yes/No

2. Do your mother and father both live at home with you? Yes/No
   If yes: Who lives at home with you?

3. Have you ever been to hospital to stay overnight? Yes/No
   If yes: prompt for information regarding the reason for that stay in hospital.

4. Has anyone in your family (parents, siblings, or grand-parents) been to stay in hospital overnight? Yes/No
   If yes: prompt for information regarding the reason for their stay in hospital.
**Appendix 2: Illness items included in the study**

<table>
<thead>
<tr>
<th>Item number</th>
<th>Illness Item</th>
<th>Number of focus groups mentioning the item</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Asthma</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>Cancer</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>Meningitis</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>Eczema</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>Hayfever</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Headache</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>Stomach ache</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>Toothache</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>Flu</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>Chicken pox</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>Bee sting</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>Broken leg</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>Diarrhoea</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>Tonsillitis</td>
<td>3</td>
</tr>
<tr>
<td>15</td>
<td>Migraine</td>
<td>3</td>
</tr>
<tr>
<td>16</td>
<td>Food poisoning</td>
<td>3</td>
</tr>
<tr>
<td>17</td>
<td>Diabetes</td>
<td>3</td>
</tr>
<tr>
<td>18</td>
<td>Earache</td>
<td>3</td>
</tr>
<tr>
<td>19</td>
<td>Verruca</td>
<td>3</td>
</tr>
<tr>
<td>20</td>
<td>Sunburn</td>
<td>3</td>
</tr>
<tr>
<td>21</td>
<td>Head lice/nits</td>
<td>3</td>
</tr>
<tr>
<td>22</td>
<td>Nose bleed</td>
<td>3</td>
</tr>
<tr>
<td>23</td>
<td>Cut</td>
<td>3</td>
</tr>
<tr>
<td>24</td>
<td>Mosquito bite</td>
<td>3</td>
</tr>
<tr>
<td>25</td>
<td>Leprosy</td>
<td>3</td>
</tr>
</tbody>
</table>
Appendix 3: Recruitment letter for parents and consent form for children’s participation in the study

Dear Parent,

Re: Research into children’s understanding of illness

I am carrying out a research project to look at what children understand about different illnesses. (headteacher) of St Joseph’s School, has agreed that I may conduct this research with pupils at your school. Your child is a member of one of the classes chosen for the project. This research is important for helping us know what children need to learn about illnesses they may come across. Teaching children about illness, and how to prevent it, is a good way of helping them be more healthy now, and when they are older. Giving children information about illness can also help them cope better if they become unwell.

A total of 10 children need to be selected from each class involved in the research project. I am writing to ask whether you would agree for your child to take part. Children who do take part will be seen within school hours for a one off interview lasting about 30 minutes. In this interview, children will be asked to complete two types of task. The first will involve picking out pictures of objects named by the interviewer. The second will involve a game, where children are asked to sort cards into different groups. Five children will be asked to repeat this game a second time, one week after the first interview. Children will not be asked to do anything else after these interviews. All information will be kept confidential.

I hope you can see the benefits of this project. However, all parents have the right to say no to their child taking part. This decision will not affect their schooling, or future opportunities, in any way. Children who do take part in the project will not miss out on important classes or activities.

I would be grateful if you could please complete the form attached to this letter, to indicate whether or not you would be willing for your child to take part in this project. It would help if the form could be returned to me, using the envelope provided. Thank you for your help in this matter. If you have any questions about the project, please contact me at the above address.

Yours sincerely

Liz Chorlton, MSc
Psychologist in Clinical Training
Consent form

Research Project: Children’s understanding of illness

I have read the letter about the research project on children’s understanding of illness. I understand what will be involved in the study. I know that I have the right to say no to my child participating and that this decision will not affect their schooling, or their involvement in future activities within the school. I also understand that I may choose to withdraw my child from the project at any point, and that my child can choose to drop out of the project at any point.

Please complete the details below and tick one of the boxes to indicate whether or not you would be willing for your child to take part in the project at St Joseph’s School.

