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RESEARCH TITLE:
'The Psychological Adjustment of Mothers and Children to Encopresis'

VOLUME I

GEMMA DOLD

2002
I certify that all the material in this portfolio, which is not my own work has been identified and that no material is included for which a degree has previously been conferred upon me.

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This work has been completed with sincere gratitude to the Clinical and Research Supervisors, the Course Team and my fellow trainees who have helped to support, guide and inspire me during the three year course.

Special thanks are extended to the volunteers who participated in the research work presented in this volume.

I would like to dedicate this volume to my family and friends who have wholeheartedly supported and encouraged me throughout studies.
ESSAY 1: ADULT MENTAL HEALTH ......................................................... 15

“Both behaviour therapists and cognitive therapists may use
behavioural techniques in the treatment of anxiety disorders and
depression. However, the underlying theoretical rationales for the use
of these behavioural techniques differs. Critically evaluate these
different theoretical rationales by drawing on the literature from anxiety
and depression.”

ESSAY 2: PEOPLE WITH LEARNING DISABILITIES ........................................ 33

“What is the impact of others’ expectations on the communicative
abilities of people with learning disabilities and how might a clinical
psychologist work with these issues?”

ESSAY 3: CHILD, ADOLESCENT AND FAMILY ........................................... 55

“Critically evaluate psychological theories of child abuse and their
contribution to clinical practice.”

ESSAY 4: OLDER ADULTS ................................................................. 73

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

ESSAY 5: NEUROPSYCHOLOGY ............................................................... 93

“In addition to Neuropsychology, what other knowledge and skills are
necessary to carry out effective cognitive rehabilitation?”
OVERVIEW OF CLINICAL EXPERIENCE

CORE PLACEMENT 1: ADULT MENTAL HEALTH .................................................. 115

CORE PLACEMENT 2: PEOPLE WITH LEARNING DISABILITIES ...................... 115

CORE PLACEMENT 3: CHILD, ADOLESCENT AND FAMILY ............................. 116

CORE PLACEMENT 4: OLDER ADULTS ............................................................. 116

SPECIALIST PLACEMENT 1: NEUROPSYCHOLOGY ........................................... 117

SPECIALIST PLACEMENT 2: NARRATIVE/SYSTEMIC ......................................... 117

CASE REPORT SUMMARIES

CORE PLACEMENT 1: ADULT MENTAL HEALTH ............................................. 119

Case Report Summary .................................................................................... 120

"Assessment and Treatment of Depression and Anxiety in a 55year old Housewife Using a Cognitive Behavioural Approach"

CORE PLACEMENT 2: PEOPLE WITH LEARNING DISABILITIES ...................... 121

Case Report Summary .................................................................................... 122

"Assessment and Intervention with a Woman with Profound Learning Disabilities and Spastic Quadriplegia"
<table>
<thead>
<tr>
<th>CONTENTS</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CLINICAL DOSSIER (CONTINUED)</strong></td>
<td></td>
</tr>
<tr>
<td><strong>CORE PLACEMENT 3: CHILD, ADOLESCENT AND FAMILY</strong></td>
<td>123</td>
</tr>
<tr>
<td>Case Report Summary</td>
<td>124</td>
</tr>
<tr>
<td>“Assessment and Intervention with a Twelve year old Female Child</td>
<td></td>
</tr>
<tr>
<td>Presenting with Post Traumatic Stress, using a Cognitive-Behavioural</td>
<td></td>
</tr>
<tr>
<td>Approach”</td>
<td></td>
</tr>
<tr>
<td><strong>CORE PLACEMENT 4: OLDER ADULTS</strong></td>
<td>125</td>
</tr>
<tr>
<td>Case Report Summary</td>
<td>126</td>
</tr>
<tr>
<td>“Neuropsychological Assessment of a Sixty-Five year old Alcoholic</td>
<td></td>
</tr>
<tr>
<td>Woman”</td>
<td></td>
</tr>
<tr>
<td><strong>SPECIALIST PLACEMENT 1: NEUROPSYCHOLOGY</strong></td>
<td>127</td>
</tr>
<tr>
<td>Case Report Summary</td>
<td>128</td>
</tr>
<tr>
<td>“Neuropsychological Rehabilitation with a 49 year old Woman in the</td>
<td></td>
</tr>
<tr>
<td>Early Stages of Huntington’s Disease”</td>
<td></td>
</tr>
</tbody>
</table>
Acute Psychiatric Services: An Exploratory Evaluation of Staff Training in Cognitive Behavioural Therapy, Based on Service User Satisfaction

Abstract

Introduction

The Need for Change in Acute Psychiatric Wards

Patient Satisfaction as a Measure of Effectiveness

The Current Research

Research Aims

Setting

Method

Design

Participants

Ethical Considerations and Exclusion Criteria

Interview Development

Confounding Variables

Measures

Procedure

Results

The Data

Response Rates

Participants

Client Satisfaction Questionnaire

Table A: Client Satisfaction Questionnaire

Named Nurses and Contact with Staff

Table B: Contact With Named Nurses and Staff

Satisfaction with Communication

Table C: Satisfaction with Communication

Ward Atmosphere Scale
**CONTENTS**

**RESEARCH DOSSIER (CONTINUED)**

<table>
<thead>
<tr>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discussion</td>
</tr>
<tr>
<td>Changes in Overall Satisfaction</td>
</tr>
<tr>
<td>Satisfaction with Staff Contact</td>
</tr>
<tr>
<td>Impact of Reconfiguration of Day Services</td>
</tr>
<tr>
<td>Limitations</td>
</tr>
<tr>
<td>Recommendations</td>
</tr>
<tr>
<td>References</td>
</tr>
<tr>
<td>Appendices</td>
</tr>
<tr>
<td>1. Education Programme for Nursing Staff</td>
</tr>
<tr>
<td>2. Information Leaflet</td>
</tr>
<tr>
<td>3. Consent Form</td>
</tr>
<tr>
<td>4. Interview</td>
</tr>
<tr>
<td>5. Response Rates</td>
</tr>
<tr>
<td>6. Participant Demographics</td>
</tr>
<tr>
<td>7. Satisfaction with Communication</td>
</tr>
<tr>
<td>8. Nature of Communication</td>
</tr>
<tr>
<td>9. Behavioural Observation</td>
</tr>
<tr>
<td>10. Ward Atmosphere Scale</td>
</tr>
</tbody>
</table>

Proof of Presentation | 173
Contents

Research Dossier (Continued)

PAGE

Literature Review 176

"Critical Review of Psychosocial Factors in the Psychological Adjustment of Children with Chronic Illnesses and their Mothers"

Introduction ......................................................................................................... 175

Historical Background ........................................................................................ 176

Impact of Illness on Psychological Adjustment ............................................... 177

- Condition Type ......................................................................................... 177
- Severity ........................................................................................................ 178
- Impact of Demographic Factors ............................................................ 179

Child Parameters ............................................................................................. 180

- Child Mediational Processes ...................................................................... 180
- Child Adjustment ....................................................................................... 181

Maternal Parameters ....................................................................................... 181

- Maternal Mediational Processes ............................................................ 181

Stability of Child and Maternal Psychological Adjustment Over Time .......... 183

Evaluation of Research Methodology ............................................................... 183

- Sample ........................................................................................................ 184
- Design .......................................................................................................... 185
- Methods of Measurement ............................................................................ 186
- Relationships Among Variables ............................................................... 187
- Clinical Implications .................................................................................... 188

Future Directions .......................................................................................... 188

Conclusion ....................................................................................................... 190

References ....................................................................................................... 191
MAJOR RESEARCH PROJECT

‘The Psychological Adjustment of Mothers and Children to Encopresis’

CHAPTER 1: INTRODUCTION

1.1 Encopresis Epidemiology ................................................................. 201
   1.1.1 Etiology and Clinical Features of Encopresis .............................. 202
   1.1.2 Treatment and Outcome ............................................................ 203
1.2 Psychological Adjustment ........................................................................ 204
1.3 Parental Adjustment and it’s Importance .............................................. 205
   1.3.1 Maternal-Child Adjustment ....................................................... 206
1.4 Child Psychological Adjustment.............................................................. 207
   Behavioural and Familial Characteristics ............................................. 208
   Depression, Anxiety and Aggression .................................................... 209
   Self-Esteem ..................................................................................... 210
   The Importance of Child Adjustment .................................................. 211
1.5 Illness Perceptions .................................................................................. 212
1.6 Models and Maternal Adjustment............................................................ 213
   Figure 1: The Stress and Coping Model .............................................. 214
   Cognitive Processes in the Stress and Coping Model ......................... 215
1.7 Aims of this Study .................................................................................. 216

CHAPTER 2: METHOD

2.0 Procedure ............................................................................................ 217
2.1 Participants ........................................................................................... 218
2.2 Sample Description .............................................................................. 219
2.3 Measures ............................................................................................... 220
   2.3.1 Psychological Adjustment .......................................................... 221
   2.3.2 Illness Representations ............................................................... 222
2.4 Statistical Analysis ................................................................................ 223
CHAPTER 3: RESULTS

3.1 Hypothesis 1 .................................................................................................. 228

3.2 Hypothesis 2.................................................................................................. 228

3.3 Hypothesis 3.................................................................................................. 229
  Illness and Demographic Variables ................................................................. 229
  Perceived Child Adjustment and Psychological Processes ............................ 229

3.4 Hypothesis 4.................................................................................................. 231
  Additional Findings .......................................................................................... 233

3.5.0 Hypothesis 5............................................................................................... 233

3.5.1 Hypothesis 6............................................................................................... 233
  Additional Findings .......................................................................................... 234

3.6 Hypothesis 7.................................................................................................. 235
  Mediating Factors ............................................................................................ 239

3.7 Causal Attributions ...................................................................................... 239

CHAPTER 4: DISCUSSION

4.1 Levels of Maternal and Child Psychological Adjustment ............................ 241

4.2 Maternal Psychological Adjustment and Illness and Demographic
  Variables ............................................................................................................ 242

4.3 Maternal and Child Psychological Adjustment ........................................... 245

4.4 Predicting Psychological Adjustment from Illness Representations
  and Perceived Child Adjustment ....................................................................... 247

4.5 Perceived Causes of Encopresis ................................................................. 249

4.6 Limitations and Future Research Directions ............................................. 250

4.7 Conclusions ................................................................................................. 252

REFERENCES ................................................................................................. 253
<table>
<thead>
<tr>
<th>Appendix</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1: Ethics Approval</td>
<td>264</td>
</tr>
<tr>
<td>Appendix 2: GP Letter</td>
<td>267</td>
</tr>
<tr>
<td>Appendix 3: Initial Letter</td>
<td>268</td>
</tr>
<tr>
<td>Appendix 4: Information Sheet</td>
<td>270</td>
</tr>
<tr>
<td>Appendix 5: Consent Form</td>
<td>271</td>
</tr>
<tr>
<td>Appendix 6: Second Letter</td>
<td>272</td>
</tr>
<tr>
<td>Appendix 7: Reminder Letter</td>
<td>273</td>
</tr>
<tr>
<td>Appendix 8: Questionnaire Booklet</td>
<td>274</td>
</tr>
<tr>
<td>Appendix 9: Brief Symptom Inventory</td>
<td>282</td>
</tr>
<tr>
<td>Appendix 10: Transformed Data</td>
<td>284</td>
</tr>
</tbody>
</table>
QUALITATIVE RESEARCH PROJECT

"Exploring the Personal Accounts of Men's Transitions to Fatherhood using Interpretative Phenomenological Analysis"

Introduction ......................................................................................................... 285
Methodology ......................................................................................................... 287
  Participants ........................................................................................................ 287
Design and Measures ........................................................................................... 287
Procedure ............................................................................................................. 288
Analysis and Results ............................................................................................ 290
  Table 1: Demographics Concerning Father ................................................... 290
  Table 2: Demographics Concerning First Born Child .................................... 290
  Table 3: Fathers’ Themes ............................................................................... 291
Change in Relationships ...................................................................................... 292
  With Wife/Partner .......................................................................................... 292
  With Friends ................................................................................................ 293
  With Work Colleagues ............................................................................... 294
  With Parents ................................................................................................ 294
Discussion and Overview .................................................................................... 295
  Theoretical Implications ............................................................................... 295
  Implications for Practice .............................................................................. 295
  Limitations ...................................................................................................... 296
References ............................................................................................................. 297
Appendix .............................................................................................................. 298
  1. Interview Schedule .................................................................................... 299
  2. Background Information .......................................................................... 301
  3. Interview Transcript .................................................................................. 303
  4. Research Information Sheet ..................................................................... 307
  5. Research Consent Form ............................................................................ 308
• Adult Mental Health

• People with Learning Disabilities

• Child, Adolescent and Family

• Older Adults

• Neuropsychology

1999 - 2002
"Both behaviour therapists and cognitive therapists may use behavioural techniques in the treatment of anxiety disorders and depression. However, the underlying theoretical rationales for the use of these behavioural techniques differs. Critically evaluate these different theoretical rationales by drawing on the literature from anxiety and depression."

**Core Placement 1**

**December 1999**

Year 1
Both behaviour therapists and cognitive therapists may use behavioural techniques in the treatment of anxiety disorders and depression. However, the underlying theoretical rationales for the use of behavioural techniques differs. Critically evaluate these different theoretical rationales by drawing on the literature from anxiety and depression.

Both behaviour therapy (eg: Eysenck, 1994, 1997; Wolpe, 1958, 1990) and cognitive therapy (eg: Beck 1976 cited in Beck, Rush, Shaw and Emery, 1979) utilise behavioural techniques in the treatment of anxiety and depression, but do so on the basis of their different underlying theoretical assumptions. Hence, they claim that therapeutic improvements are achieved through different processes. Behaviour therapy originally developed behavioural techniques on the basis of conditioning theories of learning, and claimed that maladaptive behaviour was therapeutically improved through a process of ‘unlearning’ of the stimulus-response association (Wolpe, 1990). This approach was hailed as an ‘evolutionary development’ (Latimer and Sweet, 1984; Sweet and Loizeaux, 1991). The ‘cognitive revolution’ that followed hypothesized that cognitive processes play a more active and mediatory role on behaviour and emotional responses. It adapted behavioural techniques to enable the client to set up hypotheses to test their ‘faulty’ or automatic negative cognitions and to facilitate behaviour change by design, rather than by chance (Beck, 1976 cited in Beck, Rush Shaw and Emery 1979; Mahoney, 1977 cited in Wolpe 1990; Meichenbaum, 1997 cited in Wolpe 1990).

Critical evaluation of the theoretical rationales proposed for the use of behavioural techniques will draw upon examples from the literature on anxiety and depression. Since behaviour therapy and cognitive therapy do not arise from single, cohesive theories, it will focus on the conditioning theories of behaviour therapy (Pavlov, 1927, 1928 cited in Rim and Masters, 1979; Skinner, 1953: Wolpe, 1958 cited in Wolpe 1990) and Beck’s theory of cognitive therapy (Beck 1976 cited in Beck, Rush, Shaw and Emery, 1979). By introducing the origins and scientific foundations of behaviour
and cognitive therapy, looking at the behavioural techniques of systematic desensitisation, relaxation and pleasant activity scheduling, and considering empirical evidence for their clinical effectiveness, the inherent weaknesses of the theoretical rationales for the use of these behavioural techniques will be critically evaluated.

**BEHAVIOUR THERAPY**

**DEVELOPMENT AND SCIENTIFIC FOUNDATION**

Behaviour theories emerged in the 1950s due to a growing concern about the reliability and validity of the dominant psychotherapeutic view at that time - psychodynamics (Eysenck, 1952a cited in Wilson, 1997). It led to the emergence of a therapy that directly concerned itself with the clients' observable, maladaptive behaviours (emotions and cognitions) and derived therapeutic techniques from experimentally validated learning principles such as classical conditioning (Pavlov, 1927, 1928 cited in Rim and Masters, 1979), operant conditioning (Skinner, 1953 cited in Wolpe, 1990), and counter-conditioning (Wolpe, 1958 cited in Wolpe, 1990). Validated by demonstrating that fear analogues could be generated and later extinguished in animals these theoretical principles were largely extrapolated to the clinical problem of anxiety (Wolpe, 1958 cited in Wilson, 1997). By conceptualising human anxiety disorders in terms of Pavlovian and Hullian learning principles Wolpe (1958) developed systematic desensitisation specifically for the alleviation of maladaptive anxiety (Wolpe, 1958, 1969, 1973 cited in Rim and Masters, 1979). It was proposed that this behavioural technique would enable the client to learn adaptive responses, which would interfere with the clients maladaptive functioning and eliminate maladaptive behavioural responses (Eysenck, 1965 cited in Sheldon, 1995). A large number of specific techniques have since developed under the label of 'behaviour therapy' including relaxation, systematic desensitisation, activity scheduling and social skills training.

The use of rigorous scientific experimentation with animals to generate a scientific understanding of human behaviour is argued to provide behaviour therapy with 'both scientifically based problem assessments and scientifically based interventions' (Wilson, 1997, pg. 548). However, the use of learning theory as a complete explanation for human behaviour, cognitions and emotions has been criticised for
depending upon animal experiments to form a scientific foundation for complex human behaviours, for over-interpreting highly controlled animal experiments (Rachman, 1997), and over-simplifying human anxiety disorders (Gelder, 1997).

**SYSTEMATIC DESSENSITISATION IN ANXIETY**

Behaviour therapists (eg: Eysenck and Rachman, 1965 cited in Gross, 1992) assume that the fundamental process by which humans acquire adaptive and maladaptive behavioural responses is that of learning. The two-factor theory of fear and avoidance learning first combined the two processes of classical and operant conditioning to try and explain the development and maintenance of anxiety (Mowrer, 1947, 1960 cited in Latimer and Sweet, 1984). First, the client learns to fear a neutral stimulus (Object, event or situation), when that stimulus is paired with the occurrence of an aversive event that prompts a fear reaction (Wolpe and Rachman, 1960 cited in Gross, 1962). Then, reinforced by the reduction of anxiety, the client subsequently learns to escape or avoid the situation, which maintains the fear (operant conditioning). Avoidance fails to provide the client’s fear with a chance to undergo extinction and only strengthens negative reinforcement. On the basis of these learning principles behavioural techniques such as systematic desensitisation were believed to operate on several theoretical principles (Eysenck, 1994; Wolpe, 1958, 1969, 1973 cited in Rim Masters, 1979) the components of which will be considered in turn.

**EXTINCTION AND CLASSICAL CONDITIONING**

According to the principles of classical conditioning, exposure to the anxiety-provoking stimuli without the associated aversive event should lead to the eventual extinction of the conditioned response. Although systematic desensitisation is believed to operate according to processes of extinction, early comparisons to determine whether similar underlying processes are involved in both were inconclusive (Rim and Masters, 1979). Therapeutic benefits of extinction also largely depend upon the client staying in the situation for long enough to receive disconfirmation. This has been constructed as a rather simplistic and ‘hit or miss’ approach to treating anxiety (Salkovskis, 1996).
In the field of conditioning new fear responses in animals were produced by simple paired-associations, yet conditioning is not as simple as Pavlov first envisaged (Davey, 1981 cited in Sheldon, 1995). Pavlov’s theory of paired-conditioning predicts that a fear response could be conditioned with sufficient pairing and extinguished when the feared object or situation is repeatedly experienced without the aversive event. However, it does not explain how well-conditioned human phobia’s can be very resistant to extinction (Sheldon, 1995), how humans develop fear responses through a single exposure and how humans develop powerful fears of things that they have never, or will never directly encounter (Gross, 1992). The etiology and maintenance of fear indicates a more complex process which may involve cognitive misinterpretations of physical symptoms eg: “I think I’m going to faint” (Clark et al, 1997; Rachman and Levitt, 1998 cited in Emmelkamp, 1994) and negative thinking (Marshall, Bristoll and Barbarree, 1992 cited in Emmelkamp, 1994).

**Graded Exposure and Relaxation**

The ‘systematic’ component of systematic desensitisation involves a gradual exposure (mainly through imagination) in a hierarchical fashion, so that the client can progressively learn to inhibit their anxiety as they encounter closer approximations to the actual feared stimulus. Exposure starts with the least anxiety provoking and progresses to the most anxiety provoking and is achieved whilst the clients uses relaxation techniques. Although studies of clinical effectiveness indicate that exposure is an essential component in systematic desensitisation (Kazdin and Wilcoxon, 1976 cited in Gross, 1992; Leitenberg, 1976 cited in Wilson, 1997), they have led to a debate over the relative importance of graded exposure and relaxation in the therapeutic process. Contrary to Wolpe’s theoretical rationale for systematic desensitisation, the concepts of graded exposure and relaxation have been found to be less important than previously thought (Cook, 1968 cited in Sheldon, 1995). Similar treatment effectiveness has been found when the hierarchy is presented with or without relaxation, presented in order, in reverse or randomly (Gross, 1992), or is presented or not presented at all (flooding) (Emmelkamp, 1982 cited in Emmelkamp, 1994; Sturgis and Scott, 1984 cited in Andrews et al, 1994).
Relaxation techniques are proposed to reduce anxiety on the principles of counter-conditioning (Davison, 1968 cited in Emmelkamp, 1994) or reciprocal inhibition (Wolpe, 1958 cited in Emmelkamp, 1994). This maintains that it is not possible for opposite states such as anxiety and relaxation to exist at the same time (Wolpe, 1958). It proposes that the substitution of a maladaptive behavioural response (anxiety) with another, incompatible response (relaxation) should ‘desensitise’ the client to their anxiety. Unfortunately in clinical practice, relaxation does not always produce the effects predicted by Wolpe’s theory. A fairly frequent difficulty encountered with relaxation is the production rather than the reduction of anxiety (relaxation-induced anxiety; Heide and Borkovec, 1984 cited in Andrews et al, 1994).

**Operant Conditioning**

According to the principles of operant conditioning, behavioural techniques enable the client to repeatedly experience the conditioned object or situation without reinforcement (escape or avoidance). Skinner (1953 cited in Rim and Masters, 1979) assumes that learning takes place in the presence of reinforcement (Gross, 1992) and many people who experience profound traumas do not develop anxiety disorders in the presence of reinforcement (eg: Freud and Dan, 1951 cited in Gross, 1992). Behavioural treatment techniques draw upon Skinner’s work as if it has the predictive capacity of a theory, yet his work was largely atheoretical and sought only to describe and explain observable behaviour rather than to predict it (Rachman, 1997).

Conditioning theories generally leave several questions unanswered, for instance why do escape and avoidance behaviours fail to extinguish when the conditioned stimulus is not reinforced and why is fear maintained when the original trauma is forgotten or never occurs again? (Salkovskis, 1996). Claims that there is considerable empirical evidence to support treatment efficacy (Wilson, 1997) are somewhat misleading. Firstly, the modification of a maladaptive human response by learning principles does no necessarily prove the underling theory, which assumes that it was acquired through learning in the first place (Davison, 1968a cited in Rim and Masters, 1979). Secondly, most studies are not clinically relevant because they investigated mildly distressed students, rather than clients with anxiety found in the clinic (Emmelkamp, 1994). Even though systematic desensitisation is probably the most investigated of all the
behavioural technique, the theoretical rationale for its use remains unclear (Emmelkamp, 1994).

Pleasant Event Scheduling and Social Skills Training in Depression

Although early progress was largely achieved in analysing and treating anxiety disorders with behaviour therapy in the UK, little success was achieved analysing and assessing depression by purely behavioural means (Rachman, 1997). Much of the early work conducted with behaviour therapy focused on anxiety disorders and relatively few of the learning principles have successfully been applied to depression (Sheldon, 1995). Drawing on the principles of operant conditioning, the theory of ‘learned helplessness’ (Overmier and Seligman, 1967 cited in Rim and Masters, 1979; Seligman ad Maier, 1967 cited in Rims and Masters, 1979) did however, make an impact on clinical psychology when it emerged. Low rates of response-contingent reinforcement were experimentally demonstrated to produce gross deficits in eliciting escape responses in dogs, which was considered to the ‘basic experimental analogue of depression in human beings’ (Rim and Masters, 1979). Therefore, treatment approaches such as pleasant activity scheduling (Lewinsohn, 1975 cited in Emmelkamp, 1994) and social skills training (Sanchez, Lewinsohn and Larson, 1980) cited in Emmelkamp, 1994) were developed to therapeutically treat depression by increasing the rate of reinforcement for adaptive behaviour.

Lewinsohn’s basic theoretical rationale for using pleasant activity scheduling and social skills training was based in the premise that a lack of social skills caused lower rates of positive reinforcement. Empirical evidence does suggest that depressed individuals display fewer social skills than controls and that there is a correlation between rate of pleasant activities and mood ratings (eg: Lewinsohn and Hoberman, 1982 cited in Emmelkamp, 1994). However, these associations do not necessarily imply a causal relationship in depression, since social skills may have become impaired as a consequence of the depression. Contrary to Lewinsohn’s (1975 cited in Emmelkamp, 1994) theoretical rationale for pleasant activities causes an increase in mood (Biglan and Craker, 1983 cited in Emmelkamp, 1994) or a causal relationship between unpleasant activities and depression (Hoevanaars and van Sohn, 1990 cited in Emmelkamp, 1994). The theoretical rationale for the use of social skills training is
equally unclear in social phobia. Emmelkamp, Mersch and Vissia (1985a cited in Andrews et al, 1994) noted that social anxiety could improve even with the persistence of poor social skills. The complexity of social skills training on the whole, which offers a package of behavioural techniques such as exposure, desensitisation and modelling, has made it difficult to determine the most effective component (Emmelkamp et al, 1985a cited in Andrews et al, 1994, Marks 1985 cited in Andrews et al, 1994).

CLINICAL EFFECTIVENESS OF BEHAVIOURAL TECHNIQUES

Due to the broad use of theoretical principles and treatment strategies of behaviour therapy it is argued that it’s behavioural techniques can be applied to a range of problems (Rachman and Wilson, 1980 cited in Sheldon, 1995; Wilson, 1997). However, little success has been achieved in analysing, assessing and treating depression by purely behavioural means (Rachman, 1997; Sheldon, 1995) and research by cognitive therapists indicates that different treatment strategies are required for the treatment of different anxiety disorders. Systematic desensitisation appears to be more clinically effective when applied to relatively simple or minor phobias such as animal phobias (McGlynn et al, 1981 cited in Gross, 1992; Rachman and Wilson, 1980 cited in Gross, 1992). And less effective for more complex anxiety disorders such as agoraphobia and generalised anxiety disorder ( Rapee, 1991b cited in Andrews et al, 1994). Generalised anxiety disorder is considered a largely cognitive anxiety disorder without a central symptom, which makes it harder to define from a behavioural viewpoint and therefore limits its diagnostic criterion ( O’Neill, 1985a, 1985b cited in Andrews et al, 1994). It is largely acknowledged that cognitive behaviour theory appears to be more clinically effective over a wider range of problems than other treatments, including generalised anxiety disorder (Eysenck, 1994).

COGNITIVE THERAPY

DEVELOPMENT AND SCIENTIFIC FOUNDATION

With the growing dissatisfaction with behaviour therapy’s lack of regard for the client’s beliefs and attitudes and it’s relative inability to prescribe, predict and treat depression, Beck (1976 cited in Beck, Rush and Emery, 1979) developed a treatment
for depression which he called cognitive therapy. Cognitive therapy advanced previous scientific knowledge on the etiology, maintenance and treatment of anxiety and particularly depression. Rather than being based on experimental findings, cognitive learning therapies such as Beck (1976 cited in Beck, Rush, Shaw and Emery, 1979), Meichenbaum (1977 cited in Rim and Masters, 1979) and Ellis (1971b, 1977 cited in Rim and Masters, 1979) were based on ‘insightful clinical observation’ (Gelder, 1997, p. 290) and were highly influential. Behaviour therapy extrapolated its theories from experimentally validated behaviour principles and established the foundations for empirical standards within psychology for today. Yet cognitive theory has been less systematic about establishing scientific evidence for the existence of ‘hypothetical’ concepts such as cognitions (eg: Eysenck, 1994; Skinner, 1950, 1974 cited in Rim and Masters, 1979). The only unobservable and comprehensive phenomena in cognitive models such as Beck’s not only make it harder to empirically test and disprove his theory but also reduce the accuracy of its predictions (Gelder, 1997).