I am willing for my child to be involved in this project  

I would prefer my child not to take part in this project  

Name of Child:  

Age:  

Name of Parent:  

Signature of Parent:  

Date:  

Please return the completed form to me, at St Joseph’s School, using the envelope provided.
Appendix 4: Instructions for card sort task

Information about the Study
Researcher: “I am doing a research project to find out what children of different ages know about illnesses. I want to find out what things you know about, as well as what you don’t know about. So if you have heard of something, but don’t know much about it, please tell me anyway. There are no right or wrong answers. I am just interested in finding out what you children of your age think.

Whatever you tell me about illnesses will be kept between me and you. I will not tell anyone else. If you don’t want to answer some of the questions, or play any of the games, please tell me and you won’t have to do them. If you decide that you don’t want to take part any more, you just have to tell me.

Do you have any questions? If you think of any questions, please ask me.”

British Picture Vocabulary Scale (BPVS II)
Researcher: “To start off with, I am going to ask you to play a guessing game with me. It is not about illnesses, but is about objects, or things, you might come across in daily life.”

The standard administration instructions for the BPVS II will then be followed.

Structured Card Sort Task
Familiarity with the illness items
Researcher: “I have some cards here. On each card there is the name of an illness, or something which can make you feel ill. I am going to go through the cards one at a time and I would like you to think about what you know about this thing.

If you have never heard of it, put the card in a pile here (point) under the label which says I have never heard of it before. If you have heard of it but don’t really know anything about it, put it below this label (point), which says I have heard of it but don’t know anything about it. If you know a bit about the illness, put it in a pile under this label (point), which says I know a bit about it. If you know a lot about it, put the card under this label (point), which says I know a lot about it. I will read the items on the cards to you and ask you where you think each one should go. Do you understand what you need to do? Do you have any questions?”

Experience with Illness
Researcher: “We are going to go through this pack of cards again. This time I want you to tell me about whether or not you have had the things yourself, or whether you know someone who has had them.

I want you to put the cards in piles under these four labels. They are I have had this myself; I haven’t had it myself, but someone in my family has had it; no one in my family
has had it, but a friend has had it; or I don't know anyone who has had it. I will read the items on the cards one at a time. I would like you then to put each card in the pile which is true for you. Do you understand? Do you have any questions?"

**Free Card Sort Task**

**Researcher:** "This time, I want to find out what you think and feel about the things on these cards (24 illness cards). I want you to think about which items on the cards are similar to each other and which ones are different.

I want you to sort the cards into groups, so that all the things in each group are the same in some important way, but are different from things in other groups. You can put the cards into as many groups as you want and you can put as many cards as you want in each group. There are no right or wrong answers. You can sort the cards into groups in any way you want. It's up to you. Do you understand what I want you to do? Do you have any questions?"

"Let's have a look at what you have in each group. Here you have.. Are you happy with that?"

**Subsequent free sorts**

**Researcher:** "I want you to think about other ways in which these cards can be grouped. Can you think of any other important ways in which some of these things might be similar? Can you sort the cards into groups in a different way to before, so that all the things in each group are alike in some important way, but are different from the things in other groups?"

"Let's have a look at what you have in each group. Here you have.. Are you happy with that?"

**Debriefing**

Thank you for taking part in this research. You had lots of ideas which will be very helpful for me. Do you have any questions?

I am going to see some other children in your class and in other classes. I would like them to come up with their own ideas and not copy your ideas. So it would help if you didn’t talk about what you did with other children, until they have done it themselves. Thank you for your help.
Appendix 5: Items concerning responses to illness

Children were asked to select which of the following they believed to be helpful courses of action to take in response to illness.

**Action**
- Seeing a doctor
- Medicine
- Going to hospital
- Keeping warm
- Have an operation
- Rest

- Stop drinking water
- Don’t wash
- Watch lots of television
- Getting angry with your mum

Rest
Appendix 6: Thank you letter to parents

Dear Parent

Re: Research into children’s understanding of illness

Thank you for allowing your child to take part in this research project, being carried out at West Hill School. The study has now been completed and no further involvement will be required by children in the school. Each child who took part in the project completed a short interview with myself. This was about their understanding of illness and of what people should do if they get sick.