Despite empirical validation for the efficacy of cognitive treatments (APA, 1995 cited in Wilson, 1997) less validation has been found for how the mechanisms of change operate (Wilson, 1997). Even Beck (Hollon and Beck, 1986, p. 451) acknowledged that ‘there is not as yet, compelling evidence that cognitive therapy works, when it works, by the virtue of changing beliefs and/or information processing’. Although some advocates of behaviour therapy recognise that behaviour may be mediated by internal states (eg; Wolpe, 1958 cited in Rim and Masters, 1979), they generally criticise cognitive therapy on methodological grounds for depending on unobservable cognitive processes recalled through methods such as introspection and self-report, which reduce the predictive capacity, reliability and validity of psychology (Skinner, 1953 cited in Corrigan, 1990).

**Behavioural Techniques in Cognitive Therapy**

Cognitive Theory and treatment are guided by several intrinsic assumptions. Firstly, that individuals are actively involved in constructing their reality and not passive victims of their environments (Beck, 1967, 1987 cited in Salkovskis, 1997). Secondly, that cognitions (eg: automatic thoughts) play an important role in mediating behaviour
and emotion and in doing so, maintain symptoms of anxiety or depression (Beck, 1987, 1991 cited in Clark and Steer, 1996; Haaga, Dyck and Ernst, 1991 cited in Clark and Steer, 1996). Thirdly, that cognitive processes not open to consciousness can be accessed by training clients to recognise them through the use of behavioural techniques. Fourthly, that change in the cognitive mediating factors, whether directly through cognitive challenging techniques or indirectly through behavioural techniques, will elicit improvements in the behavioural and emotional components of the anxiety or depression (Salkovskis, 1996).

Cognitive therapy uses a variety of behavioural techniques, which have evolved from behaviour therapy, and provides greater flexibility in treatment (Beck, 1996). Since behavioural techniques were principally developed from early laboratory experiments and applied to human behaviour by behaviourists (Wolpe, 1958 cited in Rim and Masters, 1979), cognitive therapy heavily draws upon learning theory (Rim and Masters, 1979; Sheldon, 1995). Behavioural techniques play an important role in cognitive therapy by producing symptom relief and providing the client with coping strategies that support the cognitive models of anxiety and depression.

Early support for the use of behavioural techniques within cognitive therapy appears to have come from studies such as Taylor and Marshall (1997 cited in Rim and Masters, 1979). This study compares group treatments of cognitive therapy, behaviour therapy (eg: assertive behaviour, engaging in more positively reinforcing activities) and cognitive behaviour therapy with that of non-treated controls. The findings indicated that all three therapies produced significant improvements, but that on measures of depression, self-esteem and self-acceptance, cognitive behaviour therapy produced (marginally) more significant improvements. Although this was generally heralded as strong support for Beck and the use of behavioural techniques within cognitive therapy, it fails to provide insight into the process of change modelled by the combination of cognitive and behavioural techniques (Rim and Masters, 1979).
Systematic Desensitisation

Behavioural techniques are used to train clients in specific behavioural skills, eg: relaxation and social skills training, which can be used alongside cognitive techniques to assist the client to engage in their feared activities (Dryden and Golden, 1986). The use of behavioural techniques, such as self-monitoring and reality testing of negative beliefs in vivo and as homework is advocated as an important part of cognitive therapy. It enables the client to practice new behaviours at home and is believed to shorten therapy time (Dryden and Golden, 1986). Cognitive therapists largely altered the theoretical rationales for the use of behavioural techniques by including a cognitive element to the already established treatment techniques such as systematic desensitisation. However, systematic desensitisation in cognitive therapy still involves the concepts of graded exposure and relaxation, which as previously discussed, have been found to be less important than previously thought (Cooke, 1968 cited in Sheldon, 1995). Cognitive therapists believe that systematic desensitisation operates on several theoretical principles, the components of which will be considered in turn.

Behavioural Experiments

During treatment clients are encouraged to envisage their automatic negative beliefs as experimental hypothesis, which with training and the use of their own behaviours as experiments, they can test for validity and rationality (Beck et al, 1990; Young, 1994 cited in Beck, 1996). It is predicted that emotional and behavioural responses will be modified by the testing and subsequent modifying of the content of the clients cognitions, through behavioural techniques such as systematic desensitisation. This is conducted on the basis of Beck’s cognitive model in which anxiety is viewed as being cased and maintained by catastrophic misinterpretations of ambiguous bodily sensations (Clerk et al, 1997). Misattributions of physical sensations have been demonstrated in panic (eg: Clark et al, 1997; Rachman, Levitt and Lopatka, 1987 cited in Wolpe, 1989) as well as the therapeutic benefit of correcting these misattributions. In an experimental approach, Rapee et al, (1986 cited in Gelder, 1997) anxiety was substantially reduced when clients were reassured that their physical symptoms were the result of increased CO2 inhalation, a known trigger of panic attacks (Gelder, 1997). However, Wolpe and Rowan (1988 cited in Wolpe, 1989) argued in a study of
panic disorder that misattributions are a consequence rather than a cause of the panic. They also argue for the importance of conditioning in the acquisition of the fear response and in therapeutic mechanisms which cognitive therapists claim are ‘cognitive’.

The rationale for using behavioural techniques in cognitive therapy should predict improvements in clinical effectiveness, but the results are mixed. Cognitive therapy combined with behavioural techniques have produced considerable improvements on cognitive therapy alone in panic disorder (Barlow et al, 1989 cited in Andrews et al, 1994; Beck et al, 1992 cited in Andrews et al, 1994), but in a review of five studies by Latimer and Sweet (1984), no significant advantage was observed. Cognitive therapy also predicts that anxiety-provoking cognitions decline as a result of the testing out of an experimental hypothesis. However, the mechanism by which exposure produces fear-reduction is unclear. A study by Rachman (1993 cited in Eysenck, 1994) comparing the impact of cognitive therapy (without behavioural techniques) and behaviour therapy (exposure) on the reduction of fear and number of anxious cognitions, indicated that fear declined more in behaviour therapy and negative cognitions declined equally. Cognitive therapy does not assume that behavioural techniques alone can produce a reduction in fear and negative cognitions, and this study suggested that the use of ‘behavioural experiments’ are not an essential component in the treatment of anxiety.

**Relaxation and In Vivo Exposure**

Secondly, Beck (1976 cited in Gross, 1992) assumes that the client is able to think about an object or feared event more objectively, and able to reach the conclusion that their fear is irrational and the feared situation not dangerous when they are relaxed. Relaxation alone has been proven to induce clinically significant improvements of anxiety in panic disorder and agoraphobia (Michelson and Marchionne, 1991 cited in Andrews et al, 1994), but Beck’s theory did not predict the occurrence of relaxation-induced anxiety. Clients commonly find the constant wandering of their minds from topic to topic very distracting and anxiety-provoking (Heide and Borkovec, 1984 cited in Andrews et al, 1994). Furthermore, a study by Andrews et al (in press cited in
Andrews et al, 1997) indicated no difference in success rates for agoraphobics when relaxation was or was not included.

Exposure or production of the panic sensations in vivo enables the client to master anxiety management techniques and to experience the phobias situations in successive approximations (hierarchy) without the anticipated catastrophe (Andrews et al, 1994). It is thus argued that in vivo exposure enables anxious clients to disconfirm their fears through the repeated experience of the feared situation or object without the catastrophic event occurring. The use of in-vivo exposure, compared to imaginal, in cognitive therapy is supported by the production of longer-lasting relief for the majority of agoraphobics (Fava et al, 1995).

**Pleasant Activity Scheduling and Social Skills Training in Depression**

Cognitive therapy recognises the importance of different therapeutic strategies in relation to different (behavioural) symptoms, some of which may require immediate attention (eg: suicide ideation, insomnia, loss of appetite in depression). Through the use of systematic desensitisation and behavioural techniques such as structured activity scheduling and mastery and pleasure activities, the cognitive therapist can choose whether to focus on cognition or behaviour first depending on the severity of the symptoms. Severely depressed people may not initially be able to engage in cognitive techniques and are therefore encouraged to schedule their daily activities and increase the number of pleasurable activities. As the depression begins to lift, the focus of treatment shifts from the modification of behavioural symptoms to the modification of underlying cognitions (Shaw and Back, 1977 cited in Rim and Masters, 1979).

The use of behavioural techniques is therefore based on the belief that they increase mood, promote symptom relief and increase motivation. The lack of support for the hypotheses that unpleasant activities cause depression (Hoevannars and van Sohn, 1990 cited in Emmelkamp, 1994) and that increasing pleasant activities increases mood has already been discussed (Biglan and Craker, 1983 cited in Emmelkamp, 1994). There is considerable evidence demonstrating that depressed mood can interfere with cognitive processes involved in the interpretation of experiences (eg:
Blaney, 1986 cited in Teasdale, 1997; Morris 1989 cited in Teasdale, 1997) and that this interference leads to a tendency to interpret things more negatively (Haaga et al, 1991 cited in Teasdale, 1997). There is also some literature which indicates that targeting negative cognitions in therapy produces greater change in cognitions and improvement in mood than merely talking about them (Teasdale and Fennell, 1982 cited in Gelder, 1997). Wolpe (1989) however, argues that the treatment efficacy of cognitive therapy with behavioural techniques is invalid because studies are based on 'nonpsychotic' depression and no attention was paid to non-specific effects of the therapeutic relationship. Furthermore, cognitive behavioural approaches are not believed to be as straightforward as Beck first suggested (Teasdale, 1997). Teasdale (1997) for instance, argues that the relationship between cognitions and emotional states is not one-way, but instead reciprocal. Pharmacology aimed at changing depressed emotional states rather than changing cognitions can alter cognitions just as much as cognitive therapy (eg: Simons, Garfield and Murphy, 1984 cited in Teasdale, 1997). Therefore negative cognitions could be the consequence, rather than the cause of depression.

**Clinical Effectiveness of the Inclusion of Behavioural Techniques**

The use of behavioural techniques in cognitive therapy enables several empirically testable predictions. First, cognitive therapy predicts that it will have greater clinical effectiveness than behaviour therapy alone. Yet, only a scatter of studies indicate that a cognitive component carries advantages for longer term relapse prevention (Beck et al, 1985 cited in Sheldon, 1995). Secondly, that the use of behavioural techniques will enhance the effectiveness of cognitive therapy, yet studies comparing cognitive therapy with cognitive behaviour therapy are mixed with some demonstrating only slightly superior outcome effectiveness when behavioural techniques are employed (Hollon and Beck, 1994; Emmelkamp and Mersch, 1982 cited in Sheldon, 1995). Thirdly, that the use of behavioural techniques such as experiments will actively facilitate the change rather than leaving it to chance, and enhance the clinical effectiveness of cognitive behaviour therapy.

Studies indicate that both cognitive behaviour therapy and behaviour therapy are superior to non-treatment controls, but also that outcomes can show few significant
differences in anxiety (Sheldon, 1995) and depression (e.g., Elkin, Shea, Watkins and Collins, 1986 cited in Safran, 1990: Glass and Miller, 1980 cited in Safran, 1990). Even if it is possible to determine that the use of behavioural techniques in one therapeutic approach leads to greater clinical effectiveness, we cannot conclusively attribute the success of the treatment to the differences in theoretical rationale for using the techniques. A comprehensive review of the empirical literature (Lambert, 1986 cited in Safran, 1990; Lambert, Shapiro and Bergin, 1986 cited in Safran, 1990) estimated that non-specific factors such as therapeutic relationship account for up to forty-five percent of the variance in outcome, whilst specific technical factors only account for fifteen percent of the variance.

**CONCLUSION**

Although behaviour therapy and cognitive therapy incorporate behavioural techniques, the theoretical rationales proposed to explain their use differ with respect to the underlying assumptions of the two approaches. Although behaviour theory appears to offer a more ‘simplistic’ theoretical rationale for the use of behavioural techniques based on modifying observable phenomena, it boasts a broader scientific basis for the development of behavioural techniques (Wilson, 1997). Cognitive therapy on the other hand, largely draws upon the behavioural techniques established through learning principles, but advances the theoretical rationale for their use on the basis of cognitive factors. Although hailed as a relative strength of cognitive therapy, the unobservable nature of cognitions inherently weakens the theoretical rationales for therapeutic intervention. Although the theoretical rationales for the use of behavioural techniques have generated new research, stimulated discussion and offered practical guidance in solving everyday problems, the theoretical process of change facilitated by behavioural techniques in behaviour therapy and cognitive therapy still remains unclear (Emmelkamp, 1994; Rim and masters, 1979). With the growing emphasis on evidence-based practice and cost effectiveness in the NHS, it has now become increasingly more important for therapists to revise and further validate the theoretical rationales for using behavioural techniques in clinical practice.
REFERENCES


TITLE

“What is the impact of others’ expectations on the communicative abilities of people with learning disabilities and how might a clinical psychologist work with these issues?”

CORE PLACEMENT 2

MAY 2000

Year 1
What is the Impact of Others' Expectations on the Communicative Abilities of People With Learning Disabilities and How might a Clinical Psychologist Work With These Issues?

Providing a single definition of the term ‘Learning disabilities’ is difficult due to the heterogeneity of intellectual, cognitive and linguistic impairments. The term however, broadly refers to individual’s who have an intelligence quotient of less than 70 on standardised intelligence measures (Rondal and Edwards, 1997) and whose language problems largely contribute to their disabilities (Ceci, 1986 cited in Warren and Yoder, 1997). A considerable amount of research has investigated the nature and relationship of language and cognitive deficits in people with learning disabilities (PLD) (eg: Chomsky, 1965 cited in Warren and Yoder, 1997; Skinner, 1957). However, this fails to explain how an individual with substantial language and cognitive skills can still demonstrate major communicative deficits (Speckman, 1981 cited in Kavale et al, 1987; Van der Gaag and Dormundy, 1993). Communication is more than just language and exists in more than an intrinsic vacuum (Abrams, 1973 cited in Daniels, 1987). Communication is in fact an interactive process during which the opportunities to use language skills are influenced by the demands and expectations of others’ (Guyette, 1978 cited in Bradshaw, 1998). Hence, the development and maintenance of communicative abilities in people with learning disabilities are largely dependent on the way in which people (parents, teachers, staff, professionals) adjust their interpersonal behaviours. This is done in accordance with their expectations (Purcell et al, 1999; Vygotsky, 1962 cited in Bradshaw, 1998).

People without disabilities often take communication for granted and can be unaware of the barriers that they impose on effective communication with people with learning disabilities (Kaiser and Goetz, 1993). People with learning disabilities (PLD) on the other hand, may not only have to compete with sensory or motor impairments and concomitant syndromes or disorders (eg; Down’s Syndrome, Williams Syndrome, autism), but also have to compete with negative social attitudes (Kavale, et al, 1987).
This can lead to attempts to hide incompetence or feign competence, which may further increase expectations or draw further attention to incompetencies (Keman and Sabsay, 1997). Although there is still considerable debate over the nature, development and remediation of language difficulties in PLD, what will mainly be discussed here are the broader issues found within the systems that a clinical psychologist may work with. In order to understand the social, emotional and behavioural impact on the communicative abilities of a PLD, it is important to consider the type of expectations held by other people (eg: parents, teachers, staff and professionals) and how these expectations are transmitted. This will also help to illustrate why and how a clinical psychologist might work with the broader issues, rather than just ‘treating’ the individual.

**Nature of Communication Difficulties in PLD**

Communication is a process during which a sender conveys meaning to a receiver through verbal mediums (words, tone, pitch, intensity, frequency) and/or non-verbal mediums (gestural, facial expression, movements, activity engaged in, posture). It involves the use of both expressive and receptive language skills. Fogel’s (1993 cited in Grove et al, 1999) information-processing approach conceptualises communication as a ‘continuous process of mutual social co-ordination’ and provides a useful conceptual approach to breakdowns in communication with PLD. Successful communication relies upon the receiver being able to extract the information and meaning without error, on the basis of shared information (eg: Sperber and Wilson, 1987 cited in Keman and Sabsay, 1997). However, mild and moderate PLD often have difficulties using appropriate forms of language (words, gestures, facial expressions) and often make grammatical errors and irrelevant comments, use inappropriate tones or elevations of voice, provide piecemeal information, excessive intimate details, omit important information and/or use incomplete sentences (Keman and Sabsay, 1997). For example, when asked why he was being thrown out of his flat, Carl replied:

‘Well, a couple of reasons. They didn’t – Number one, they didn’t fumigate or anything the building. They go, ‘That’s a brand new door there’. And they say – the guy in one-oh-two smashed the other door’. (pg 232, Keman and Sabsey, 1997)
PLD generally communicate at a low rate (Rowland, 1990 cited in Bradshaw, 1998) and more moderately disabled people demonstrate difficulties in expressing intended meaning, conducting appropriate social behaviour (eg: standing too close) (Kernan and Sabsey, 1997) and in initiating and responding to verbal and non-verbal messages (Blackwell et al, 1989). The more severe people also frequently have sensory and motor co-ordination impairments, which makes it even harder for them to use language to express their needs and interests without ambiguity and the use of non-conventional behaviours (Van der Gaag and Dormundy, 1993). Over the years, developmental theories have debated over the etiology and relative influences of genetics and environmental influences on language development in PLD and the nature of the problems: delay or deviance. These theories have had a considerable impact on the way communication abilities in PLD have been conceptualised and ‘treated’ in the past and therefore deserve some consideration.

**Theories of Normal Language Development**

In the 1960’s and 1970’s there was considered debate over the influence of ‘nature’ or ‘nurture’ on the development of language skills (eg: Chomsky, 1965; Skinner, 1957). Strong nativists such as Chomsky believed that language development was a result of innate, in-built brain mechanisms (Language Acquisition Device) and held little hope for remediation of language impairments. Advocates of an interactionist approach (eg: Bates, O’Connell and Shore, 1987 cited in Remington, 1997) however, viewed language development in terms of the acquisition of learning processes based on parent-child interactions and provided hope for remediation through behavioural intervention programmes (Snow, 1994 cited in Warren and Yoder, 1997). The debate over the impact of parent-child interactions still remains unresolved (eg: Chomsky 1965 cited in Warren and Yoder, 1997; Gallaway and Richards, 1994 cited in Warren and Yoder, 1997). Piagetian theory on the other hand, assumes that cognitive abilities are necessary prerequisites for language abilities and that the latter is always equivalent to the former (Rice and Kemper, 1984 cited in Warren and Yoder, 1997). Yet, the evidence for this is inconsistent. In Williams Syndrome (which causes moderate learning disabilities and poor visuospatial skills) expressive language abilities have been found to be in advance of cognitive abilities (Bennett, La Veck and
Consequently, reliance on cognitive abilities as indicators of communicative abilities can lead to under- or over-estimates.

**Theories of Language Development in PLD**

A large amount of research has gone into the debate concerning whether reasons for poor communication skills in PLD are a result of developmental delay (e.g., Weisz, Yeates and Zigler, 1982 cited in Kamhi et al, 1997) or the involvement of different/deviant cognitive processes (e.g., Das, 1972, 1984 cited in Kamhi et al, 1997). Language acquisition is believed by some researchers to be delayed in relation to cognitive abilities rather than deviant and therefore amenable to remediation through formal language teaching. Many autistic children do appear to fail to develop joint gaze in infancy (Munday and Sigman, 1989 cited in Beveridge et al, 1997), have problems with pronouns (i.e., I/you, me/he/she) and problems with the pragmatics of communication (Wuff, 1985 cited in Beveridge et al, 1997). Yet, the evidence-base for formal language teaching interventions and alternative and augmentative communication approaches (e.g., Makaton), at present, is poor (Franklin and Beukelman, 1990 cited in Beveridge et al, 1997). Furthermore, research into the developmental acquisition of words in PLD illustrates that vocabulary growth is both slower and uneven and that their total lexical resources may be rather different (Barrett and Diniz, 1997 cited in Beveridge et al, 1997). Thus, a simple delay-deviance description may be inadequate and may even overestimate the importance of intrinsic factors. Extensive research has investigated the intrinsic incompetencies of people with learning disabilities (PLD) in linguistic skills and their developmental and cognitive correlates (e.g., Mittler, 1978 cited in Leudar, 1997) yet, systematic constraints on communication by extrinsic factors such as other peoples' expectations has attracted considerably less attention (van der Gaag, 1988).

**Expectations**

The way in which people use their intuition and communication skills to support the PLD is vital for the development and maintenance of communicative abilities (Golbait, 1996 cited in Bradshaw, 1998). Adjustments in interpersonal behaviours made by parents, teachers, staff and professionals, depend upon the accuracy of their
perceptions of the individuals’ communicative competence (Purcell et al, 1999). The act of ‘labelling’ someone with a learning disability however, often automatically generates negative socially constructed views, which reduce expectations and opportunities (Leudar, 1981 cited in Leudar, 1997). This is often because the importance of intrinsic factors such as; cognitive abilities, memory, understanding, concentration, social skills) are overestimated (van der Gaag, 1998) and because it is assumed that PLD’s have different needs, that they cannot communicate or that someone without any expressive communication skills also has no receptive skills (van der Gaag and Dormundy, 1993). Low expectations of PLD can lead to social barriers to communication being imposed, which include not making the effort to understand or respond to non-verbal gestures, providing brief time intervals for the person to respond, not knowing sign language and failing to speak more clearly, slowly and simply (Kaiser and Goetz, 1993).

O’Brien (1981 cited in Bartlett, 1997) describes how expectations can form a vicious circle. Low expectations reduce opportunities for communication, which increase negative experiences, which lead to more severe delays in performance and reinforcement of the earlier belief that the individual will never achieve much. Equally, high expectations (eg: that the child will eventually ‘catch up’) lead to higher demands, which increase the likelihood of failure, which increase negative experiences, which reduce opportunities, which restrict the use of communication skills and eventually intensify the demands. Expectations may vary across different people and their level of interaction with the PLD. Examples, of different expectations of key people (eg: parents, teachers, staff and professionals) involved with PLD will be discussed.

**Parental Expectations**

Blackwell et al (1989) suggest that parents often overestimate communicative abilities in non-verbal children because research findings demonstrated that parental ratings were significantly higher than the researchers. Yet, this is not conclusive evidence because it could equally indicate that parents have greater insight into their children’s abilities than researchers (Purcell et al, 1999). As the child with learning disabilities develops, low parental and sibling expectations based on the child’s poor expressive
skills can result in overprotection and fewer demands. This in turn, may inadequately prepare them for the regulations and rules of school and demands of society and cause further communication and behavioural problems (Daniels, 1987). Conversely, a child who has relatively good expressive skills may be exposed to higher expectations, which overestimate their comprehension abilities. This becomes problematic when parents perceive them as being ‘deliberately’ difficult or uncooperative and unworthy of effort, further increasing barriers to communication (Daniels, 1987). The concept of being less competent than others’, whether as a consequence of over or underestimated abilities fosters negative behaviour and low self-esteem, which predisposes the child for failure both at home and at school (Daniels, 1987).

**Teachers Expectations**

Research in the field of Social Psychology has indicated that teachers’ expectations of pupils can be very important determinants of intellectual performance (Rosenthal and Jacobson, 1966; 1968 cited in Blanck, 1993). The label of ‘learning disability’ for a pupil generally creates negative expectancies in teachers (Foster, Schmidt and Sabatino, 1976 cited in Valletutti, 1987) and they typically rate children with learning disabilities in a non-positive way as being less cooperative, less socially acceptable and less tactful (Bryan and Bryan, 1978b cited in Valletutti, 1987). Expectancy effects can be transmitted both verbally and nonverbally, as described by Rosenthal’s affect/effort theory (1989 cited in Darley and Oleson, 1993). Teachers were observed to change their affect towards the pupil, which was primarily transmit nonverbally (eg: smiles, frowns, voice tone shifts) and to change the degree of effort they put into teaching the pupil, which was primarily communicated verbally (warm responses). The role of these factors in transferring the perceiver’s expectations to the recipient’s behaviour (self-fulfilling prophecy) has been supported and will be discussed later (Harris and Rosenthal, 1985 cited in Darley and Oleson, 1993). In the classroom setting, learning-disabled children were also observed to receive more negative reinforcement and less positive reinforcement from their teachers than their peers (Lerner, 1981 cited in Valletutti, 1987).

Parents and teachers alike often base their expectations of PLD on the perceived presence or absence of expressive language abilities. Research in school settings
demonstrates how expressive language skills can give the impression of social and communicative competence, even when they involve contradictions and incomplete thoughts (Beveridge and Berry, 1977 cited in Kamhi et al, 1997). For example (pg. 233: Kernan and Sabsay, 1997);

‘There are two things not to do at Christmas time: not to spend too much and watch your spending’.

Conversely, teachers tended to underestimate communicative abilities when children who had a superior language capacity rarely engaged in verbal communication with others (Beveridge and Berry, 1977). For those PLD who are no longer in education and not at home with their family, staff expectations can be very important determinants of their communicative abilities.

**EXPECTATIONS OF CARE STAFF AND PROFESSIONALS**

Care staff training often includes familiarisation with the principles of Social Role Valorisation (SRV), originally referred to as ‘Normalisation’ (Wolfensberger, 1983, 1992 cited in Bartlett, 1997). The principles of normalisation however, unfortunately generated several misconceptions, which included an attempt to make PLD ‘normal’ (Sinha, 1986 cited in Bartlett, 1997). Beliefs in establishing a ‘normal adult life’ can lead to high expectations of the individual’s abilities and the provision of unrealistic communication opportunities. Research indicates that staff tend to overestimate the individuals’ abilities to understand verbal language (McConkey et al, 1995; Purcell et al, 1999) and to rely heavily on directive styles of communicating and teaching (giving corrections and instructions), which become barriers to effective communication. Research findings also indicate that staff generally appear to have a limited awareness of the use of non-verbal signals (posture changes, facial expressions, gestures) as a means of communication (McConkey et al, 1999) and that they become more controlling the greater they perceive the disability (eg: provide less opportunities for initiating or responding by either verbal or non-verbal means) (Berchin and Swain, 1988 cited in van der Gaag and Dormundy, 1993).

Observational research of staff behaviours however similar to ‘test’ situations, which aim to identify individuals’ abilities, may be considerably context-bound. The
emphasis on observation and ‘clinical analysis’ of an individual’s communicative behaviour, promotes the expectation that the use of a structured assessment will lead to an accurate evaluation of the individual’s communication skills. On the basis of this evaluation a seemingly appropriate intervention is developed. Assessment schedules, however do not consider the emotional and psychological impact that a communication difficulty has upon the individual and how a history of negative communicative experiences may have reduced the individual’s desire to demonstrate their communication skills, regardless of ability (Miller, 1990 cited in van der Gaag and Dormundy, 1993). PLD may also lack the motivation to attempt standardised tests, be less attentive, less able to maintain attention during a long assessment session and to feel uncomfortable about having their ‘poor’ performances scrutinised. Thus, even professionals may unintentionally fall into the trap of underestimating or overestimating an individual’s ability to communicate and elicit communicative abilities that confirm their expectations.

**IMPACT OF EXPECTATIONS**

Literature on interpersonal expectations drawn from the field of Social Psychology, describes how expectations can form a self-fulfilling prophecy. By acting towards the recipient in ways consistent with their expectations, people can elicit behaviours that confirm their initial expectations (Darley and Oleson, 1993). For example, if someone gives an instruction in an unclear way, which conveys lack of confidence and a sense of intimidation, people are less likely to understand it and comply (LaVigna and Donnellan, 1986 cited in Perry, 1995). This impact of expectations on the communicative abilities of someone with PLD is clearly evident within legal contexts.

**LEGAL CONTEXT**

The expectation that communication will occur irrespective of personal and social contexts can lead to a failure to provide appropriate opportunities for communicating and have a detrimental affect on the communicative abilities of the PLD (van der Gaag, 1989 cited in van der Gaag, 1998). Under the Police and Criminal Evidence Act 1984 (cited in Bull, 1995), police officers were encouraged to take ‘special care’ with PLD, but little effort was taken to adjust their expectations. The skill of the
interviewer to adjust to the PLD is often crucial in the quality of the statement obtained and the likelihood of a false confession (Cahill, Grebler, Baker and Tully, 1988 cited in Bull, 1995). For example, a confused lady with moderate learning disabilities claimed that 'Dr. Grey had taken her clothes off and stomped all over her body with his feet' (pg. 258 in Keman and Sabsay, 1997). This could have become a serious accusation, but she was in fact trying to refer to another client who had taken her clothes off (nothing sexual happened). Thus, the style of questions, the interviewer's behaviour, the interviewee, and the environment are all likely to contribute to confusion, suggestibility and acquiescence, which are particular problems observed in PLD (Gudjonsson, 1992 cited in Bull, 1995).