The information from this project will be kept confidential and individual children’s responses will only be seen by the researcher. A summary of the main findings from the project will be available next Easter. If you would like a copy of this, or have any further questions about the research, please contact me at the above address.

Yours sincerely

Liz Chorlton, MSc
Psychologist in Clinical Training
Appendix 7: Additional results from the data analysis

Table A: First rater content analysis of children’s explanations of illness groups

<table>
<thead>
<tr>
<th>No.</th>
<th>Category Label</th>
<th>Number of statements</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Child did not know</td>
<td>24</td>
</tr>
<tr>
<td>2</td>
<td>Answer did not make literal sense</td>
<td>2</td>
</tr>
<tr>
<td>3</td>
<td>Statement of similarity with no explanation</td>
<td>22</td>
</tr>
<tr>
<td>4</td>
<td>Perceived severity</td>
<td>9</td>
</tr>
<tr>
<td>5</td>
<td>Cause</td>
<td>30</td>
</tr>
<tr>
<td>6</td>
<td>Identity - Symptoms involved</td>
<td>118</td>
</tr>
<tr>
<td>7</td>
<td>Identity - Location</td>
<td>20</td>
</tr>
<tr>
<td>8</td>
<td>Identity - Nature of illness</td>
<td>2</td>
</tr>
<tr>
<td>9</td>
<td>Personal vulnerability</td>
<td>18</td>
</tr>
<tr>
<td>10</td>
<td>Comorbidity</td>
<td>18</td>
</tr>
<tr>
<td>11</td>
<td>One illness influencing another</td>
<td>9</td>
</tr>
<tr>
<td>12</td>
<td>Consequences</td>
<td>30</td>
</tr>
<tr>
<td>13</td>
<td>Timeline</td>
<td>6</td>
</tr>
<tr>
<td>14</td>
<td>Cure</td>
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Table B: Second rater content analysis of children’s explanations of illness groups

<table>
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<th>No.</th>
<th>Category Label</th>
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<td>Answer did not make literal sense</td>
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<td>4</td>
<td>Statement of similarity with no explanation</td>
<td>24</td>
<td>18</td>
</tr>
<tr>
<td>5</td>
<td>Perceived severity</td>
<td>16</td>
<td>9</td>
</tr>
<tr>
<td>6</td>
<td>Cause</td>
<td>28</td>
<td>21</td>
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<td>7</td>
<td>Identity - Symptoms involved</td>
<td>95</td>
<td>81</td>
</tr>
<tr>
<td>8</td>
<td>Identity - Location</td>
<td>21</td>
<td>18</td>
</tr>
<tr>
<td>9</td>
<td>Identity - Nature of Illness</td>
<td>7</td>
<td>2</td>
</tr>
<tr>
<td>10</td>
<td>Personal vulnerability</td>
<td>18</td>
<td>15</td>
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<td>11</td>
<td>Comorbidity of illnesses</td>
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<td>4</td>
</tr>
<tr>
<td>12</td>
<td>One illness influencing another</td>
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<td>Consequences</td>
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<tr>
<td>15</td>
<td>Cure</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>

Table C: Breakdown of number of additional children referring to individual illness themes in multiple clause responses

<table>
<thead>
<tr>
<th>Category label</th>
<th>No. of children mentioning theme</th>
<th>Percentage of extra children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perceived severity</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Cause</td>
<td>3</td>
<td>7.5</td>
</tr>
<tr>
<td>Identity</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Personal vulnerability</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Comorbidity</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>One illness influencing another</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Consequences</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>Timeline</td>
<td>1</td>
<td>2.5</td>
</tr>
<tr>
<td>Cure</td>
<td>3</td>
<td>7.5</td>
</tr>
<tr>
<td>Personal/family experience</td>
<td>1</td>
<td>2.5</td>
</tr>
</tbody>
</table>