**IMPACT OF QUESTIONING STYLE AND INTERVIEWER'S BEHAVIOUR**

Cahill et al.'s, (1988 cited in Bull, 1995) study of 100 police interviews with 'mentally vulnerable witnesses' discovered many hazardous styles of questioning which effected witness responses. Asking leading questions and suggesting the answer caused the witness to agree, pressurising the witness caused confabulation, repeated questioning caused the witness to believe that their first response was incorrect and to change their response and using multiple questions in one sentence generally caused confusion (Cahill, 1998 cited in Bull, 1995). Interviewers were also observed to misunderstand what the interviewee meant, fail to check whether they have understood the interviewee or vice versa and to ignore information that did not fit into their hypothesis of what happened. Consequently, witnesses were more likely to answer yes to questions even when they did not accurately reflect their memory, to offer token guesses when they repeatedly said 'I don't know' and to acquiesce (say yes to all yes-no questions). Perlman, Ericson, Esses and Isaacs (1994 cited in Bull, 1995) also determined that adults with mild learning disabilities were more likely to conform with the expectations of the authority figure and to agree to misleading questions, even when they realised something was wrong.

The likelihood of interrogative suggestibility is thought to increase when PLD believe or are told that they lack competence and control over the interview (Gudjonsson, 1991 cited in Bull, 1995). Low self-esteem and perceived lack of competence is a particular problem in PLD.
SELF-ESTEEM

Our communication and language abilities are fundamental to the way we perceive and evaluate ourselves and others’ and communication difficulties can contribute to behavioural and emotional problems (Blackwell et al, 1989). A lifetime of communication difficulties can lead to low self esteem, social isolation, loneliness, lack of trust, victimisation, abuse, frustration and anger, learned habits of compliance and disempowerment (Flynn, 1989; van der Gaag and Dormundy, 1993). An expectancy of not being able to communicate and satisfy one’s needs can cause acceptance that one’s position is beyond the possibility of change and greatly reduce an individuals’ interest and motivation to interact with other people (van der Gaag, and Dormundy, 1993). An individual may adopt a specific role and enter into an “implicit social contract” with other people, which alters all their future interactions and use of their communicative abilities (Goffinan, 1959 cited in Darley and Oleson, 1993). Although withdrawal, anxiety and role acceptance may have developed as strategies to cope with expectations, it is possible that they inadvertently reinforce others’ expectations and may subsequently hinder the disconfirmation of negative expectations (Jones, Farina, Hastorf et al, 1984 cited in Darley and Oleson, 1993). For example, during a communicative interaction, increased anxiety and frustration may not only reduce the ability of a PLD to coherently organise information, but influence their behaviour and conduct. This is demonstrated in by a case presented by Kernan and Sabsay (1997):

A married man with mild LD, who lived in the community, frequently encountered problems with communicating. Consequently, he would prepare himself for conflict and when miscommunications did occur he would easily became angry, defensive self-righteous and confused. This made it even harder for him to explain his problems coherently and people easily gave up trying to explain to him.

Although some PLD are unaware of the stigma attached to their disabilities, there are many with mild learning disabilities who are aware (Edgerton, 1967 cited in Kernan and Sabsay, 1997) and who actively try to safeguard their self-esteem by raising other people’s expectations of them. Strategies that PLD utilise to avoid revealing their incompetence include; trying not to say too much, feigning understanding, agreeing to
something when they sense agreement is required (this is very problematic in a legal context), avoiding situations altogether or using someone else to help them (Keman and Sabsay, 1997). Strategies to create positive impressions of competence include, memorising jokes, phrases and comments even if they do not know what they mean, boasting about real or false accomplishments and talking about their areas of special interest (Keman and Sabsay, 1997). Successful attempts to hide incompetence and feign competence will ultimately raise other people’s expectations and hence, further reduce their communicative abilities. Conversely, unsuccessful attempts to enhance others’ expectations draws attention, rather than diverts it, to their limitations and poor self-esteem (Sabsay and Platt, 1985 cited in Keman and Sabsay, 1997). People with more severe learning disabilities who have less strategies (limited vocal sounds or manual signs) to communicate their needs and are therefore, most likely to discover through trail and error and reinforcement, that challenging behaviour is a more effective method of communicating (Bott, Farmer, and Rohde, 1997 cited in Warren and Yoder, 1997).

CHALLENGING BEHAVIOUR

‘Challenging behaviours’ have more recently become recognised as forms of communication, which are used when more acceptable and effective methods of expression are not possible (Riechle and Wacker, 1993 cited in Thurman, 1997). For example, the communication hypothesis (Donnellan, Mirenda, Mesaros and Fassbender, 1984 cited in van der Gaag and Dormundy, 1993) views challenging behaviour as both intentional and functional equivalents of verbal requests. Self-inflicted injurious behaviour (SIB) is also viewed as a form of communication when attention or comfort given by the carers seemingly increases the likelihood of the SIB. The functional effect of challenging behaviour often ensures that demands are avoided, social attention is received, comfort is given, boredom is relieved, or favourite foods received (used by carers to comfort the individual). Cullen, (1988 cited in van der Gaag and Dormundy, 1993) discovered that staff reacted to communicative behaviours on only 4% of occasions, leaving 90% of them unnoticed and commented that it was ‘hardly surprising’ that PLD develop unusual and challenging behaviour to attract attention to their needs. Evidence such as this, supports the notion that low expectations may cause an individual to resort to more
extreme behaviours and that these behaviours are unlikely to change, until staff behaviours do.

**Clinical Psychologists Role**

There is no simple or single intervention approach for challenging behaviour as each individual’s communication problems and behaviours are idiosyncratic. The realisation that challenging behaviours are forms of communication has led to early behavioural procedures being superseded by functional, communication-centred methods (eg: Emerson, 1993 cited in Thurman, 1997; McGee and Menolascino, 1991). Emphasis is placed on an integrative approach to training staff with the support of speech and language therapists, to identify why people communicate, opportunities for communication and the different modes of communicating. It is also important to reduce the reliance on assumptions and pre-empting of verbal, nonverbal and environmental needs (Halle, 1988 cited in Thurman, 1997). As illustrated, there are many different expectations, which influence the communicative abilities of a person with learning disabilities and hence, many different issues with which the psychologist can work. The literature on family therapy (eg: Goldenberg and Goldenberg, 1980 cited in van der Gaag and Dormundy, 1993) illustrates the importance of examining the wider system or environment of the individual. The individuals’ system comprises the different people involved and different settings involved eg: group home, family home, day centre, and institution. Enhancing the quality of interactions within the different settings and with different people will have an impact on the individuals’ communicative abilities and how the different systems interact. It is extremely important for the clinical psychologist to assist people such as carers, parents, teachers and professionals to adjust their perceptions of the individuals communicative abilities, so that they can modify the nature and style of their interactions (Money, 1997 cited in Purcell et al, 1999). Issues such as these can be addressed through comprehensive assessments, therapy, education and training, supervision, support to managers and consultancy work.

**Assessment**

Perhaps the most fundamental role of the clinical psychologist is to provide a systematic assessment of the problems through a formal functional analysis, to
determine the precise nature and function of the individual’s behaviour. Although the exact components of functional analysis may vary, it generally involves behavioural assessment, naturalistic observations of challenging behaviour across different contexts with different people, interviewing and information gathering from the individual and people involved with them, psychometric measures (depending on ability and purpose), a motivational survey to identify potential reinforcers, (Beck Depression Inventory) and a behavioural or process analysis. The latter refers to systematic recording of the target behaviours, their antecedents and their consequences in order to determine the functional of the behaviour (Sturmey, 1996). Perry, (1995) also advocates observation during ‘naturalistic’ demand situations, to determine the carers interactional styles and the impact it has on compliance. A detailed speech and language therapy assessment is also important in determining the individual’s level of expressive and receptive language functioning. Utilising data from the comprehensive assessment an appropriate multi-component intervention package can then be designed to suit the needs of the individual in question, to specify the levels (eg; individual, staff, parents, organisational) at which the intervention should be targeted and to establish more realistic expectations (Perry, 1995).

**THERAPEUTIC TECHNIQUES**

If emotional disturbance and extreme anxiety is present to a considerable degree (in the individual or even their carers), then treatment of the depression, self-esteem, anger management or anxiety disorder must take precedence. With mild to moderate forms of learning disability this may involve cognitive behavioural therapy (eg: Beck, 1976: cited in Lindsey and Powell, 1987) or behavioural therapy (Clark, 1983: Eysenck, 1960: cited in Lindsey and Powell, 1987) either individually or in group therapy. Sex therapy, bereavement counselling and social skills training may also be appropriate when adapted to the abilities of the individual. Emotional support may also be important for the carers of the PLD, particularly parent-carers. Failure in coming to terms with the disability, to grieve or to adjust their expectations, as well as a failure to address primary or secondary emotional or mental health problems in the individual may cause a wider intervention programme to fail. This will only reinforce other peoples’ perceptions of the individual as ‘hopeless’ and beyond help and foster
more emotional problems (Rosner, Abrams and Daniels, 1981b: cited in Daniels, 1987).

**EDUCATION AND TRAINING**

Since social and physical barriers imposed by society have a greater influence on communication disabilities than the individuals 'inabilities' (van der Gaag, 1998), education and training to establish a shared knowledge base is essential. The need for education and training is highlighted by a UK Social Services Inspectorate Report (1989 cited in Bartlett, 1997). Only 13% of care staff had a qualification related to working with PLD, there was no evidence of systematic staff training in the community and the modular training programmes that do exist, lack evidence of effectiveness (Daniels and Sandow, 1987 cited in Bartlett, 1997). Parents may receive even less training than staff. It is particularly important that people learn to recognise non-verbal behaviours as a means of communication and to adjust their interactions in different settings to optimise the potential for communicative interaction and that systematic monitoring (Kersner and Wright, 1996: cited in Purcell et al, 1999). Basic learning principles such as operant or classical conditioning (Remington, 1996: cited in Remington, 1997) are responsible for learning, which can occur without speech or any other form of symbolic communication. Understanding the way in which challenging behaviour develops and functions as communication also provides a basis for altering expectations, improving communication and developing successful interventions.

Education programmes can provide information about PLD, the different degrees of intellectual, cognitive, physical or linguist impairments. A description of the aetiology, behaviours, disabilities, abilities, psychological impact and intervention techniques within a range of common syndromes and disorders (eg; Down’s Syndrome, Autism) would also help people to establish more realistic expectations. Where possible, the communication context could be made more concrete by teaching informal gestures and signs such as makaton (Walker, 1976: cited in Bartlett, 1997), or familiar objects of reference for supporting verbal communication with people with severe disabilities (McLarty, 1995; Parks, 1997: cited in Bartlett, 1997). However, it should be noted that teaching formal language skills such as signing, has been found
to create heavily context-dependent learning and can demonstrate poor spontaneous generalisation of the linguistic skills to the natural living environment (Remington, 1997).

With their application in more natural environments in which the PLD will need to communicate, behaviour change techniques such as prompting, shaping and reinforcement have retained their importance in developing communication skills (Remington, 1997). For example, the incidental teaching model (Hart and Risley, 1975: cited in Remington, 1997) applies the principles of structured teaching during the individuals' normal daily activities. Thus activities such as dressing can create the opportunity for introducing choice, requesting and naming, which enables spontaneity, active participation and built-in reinforcement. The ‘discrete trial format’ (Lavinga and Donellan, 1986; Koegel, Russo and Rincover, 1977: cited in Perry, 1995) also provides training of an alternative style of instruction giving, which provides clear instructions, time for the individual to respond and differential reinforcement of behaviours alternative to the challenging behaviour. This has been found effective in reducing the individuals’ use of mid- to late-cycle challenging behaviours and aims to develop both expressive and receptive language skills (Carr, Robinson, and Palumbo, 1990: cited in Perry, 1995).

The application of research findings and effective use of interventions is highly dependent on the expectations of and co-operation between all people working within the systems around the individual. Therefore it is important to establish good working partnerships, to recognise possible problems and provide ongoing supervision to help new learning and prevent ‘relapses’ (Cullen, 1988: cited in van der Gaag and Dormundy, 1993).

**SUPPORT TO MANAGERS AND PROFESSIONALS**

Those who allocate resources are often those who have little contact with residents and everyday settings. Therefore, education and training is equally important for service providers and managers. Helping service providers to understand and identify the diverse needs of PLD and to understand the role of challenging behaviours in trying to communicate these needs, will ensure effective allocation of resources and
enhance staff support. Intervention programmes generally become less effective when divisions fall between the carers that have to implement them and the professionals that provide them (Janicki et al, 1988). Direct carers often complain that managers and professionals hold expectations that cannot be met within the setting (eg: behavioural programmes are too time consuming, technical or tedious) (Landesmann, 1988: cited in Janicki et al, 1988). Therefore, for the successful application and generalisation of any intervention, ideally a clinical psychologist should also conduct an organisational assessment, which addresses the organisational policies, structure, systems, staff ratios, and practical constraints to any programme involving change (Tout, 1992: cited in Thurman, 1997). Imminent changes in service provision, uncertainty, staff workload and staff shortages can all mitigate against the development of more realistic expectations of PLD and the staff that support them and therefore have to be taken into account.

**Consultancy**

The development of more realistic expectations is particularly essential if PLD are to be accurately represented within the legal system. The way in which a clinical psychologist works with the issues within legal settings is perhaps similar to those already discussed? A clinical psychologist could work on a consultative basis offering education on PLD, interview training for the interviewers and their managers, assessments of the witnesses’ capabilities and support for the witnesses themselves. There is a lot to learn about how to enable witnesses with learning disabilities to give accurate evidence and how to adjust expectations and behaviours in order to enhance the effectiveness of communication in any formal interview process. Perhaps within this field, the most important area to focus on is the examination of what circumstances, if any, a PLD can be considered a reliable witness (Perlman et al, 1994: cited in Bull, 1995). There is however, in general, surprisingly little published research on the impact of expectations on communication abilities within PLD and research that has been published is likely to be affected by “publication bias” (only noticeable impacts are published).
Conclusion

Efforts to research and understand the precise nature of the subtle social processes that enhance and inhibit communication abilities in PLD are rare and problematic (Warren, 1993: cited in Warren and Yoder, 1997). People harbour a range of different expectations of people with learning disabilities and these can have a diverse and complex impact on their communicative abilities. The impact is usually a negative one, which decreases communication abilities (Kernan and Sabsey, 1997). Whatever the context (professional assessment, legal, home) the process of communication should be viewed as transactional, during which all communication partners need to work to create shared meanings. Communication is a process that relies on expectations and requires the partners to adapt to each other in terms of mode, speed and context (Kaiser and Goetz, 1993). Failures to do so generate many issues for clinical psychologists’ to work with. With the integration of people with learning disabilities into ‘the wider community’ and growing social demands to respect their individuality and choice it is also essential, for both ethical and legal reasons, for clinical psychologists to research and broaden their understanding of the impact of expectations on communicative abilities. These issues also raise the need for clinical psychologists to widen their methods for analysing the processes involved in communication and to help the wider community to move away from the view that people with learning disabilities, particularly the more severe, are deficient in communication skills (Kaiser and Goetz, 1993).
REFERENCES


TITLE

"Critically evaluate psychological theories of child abuse and their contribution to clinical practice."

CORE PLACEMENT 3

December 2000

Year 2
Child abuse is a complex and pervasive social problem that exists in all classes of society (Cicchetti and Carlson, 1989). There are many forms of child abuse: physical abuse, non-accidental injury, physical neglect, emotional abuse, emotional neglect and sexual abuse (Carr, 1999). Although co-morbidity exits (Carr, 1999), they are generally conceptualised as idiosyncratic forms of abuse. Thus, for the purpose of this essay only theoretical approaches aiming to explain the occurrence of child sexual abuse will be critically evaluated. A universally accepted definition of child sexual abuse appears to be lacking and informal formulations in research studies vary considerably (Glaser and Frosh, 1991). In a survey of research with this field, Kolvin and Trowell (1996 cited in Horne, 1999) identified three key areas that defined sexual abuse. Firstly, direct sexual acts (molestation, penetration) secondly, indirect acts (enforced watching of pornography, genital exposure) and thirdly, exploitation of a power differential between victim and abuser. Intrafamilial sexual abuse perpetrated by family relatives was furthermore, distinguished from extrafamilial sex abuse perpetrated by someone outside the family.

There are five principal theoretical approaches to child sexual abuse, which have different conceptual frameworks, explanations, levels of analysis, perspectives, methodological bases and contributions to clinical practice. These are; psychoanalytic theories, family dysfunction theories, psychological studies which investigate the abuser, feminist theories (Herman, 1981 cited in Waldby et al, 1990) which take into account gender and power relationships and Finkelhor’s (1984) multi-casual model of child sexual abuse. The first two theories will form the basis of the critical evaluation. The primary theory and explanation of child sexual abuse originated in 1896, from Freud’s psychoanalytic formulation, which dismissed abuse disclosures as fantasies and had a wide-spread and long-lasting impact on clinical practice. By the early 1940s, the ‘family dysfunction’ theory emerged (Furniss, 1983b; Mrazek and
Bentovim, 1981 cited in Corby, 1989), which advocated family responsibility and hence, intervention with the whole family. This theory has also been widely adopted within clinical practice and therapeutic literature both in relation to the causes of incest and to treatment methods (Sanderson, 1991). Despite their constructive contributions to an understanding of child sexual abuse, both psychoanalytic and family dysfunction theories have generated controversial clinical procedures.

**Epidemiology of Child Sexual Abuse**

Secrecy, shame and guilt are among the principal components of child sexual abuse, which make it difficult to research. Furthermore, variations in definition, sample differences and methodological differences in studies have caused considerable ambiguity in the literature and problems in establishing reliable epidemiological data (Brown et al, 1988 cited in Masson and O’Byrne, 1993; Horne, 1999). However, established data does indicate that prevalence ranges from two to thirty per cent in male children and four to sixty per cent in female children (Smith and Bentovim, 1994 cited in Carr, 1999). Females are up to five times more likely to be victims and more likely to be abused within the family (intrafamilial abuse) whilst males are more likely to be abused by someone outside the family (extrafamilial abuse) (Carr, 1999). Intrafamilial abuse is more common, accounting for thirty to seventy-five per cent of abuse but it is acknowledged that extrafamilial abuse is generally under-represented, -reported and -researched (Parton, 1993). In over eighty percent of the cases the abuser is male (Smith and Bentovim, 1994 cited in Horne, 1999), but many cases of sexual assault are also perpetrated by adolescents or young boys (Mahoney, 1984 cited in Parton, 1993) and female abusers have only more recently become the focus of research (Gurisik and Horne, in preparation, cited in Horne, 1999). As one can see, the emerging epidemiological data of child sexual abuse considerably refutes the fundamental assumption of Freud’s Psychoanalytic theory.

**Conceptual Framework of Psychoanalytic Theories of Sex Abuse**

There are many theories of child sexual abuse within the psychoanalytic tradition, all of which heavily draw on Sigmund Freud’s pioneering work.
PSYCHOANalytic Concepts

The ‘Oedipus Complex’ and ‘Child Seductress’

In 1896, Freud (cited in Waldby et al, 1990) generated a theory of fantasy to explain accounts of father-daughter incest given by women suffering hysteria. The wider socio-cultural and political society in this era rejected his first theory of reality, favouring the theory that allegations of incest were products of an infantile sexual desire to seduce the father. These fantasies were conceptualised as characteristic of the ‘Oedipus Complex’. A dilemma presented by one of a series of five universal stages of childhood psychosexual development, the phallic stage (age 3-5 years), crucial for the development of ‘feminine’ and ‘masculine’ sexuality in children.

Feminine sexuality is believed to develop through the young girl’s recognition of the inferiority of her clitoris in comparison to the ‘superior’ male penis. She becomes angry with her mother for being like her and passionately envious for the real thing (‘penis-envy’) possessed by her father (Freud, 1977 cited in Sanderson, 1991).

Consequently, her innocent father becomes the sexual object of her fantasies, in the hope he will give her a penis. In the rare cases of genuine incest, the father was considered a passive victim of the child’s unconscious, seductive sexual desires which had spilt over into real life: the ‘child seductress’ (Glaser and Frosh, 1991).

Subsequent reinterpretations of the Oedipus Complex, particularly by feminist theorists (eg: Herman, 1981 cited in Waldby et al, 1990), argue that a girl’s recognition of the inferiority of the clitoris, causes a general recognition of the inferiority of women in society. This inferiority makes her both passive and vulnerable to abuse, and search for a privileged relationship with her father to elevate her own status (Sanderson, 1991). Psychoanalysts who acknowledge the reality of sex abuse (Miller, 1986, 1987a, 1987b cited in Southgate, 1989) do apportion responsibility to the father for interpreting their daughters’ need for physical and emotional affection as a need for sexual attention and abusing his male power to actively eroticise the relationship (Chodorow, 1978 cited in Waldby et al, 1990).

However, reinterpretations of psychodynamic theory have generally been ignored and fundamental assumptions about the aetiology of incest upheld, particularly in psychiatry (Waldby et al, 1990).
The ‘Pathological’ Mother

In addition to the child, psychoanalytic theories also view the mother as a crucial etiological factor and explanation for father-daughter incest. Firstly, Freud proposed that unlike boys, girls might never succeed in repressing the Oedipus Complex deep into the unconscious. Hence, never resolving the dilemma of competing with their mothers and holding socially unacceptable incestuous desires for their fathers (Corby, 1989). When mothers themselves, they are driven to use their own daughter to act out their incestuous wish for their father. Secondly, Gordon (1955 cited in Sanderson, 1991) and Rinehart (1961 cited in Sanderson, 1991) proposed that intense affectional frustration from a cold, rejecting mother caused the daughter to turn to the father in revenge, to satisfy her needs for security and affection through sexual means. Thirdly, Kaufman, Peck and Taguini, (1954 cited in Waldby et al, 1990) proposed that the mother’s hostile relationship with her own mother (the grandmother) causes her to abandon her parental responsibilities including sexual relations with her husband and give them to her daughter. Fourthly, Millers’ (1986, 1987a, 1987b) inter-generational model proposed that abusive childhood experiences may lead a mother to choose abusive partners, putting her children at risk and continuing a culture of abuse.

**Clinical Practice**

Freud’s psychoanalytic theory of child sex abuse had a widespread impact on early psychoanalysts, psychiatrists and psychiatric literature (Waldby et al, 1990) and contributed to clinical practice, years of professional denial, reinterpreting of childish fantasies, victim-blaming, mother-blaming and absolving abuser responsibility. For instance, Sloane and Karpinski (1942 cited in Waldby et al, 1990) concluded in their study of five father-daughter incest cases that incest was caused by the girls ‘desires’, ‘abnormal craving for sexual excitation’ and ‘submission to the incest’. Even two cases in 1991 reported that doctors denied incest allegations by labelling the girls as ‘jealous’ or their allegations as ‘fantasy’ (Furniss, 1991). By supporting a climate that ignores allegations of sex abuse and pleas for help, early psychoanalytic theories themselves ‘abused’ victims and may have contributed to further abuse by keeping the children at risk (Glaser and Frosh, 1991). Denial, made it possible for society to neglect the devastating effects on the victims of sex abuse, which would almost certainly have heightened the victims feelings of guilt, distress and confusion (Miller,
Such criticisms of early psychoanalytic theory are even upheld within the psychodynamic perspective (e.g., Miller, 1986). Psychoanalytic theory however, clearly indicated a link between ill-treatment in the early stages of life and long-term emotional problems. Individual therapy for sex abuse was established and aimed to unravel the processes of early development, through techniques such as free association, dream interpretation and interpretation of the clients' displaced feelings (transference) and how the therapist felt in return (counter-transference) (Corby, 1989).

**Fundamental Assumptions**

Psychoanalytic theories appear to endorse scientific credibility to several fundamental assumptions. First, Freud wrongly assumed that sex abuse was a rare phenomenon and a product of child fantasy. Not only has epidemiological research (discussed earlier) irrefutably challenged the validity of this assumption, but research on false allegations has also found that only two per cent of allegations are made-up (Ashtead, 1994 cited in Horne, 1999). Secondly, 'child collusion' or 'seduction' theories have been heavily criticised for assuming that child sexuality and strong needs for parental affection and emotional comfort are equivalent to adult sexuality (Jackson, 1982 cited in Glaser and Frosh, 1991). In the 1970s, such a belief that children invited, enjoyed or were willing, albeit passively, to engage in adult sexual activity led to a reluctance to intervene and the belief that laws on child sexual activity were repressive (Nelson, 1993). Thirdly, the assumption that affection from an incestuous father compensated for a hostile and rejecting mother and thus reflected a caring relationship also led reluctance to intervene in the past (Nelson, 1993 cited in Parton, 1993). An example of such can be evidenced in the report of the enquiry into child sexual abuse in Cleveland (Secretary of State for Social Services, 1988, p. 8 cited in Parton, 1993) which explained that sexual abuse arises 'from a normal father/daughter relationship in an isolated family, [when] a bereaved husband may sometimes, not with any great pathology in some cases, slide into a sexual relationship'. The general failure to question the nature of male-female relationship, exploitation of male power within the family and the 'normal' pathology of masculine sexuality, in such assumptions has been widely criticised by feminist theorists for shifting blame from the perpetrator to the victim (e.g., Herman, 1981 cited in Glaser and Frosh, 1991).
Explanation, Focus and Range of Convenience,
Psychoanalytic theory appears to explain father-daughter incest through a simple cause and effect model where unresolved oedipal complexes in the mother, daughter or father (Glaser and Frosh, 1991) are assumed to cause incest. The reality of sexually abusive situations is however, far more complex. By focusing on father-daughter incest, which accounts for less than a third of child sexual abuse (Finkelhor, 1984 cited in Sanderson, 1991), psychoanalytic theories limit their range of convenience and fail to acknowledge or explain other types of abuse (eg: intra-extrafamilial, homosexual, organised or ritual) with other perpetrators (eg: females) and other victims (eg: boys).

Perspective and Level of Analysis
Psychological theories, seek to scientifically demonstrate the pathology of abusing fathers and have demonstrated how adept male abusers are at rationalising their actions as consequences of provocations and overwhelming seductive powers of the victim who ‘asks for it’ (Glaser and Frosh, 1991). Psychoanalytic theory reflects this male perspective and the patriarchal society in which it developed in the 18th Century. Psychodynamic theories of childhood abuse are generally uni-dimensional and seek to explain incestuous abuse at the level of the individual. Their analysis of the problem is thus limited to the individuals they blame, namely the daughters or mothers and in later theories, the fathers (eg: Miller, 1986). Little attention is paid to the wider social, racial and cultural context in which individuals and their families live or the power imbalances within them. Even re-workings of Freud’s original ideas, still exist within a patriarchal ideology, taking for granted a certain view of masculine sexuality and male-female power relationships and remain at an individual level (eg: Herman, 1981 cited in Glaser and Frosh, 1991).

Methodological Base
The methodological base of Freud’s psychoanalytic theory of child sexual abuse is highly controversial. Freud’s (1896 cited in Waldby et al, 1990) famous theoretical reversal from a theory of child sexual abuse grounded in reality to one grounded in fantasy was based on extreme social and political pressure rather than a scientific base. Psychoanalysis as a whole, is a discipline devoted to the mapping and
explanation of subjective experience and the use of inextricably linked hypothetical concepts. Its methodological base relies on clinical observation and idiosyncratic interpretation of the observed subjective experiences. Psychoanalysis places little emphasis on experimental testability and generally precludes rigorous testability. Criticisms of the false theoretical scientific credibility accredited to hypothetical concepts such as the Oedipus complex, child seductress, and fantasy theory of child sexual abuse would therefore be justified (Rutter, 1983 cited in Glaser and Frosh, 1991).

**STRENGTHS**

Despite the damaging clinical impact of Freud's psychoanalytic theory in particular, and valid criticisms, psychoanalytic theories have made some valuable contributions to theories of sexual abuse. Freud recognised manifestations of sexuality in infants and developed one of the most systematic accounts of the nature and development of child sexuality. He explored a developmental path for sexuality and was willing to explore children's fantasies and fears around sex (Glaser and Frosh, 1991). Research findings generally appear to support the psychoanalytic view that sexuality exists in infancy and childhood (Rutter, 1983 cited in Glaser and Frosh, 1991). By accepting the reality of child sexual abuse, psychoanalysts have contributed to our understanding of the trauma of incest, its' psychological impact on the victim and its' link to subsequent psychological and psychiatric problems (eg: Miller, 1986, 1987a, 1987b cited in Southgate, 1989). It also brought attention to a need for therapy and counselling and the development of insight (Corby, 1989). Feminist re-workings (eg: Chodrow, 1978 cited in Glaser and Frosh, 1991) have acknowledged the responsibility of the father and in doing so, acknowledge male power and social status. The shift in responsibility from the child to the adult characterizes a fundamental component in treatment and progresses towards an explanation of why abusers are predominately men and why girls are vulnerable (passive) to abuse. By the 1940s an interest in family psychiatry, spurred the development of the 'family dysfunction' theory of father-daughter incest.
CONCEPTUAL FRAMEWORK OF FAMILY DYSFUNCTION THEORIES

Family dysfunction theory has become the most widely accepted explanation for the existence of and processes in incest and repeated child sex abuse (Sanderson, 1991). It’s systemic treatment methods have been widely adopted and shift the clinical focus away from the pathology of the individual, to the pathology of the family as a whole. All individual family members are considered equally responsible for producing the family dynamics, which maintain the child sexual abuse (Furniss, 1983b).

FAMILY DYSFUNCTION THEORY - CONCEPTS

‘Dysfunctional Family’

Systems theory (Minuchin, 1974 cited in Corby, 1989) proposes that families are made up of subsystems between which it is important to maintain clear generational boundaries; parent-parent, parent-child and child-child. The ‘dysfunctional’ family is one in which these ‘normal’ hierarchies and boundaries have been transgressed (Mrazek and Bentovim, 1981 cited in Corby, 1989). Although equal responsibility for the breakdown of these boundaries is advocated, the mother is primarily viewed as the ‘cornerstone’ of family functioning and hence, family dysfunction (Fairclough, 1983 cited in Sanderson, 1991). Firstly, she is described as a ‘dysfunctional wife’, who fails to meet her husbands sexual needs. Secondly, a ‘dysfunctional mother’, who is ‘emotionally rigid’ and fails to love and protect her children. Thirdly, she and the father are considered ‘dysfunctional parents’, whose ‘emotional immaturity’ permit role reversal between mother and daughter, and a break down of normal inter-generational boundaries (Lustig et al, 1966 cited in Sanderson, 1991). The father is viewed as ‘dysfunction’ because he continues to place sexual demands on the person who does the housework without noticing who this is (Jeffries, 1982 cited in Sanderson, 1991). Consequently, the daughter is also considered dysfunctional because, starved of maternal love, she fails to reject her fathers sexual advances. An example of such thinking can be evidenced in the report of the enquiry into child sexual abuse in Cleveland ‘In many cases the mothers elect the ... daughter to the role of child mother .. [this] is allowed to slide into a sexual relationship with her father. This is tolerated with little or no protest’ (Secretary of State for Social Services, 1988, p. 8 cited in Parton, 1993).
The central tenet of family dysfunction theory, is that the family as a unit is ‘dysfunctional’ and cannot acknowledge or deal with tension. It denies inappropriate intergenerational sexual relationships in order to prevent family break-up and incest functions to bind family members into a ‘collusive system’ of secrecy. (Bentovim et al, 1988 cited in Masson and O’Byrne, 1993; Furniss, 1991). This secrecy maintains repeated sexual abuse. However, the use in family dysfunction theory of descriptive labels such as ‘emotionally immature’ or ‘emotionally rigid’ provides little to explain how and why intergenerational boundaries are transgressed in the first place. There must be many families in which such individual pathologies as well as marital and sexual problems exist, but incest does not (Horne, 1999). This is not taken into account. Furthermore, an intergenerational model of sexual abuse (Furniss, 1991) fails to take into account victims of child sexual abuse who do not continue a ‘dysfunctional’ family pattern of failing to acknowledge confusions between emotional care and sexual experiences and abusers who have not been abused themselves.

**Conflict-Regulating/Avoiding Families**

Furniss (1983b) suggests two extreme forms of family pathology that typically underpin intrafamilial sex abuse. Families that avoid marital or sexual conflict by delegating the mothers’ sexual duties to the daughter are referred to as ‘conflict-avoiding’. These families present with a rigid, over-idealised self-image, which usually leads to the destruction of the family if incest is undeniably revealed. On the other hand, conflict-regulating family patterns, which Furniss (1983b) describes as typical of incest, present as a disorganised and argumentative family in which violence is frequent and generational boundary transgressions and confusions are obvious. Conflict regulators may be open about the incest within the family, and more than one child may be involved in the incest. The ‘conflict-avoiding/regulating’ dichotomy is probably the most popular description of family pathology in family system theories as the cause of general childhood difficulties. Furniss (1983b; 1991) has therefore, come under criticism for firstly, failing to provide a specific theory of the processes underlying child sexual abuse, secondly for presenting a narrow description of family types for such a complex issue (Glaser and Frosh, 1991). Furthermore, there is little empirical evidence to determine whether the family
dynamics actually distinguish incestuous from non-abusing families and little to confirm the hypothesis, which guides both research and clinical practice (Horne, 1999).

**Clinical Practice – Impact of Fundamental Assumptions**

Despite recognising that child sexual abuse is a problem in its’ own right, variants of the family dysfunctions theory regard sex abuse as symptomatic and incidental to reversed generational boundaries (Machotka, Pittman and Flomenhaft, 1967 cited in Waldby et al, 1990). The current or historical fact of sexual abuse is viewed within this theory as a red herring, which will impede therapy (Machotka et al, 1967). It also assumes that the families’ attendance and co-operation in therapy indicates the cessation of the sexual abuse. Similar to Freudian psychoanalytic theory, the clinical implication of this assumption can be devastating for the victim. Working within a narrow framework, which only addresses interactional aspects of the family dysfunction, presents a real danger of failing to address the devastating psychological impact on the victim. The therapist is also in danger of becoming part of the collusive family system and failing to acknowledge the abuse as a problem in its’ own right. For example, Furniss (1991) comments on a ‘disturbing and shameful experience’ when it was discovered after family therapy, that not only had the sexual abuse continued during therapy, but that it had done so with ‘greater severity and under increased threat to the children, who kept the secret because the abusers threatened to punish them if they disclosed’ (p.114). A metasystemic family approach in which different modes of therapy are used concurrently eg: family, group and individual therapy is therefore strongly advocated (Furniss, 1991).

The therapeutic aim of family therapy is to break the destructive family dynamics, improve communication, restore appropriate generational roles (ie: the ‘perfect’ mother), dispel the myth that the father is dangerous and increase the father’s status and power (Tilley, 1989). Feminist theorists have been highly critical of the views that abuse is a family dysfunction, that the abusers responsibility should be absolved and that families should be readily reconstituted in therapy (Dominelli, 1986; Nelson, 1987; Macleod and Saraga, 1987: cited in Corby, 1989). The assumption that all families members have equal responsibility for the transgression of intergenerational
boundaries, derives from the belief that emphasis on the abusers responsibility is unjust and more extreme beliefs that criminal cases are grossly unacceptable because they enable 'other family members to maintain a destructive denial of their own responsibility' (Machotka et al, 1967 cited in Waldby, 1990). Critics, including other family therapists, warn against absolving the abusers' personal responsibility (Masson and O'Byrne, 1993).

Another fundamental assumption is that incest only occurs in 'dysfunctional' families, who are qualitatively different from 'normal' families (Glaser and Frosh, 1991). Attempts of systems theories to define what is 'normal' in family life are generally inadequate and there is increasing evidence that stereotyped profiles of 'dysfunctional' incestuous families do not hold up empirically (Nelson, 1987 cited in Parton, 1993). Furthermore, feminist theorists argue that family dysfunction theories ignore issues of dependency in families, male power, cultural influences, social construction of masculinity and patriarchy that make abuse a possibility in 'normal' families (Glaser and Frosh, 1991; Macleod and Sarga, 1987 cited in Parton, 1993). In line with this thinking, Finkelhor (1984) argues that the potential of abuse resides within all families but the power of inhibitory factors, one of which may be the mothers' behaviour, differs in abusing compared to non-abusing families.

Like psychoanalytic theories, many family dysfunction theories view mothers and daughters as 'collusive'. Some dysfunctional family theories go as far to assume that the mother is 'the real abuser in the incestuous family' (Dietz and Craft, 1980 cited in Sanderson, 1991). Child abuse experts appear to agree that there is anecdotal evidence for the existence of poor mother-daughter relations, denial and failure to act on disclosures in incestuous families (Finkelhor, 1986b cited in Masson and O'Byrne, 1993). However, Finkelhor (1984) argues that there is no clear evidence whether the mothers' behaviour is causal or merely lowers the power of inhibitory factors. Family dysfunction theory thus, offers little to explain why mothers fail to act on a disclosure and cannot account for evidence that mothers do act to protect their daughters (Mrazek, 1982 cited in Sanderson, 1991). Conceptual criticisms of family systems theories of sexual abuse are furthermore directed at their preoccupation with the
mother and daughter, despite claiming that all family members are equally responsible (Glaser and Frosh, 1991).

**EXPLANATION, FOCUS AND RANGE OF CONVENIENCE**

Like psychoanalytic theories, family dysfunction theory has a restricted scope in that it mainly focuses on father-daughter incest, neglects other types of abuse and abusers, focuses almost exclusively on the mother (or daughter) and minimises the abusers responsibility. Family dysfunctional theories generally narrow their focus to long-term incest, and have been criticised for creating false dichotomies between normal and dysfunctional families, intra- and extra-familial abuse and long and short term abuse despite evidence for the abuse of male power as a link (Masson and O'Byrne, 1993). Family dysfunction theory also fails to differentiate between sexual abuse of a child and failing to protect the child from the abuse on theoretical, practical and ethical grounds (Glaser and Frosh, 1991). Family dysfunction theories argue that they focus on describing the typical dysfunctional family dynamics found in incest and thus how long-term abuse is maintained, not on why and for what individual reason the relationship patterns arose in the first place (Furniss, 1991). However, they do not explain why etiological patterns are not considered (Glaser and Frosh, 1991).

Furthermore, like psychoanalytic theories, family dysfunction theories attempt to explain the repetition of abuse within family generations, yet they fail to adequately explain both the possibility of a child who has no history of abuse who becomes abusive and cases where a history of abuse yields no abuse as a parent (McGehee, 1983).

**PERSPECTIVE AND LEVEL OF ANALYSIS**

Family dysfunction theories, like psychoanalytic theories virtually represent a male perspective of incest and base themselves on the works of the ‘masters’ of family therapy – Minuchin, Haley and Palazzoli – who use sexist language (Beecher, 1986 cited in Masson and O’Byrne, 1993). The victims’ protection and security should be the primary perspective of any theory of sex abuse, if it is to be considered valid. The level of analysis attempts to move away from individual pathology to a slightly broader level of family pathology. However, like many theories of sexual abuse, it appears to ignore the social context of families, issues of patriarchy, gender, race and
class and the power imbalances within them and overlook the need to pursue change in organizational policies (Beecher, 1986 cited in Masson and O'Byrne, 1993).

METHODOLOGICAL BASE
Family dysfunction theory draws on work from the three main models within the systems approach – the ‘systemic’ (Palazzoli et al, 1978, 1980 cited in Masson and O'Byrne, 1993), the ‘structural’ model (Minuchin, 1974; Minuchin and Fishman, 1981 cited in Masson and O'Byrne, 1993) and the ‘strategic’ model of family therapy (Haley, 1976, 1980 cited in Masson and O'Byrne, 1993). The latter of which contains elements of the first two models and assumes that family problems are an indicator of family dysfunction. Family dysfunction theories of sex abuse describe family dynamics that maintain abuse, although some theorists claim they have etiological validity eg: ‘the factor which brings about incest’ (Furniss, 1983b cited in Glaser and Frosh, 1991). However, retrospective analysis and formulations of child sexual abuse based on clinical observations and descriptions of family dynamics resulting from sex abuse, provide little to validate a ‘dysfunctional’ family model. Without the support of controlled research, the family patterns described are not diagnostic and possible in families where no abuse is occurring (Masson and O'Byrne, 1993).

STRENGTHS
Unlike the psychodynamic perspective, a family dysfunction model recognises and enables the conceptualisation of emotional deprivation and disturbances in family relationships (Glaser and Frosh, 1991). In doing so, Trepper and Barrett (1986 cited in Masson and O'Byrne, 1993) argue that family systems theory had a large clinical impact firstly, on the professional recognition of child sexual abuse, secondly on the awareness that child problems could indicate general family problems, thirdly on the awareness that adults had sexual fantasies about children, and fourthly on the use of family treatment. Family dysfunction theories extend the level of analysis to include the influences of marital relationships and social networks, which is supported by extensive empirical literature (Ammerman, 1990 cited in Becker et al, 1995).

Systems ideas in general are particularly useful for understanding the professional impact on the family and the families’ impact on the professional system. For
instance, Furniss (1987a) warns that professional systems can mirror aspects of disorganised family dynamics, and hence, lead to splitting, undermining between professionals and unresolvable professional dynamics. Family therapy is a widely used therapeutic treatment for child abuse in general (Keller et al, 1989 cited in Becker et al, 1995). However, the limitations of the family dysfunction theory in offering a complete theory to explain, protect and treat child sexual abuse, means that family therapy commonly appears as part of a multi-disciplinary programme, alongside individual and group work (Furniss, 1991).

**EMPIRICAL SUPPORT**

Issues in evaluating theories are relevant to both validating theoretical assumptions as well as supporting treatment effectiveness. However, progress in evaluating treatment outcome for children is generally slower compared to that for adults (Kazdin: 1988; Rutter, 1985a cited in Lane and Miller, 1997). Outcome research for the treatment practices advocated by different theories of child sexual abuse is generally problematic and methodologically weak, making adherence to a scientist-practitioner model difficult (Becker et al, 1995). Experimental studies of continuing abuse and no treatment control studies are impossible on both ethical and moral grounds and standardised outcome measures as well as longitudinal studies and follow-up studies are sorely needed (Becker et al, 1995). The definition, idiosyncrasy, complexity, secrecy and emotionality surrounding child sexual abuse means that establishing the validity of theoretical arguments and treatment outcomes with the wider professions, academic and political audience becomes inherently problematic. Consequently, not only is there a limited evidence-base to guide clinical practice but also a general difficulty in determining the most effective treatments for sexually abused children (Berliner and Wheeler, 1987 cited in Becker et al, 1995).

In view of the two theories evaluated in this discussion, there is only some evidence, although methodologically weak for treatment effectiveness for sexual abuse. This includes individual psychotherapy (Sullivan, Scanlan, Brookehouser, Schulte and Knutson, 1992 cited in Becker et al, 1995), group psychodynamic psychotherapy (Downing, Jenkins and Fisher, 1988 cited in Becker et al, 1995), and family therapy as

**CONCLUSION**

Child abuse is a highly complex and idiosyncratic phenomenon with multiple risks, etiological, maintaining and protecting factors, which requires comprehensive conceptual and theoretical models to guide effective clinical practice and empirical research. Both psychodynamic and family dysfunction theories have contributed something to our understanding of the potential causes and therapeutic interventions for child abuse, but without valid empirical support for their fundamental theoretical assumptions they have also had a devastating clinical impact. Despite their popularity, feminist theories and Finkelhor's sociological theory have highlighted what little attention psychodynamic and family dysfunction theories pay to broader cultural, social and political structures as well as particular power imbalances that gender, age and race invoke. Their clinical application is hence limited by their range of convenience, level of analysis and perspective and entirely misses the potential for overcoming general factors of structural and racial inequality and establishing wider socio-political prevention programmes (Waldby et al, 1990). Theories with different levels of analysis are not necessarily clinically invalid, but they do raise disputes over which should carry more weight (Corby, 1989). At present, in a culture of evidence-based practice, there is surprisingly little evidence to validate theoretical positions and to guide treatment decisions (Becker et al, 1995). Consequently, there is an urgent need for empirical and methodologically sound treatment outcome studies to be conducted with sexually abused children.
REFERENCES


"Discuss the Use and Effectiveness of CBT for Emotional Disorders in People with Dementia."

Core Placement 4

May 2001

Year 2
Discuss the Use and Effectiveness of CBT for Emotional Disorders in People with Dementia

Dementia is a broad diagnostic label for a syndrome of a progressive nature, which is characterised by disturbances of multiple higher cortical functioning (eg: language, memory, reasoning) and often accompanied by a corresponding decline in motivation (eg; apathy), emotional control (eg: depression, anxiety, aggression) and behaviour control (eg: restlessness, wandering) (DSM-IV, 1994). An estimated 675,000 older adults in the UK have dementia. Estimates of the prevalence of emotional disorders coexisting with dementia report depressive symptoms in thirty (Teri and Wagner, 1992 cited in Teri, 1994) to eighty-seven percent (Cummings and Victoroff, 1990 cited in Cheston and Bender, 1999) and anxiety symptoms in nine (Eisdorfer, Cohn and Keckich, 1981 cited in Koder, 1998) to thirty-eight percent (Wands et al, 1990 cited in Koder, 1998). Despite an increasingly recognised value of treating emotional disorders in depression (eg; Katzman, 1987 cited in Thompson et al, 1990), relatively few rigorously controlled research studies have been conducted into the effectiveness of therapeutic techniques for emotional disorders in dementia (Cheston and Bender, 1999). Perhaps because progressive cognitive impairments in dementia such as impaired memory, abstract reasoning, insight and capacity to learn present clear difficulties for psychological therapy (James, 1999). Cognitive-behavioural therapy (CBT) however, is time-limited, structured, problem focused, goal-orientated and multimodal and with suitable modifications for older adults with dementia may provide promising outcomes in reducing emotional distress particularly in early dementia (Thompson et al, 1990).

The use and effectiveness of CBT with depression and anxiety is being evaluated in older adults in general (eg: Gallagher-Thompson and Thompson, 1996) and in dementia, has predominantly focused on directly intervening with early dementia (Kipling and Bailey, 1999; Koder, 1998; Teri and Gallagher-Thompson, 1991) and more recently, indirectly through treatment of distressed carers (Chang, 1999;
Interventions for more advanced cognitive impairments in dementia however, appear to demonstrate a greater emphasis on behavioural techniques (Teri and Uomoto, 1986 cited in Teri and Gallagher-Thompson, 1991; Teri, 1994). The existing published research into the feasibility of CBT in dementia is primarily investigative and consists of single case studies (eg: Koder, 1998), small group designs (eg: Kipling and Bailey, 1999) and qualitative research (Noyes, Daley and French, 2000; Snyder et al, 1995). Although inferences drawn from the results are very promising, many of the studies to date far from provide rigorous and controlled experimental designs, thus rendering the efficacy of the use of CBT for emotional disorders in dementia inconclusive.

**Characteristics of Dementia**

Dementia is characterised by an interaction of cognitive, functional and emotional deficits (Marriott, 2000) and is diagnosed on the basis of the exclusion of all other possibilities. The DSM-IV (1994) criteria requires the presence of at least one disturbance of multiple higher cortical functioning, for instance, difficulties with memory (short and long-term), reasoning, abstract thinking, orientation, calculation, learning capacity, receptive and expressive language, judgement, or personality changes, which significantly interfere with the individual’s work or social life. Dementia is generally regarded as a progressive syndrome in which an early or mild phase is characterised by forgetfulness, a middle or moderate confusional phase where cognitive deficits become more pronounced and independent living becomes hazardous and a late or severe phase in which severe cognitive impairment grossly effects activities of daily living and independent living is no longer possible (DSM IV, 1994). There is however, wide individual and group variation in the clinical pattern of decline and over fifty different disorders leading to dementia have been identified (Cummings, 1987b cited in Zarit and Zarit, 1998). Three main diagnostic groups have been distinguished. Dementia of the Alzheimer’s type (DAT) accounts for almost sixty-six percent of diagnosed dementias and Lewy-Body Dementia (LBD) accounts for seven to thirty percent (Cheston and Bender, 1999). They have similar patterns of cognitive impairments with insidious onset, gradual decline and occasional plateaus of abilities, particularly in LBD. In contrast, vascular dementia accounts for ten to twenty percent of dementias, has a sudden onset caused by a series of small strokes or
infarcts, a step-wise pattern of decline, periods of relative recovery, more localised impairments than DAT and relative preservation of some higher cortical functions such as new learning (Cheston and Bender, 1999). Further identified dementias are associated with Parkinson’s, Huntington’s and Pick’s disease and are generally characterised by prominent motor disturbances, apathy, mood disorders, inappropriate emotional display and difficulties with abstract knowledge (Zarit and Zarit, 1998).

**Emotional Disorders**

**Prevalence of Emotional Disorders in Dementia**

The process of dementia generally involves the inevitable loss of abilities such as learning and remembering, making sense of the world, planning ahead and decision-making. This process of loss not only makes day-to-day living progressively harder but is also complicated by changes in social functioning and relationships, reduced self-esteem and possibly an awareness of current and future declines in abilities and performance (Cheston and Bender, 1999). The most common reaction to losses such as these is sadness (Cheston and Bender, 1999). It is thus, not surprising that with the cumulative losses in dementia that major depressive disorder is reported in approximately thirty-percent of people with AD (Teri and Wagner, 1992 cited in Teri, 1994) and depressive symptoms in up to eighty-seven percent (Cummings and Victoroff, 1990 cited in Cheston and Bender, 1999).

Depression is considered most likely within the early (Lazarus, Newton, Cohler et al, 1987 cited in Feldman and O’Brien, 1999) and middle phases of dementia (Logsdon and Teri, 1995 cited in Zarit and Zarit, 1998). However, progressively declining self-awareness and insight may mitigate against depression in severe dementia, be obscured by cognitive deficits and possibly overlooked as the detection of depression becomes harder (O’Neill and Carr, 1999). Symptoms of depression frequently co-exist with anxiety in older adults, particularly in conjunction with medical disorders (Reifler and Larson, 1990 cited in Woods and Bird, 1999). The social taboo and uncomfortable atmosphere of silence which still surrounds dementia generally creates an environment that fosters uncertainty, lack of control, lack of safety, anxiety and suspicion. Estimates of anxiety in dementia range from nine (Eisdorfer, Cohn and Keckich, 1981 cited in Koder, 1998) to thirty-eight percent (Wands et al, 1990 cited in
Koder, 1998), with approximately sixty percent of individuals exhibiting agitation (Mintzer and Brawman-Mintzer, 1996). However, there is some uncertainty about whether the etiology of these emotional disorders is organic or secondary to the losses in dementia and therefore psychological in nature (Thompson et al, 1990).

**CONCEPTUALISATIONS OF EMOTIONAL DISORDERS IN DEMENTIA**

Loss of personality, cognitive functioning and emotional control in dementia has historically been understood in terms of neurological impairment (Cheston and Bender, 1999). This organic view however, lacks interest in the emotional suffering of the individual and has led to an apathetic environment in which the sufferer is regarded as a non-person devoid of valid feelings, devoid of a lifetime of experiences and devoid of ‘personhood’ (Kitwood, 1990). Kitwood (1990) and Kitwood and Bredin (1992) described this as a ‘malignant social psychology’. A process of disempowerment, intimidation and invalidation of the person with dementia, which contributes to a loss of self-esteem, self-identity and ultimately exaggeration of the cognitive deficits and behavioural problems. The discrepancy that exists when functional incapacity is greater than that justified by the actual neurological impairment (Brody et al, 1971 cited in Mintzer and Brawman-Mintzer, 1996) is referred to as ‘excess disability’ (Kahn, 1965 cited in Cheston and Bender, 1999). If the ‘excess’ disability is reversible with appropriate psychological treatment, improved functioning and quality of life may be sustainable for a slightly longer time.

James (1999) has recently built upon Kitwood’s (1997) descriptive framework of the development of emotional disorders in dementia and provides a more detailed cognitive conceptualisation of distress in people with dementia. James (1999) proposes that a complex set of interactions between factors, such as mental health, life history, premorbid personality, current environmental and physical status, are filtered through an individuals’ cognitive abilities. Older adults with dementia who have reduced cognitive information processing abilities are therefore likely to arrive at unusual interpretations. Automatic distorted thinking processes and mood consistent negative biases (eg: catastrophising, overgeneralising, magnifying negatives) about themselves, their future and the world are believed to influence an individuals feelings and behaviours and therefore both produce and maintain depressive and anxious
symptomatology (Beck, 1976 cited in James, 1999). This interactive cognitive triad
(Beck, 1976) is a central feature of cognitive therapy and has been evidenced in the
thinking of depressed older adults with dementia, for instance; ‘I’m useless’, ‘I’m not
good for anything’, ‘I don’t know why she puts up with me’, ‘I want to die’ (Cheston,
1997 cited in Cheston and Bender, 1999) and in anxious older adults with dementia
for instance; ‘I’m terrified’, ‘I never thought it would end like this’, ‘These people are
very dangerous’, ‘What will happen to me?’, ‘Will I end up in a nursing home?’.

Behavioural symptoms of agitation, apathy, withdrawal, fatigue, low motivation, sleep
disturbance and loss of appetite in older adults with dementia have been found to
generate high rates of aversive reactions in carers (Teri, Traux and Pearson, 1988b
cited in Teri, 1994). The reactions of carers are hypothesised to generate
‘dysfunctional carer practices’, such as deception (treachery) and insensitive handling
(objectification) (James, 1999; Kitwood, 1997). This has been hypothesised to
exacerbate depression and anxiety in the person with dementia, which in turn,
exacerbates cognitive dysfunction, behavioural problems and an impaired quality of
life (O’Neill and Carr, 1999; Yesavage, 1984 cited in Koder, 1998). The inclusion of
carers in therapeutic interventions such as CBT may therefore, not only be
advantageous, but essential.

**COGNITIVE BEHAVIOUR THERAPY (CBT)**

CBT is based on Beck’s cognitive model (1976 cited in James, 1999; Beck, Rush,
Shaw and Emery, 1979 cited in Gallagher-Thompson and Thompson, 1996) and a
wide range of techniques are referred to under this heading of CBT. Some authors
place equal emphasis on the cognitive and behavioural aspects, whilst others utilise
more behavioural or cognitive techniques (Newell and Dryden, 1991). CBT provides
a systematic and structured approach for directly identifying, challenging and
modifying an individual’s specific and exaggerated negative automatic cognitions
about themselves, their future and the world. These automatic negative or
dysfunctional cognitions are believed to represent underlying core assumptions
(schemata) and mediate unpleasant emotions and maladaptive behaviours (Beck,
1976). Behavioural methods such as relaxation to enhance self-efficacy and coping
skills (particularly in anxiety provoking situations) are also used to challenge their
validity and examine evidence against their negative cognitions (Gallagher-Thompson and Thompson, 1996). CBT is time-limited, goal orientated, problem-focused and requires an active and collaborative alliance between client and therapist in order to identify suitable therapeutic goals and to develop more adaptive thought patterns, coping skills and emotional levels (Zeiss and Steffen, 1996). Although CBT has been applied to anxiety and depression largely independent of age (Cheston and Bender, 1999) when compared to research with younger adults, it's use and efficacy is generally under-researched and under-developed in older adults (Gallagher-Thompson and Thompson, 1996).

**Effectiveness of CBT for Depression and Anxiety with Older Adults**

The theoretical approaches of CBT and behaviour therapy emphasise lifelong learning and postulate that changes in thoughts, feelings and actions are achievable at any point in life (e.g. Beck, Rush, Shaw and Emery 1979; Goldfried and Davison, 1994 cited in Zeiss and Steffen, 1996). The validity of the cognitive model has more recently been demonstrated with older adults (Wilkinson, 1997) and a review of the current literature have supported the treatment effectiveness of a modified CBT with depressed community residing older adults who are cognitively intact (Gatz et al, 1998). Further studies have indicated that cognitive therapy alone in older adults is more effective than no treatment controls (Beutler, Scogin et al, 1987) and can be equally effective as behavioural or psychodynamic therapies (Thompson, Gallagher and Breckenridge, 1987). Although research literature has relatively neglected the treatment of anxiety disorders in older adults, several pilot case studies have demonstrated therapeutic efficacy of cognitive therapy in panic disorder and agoraphobia (King and Barraclough, 1991 cited in Wilkinson, 1997) and cognitive behaviour therapy in generalised anxiety disorder (Hunt and Singh, 1991 cited in Koder, 1998) with older adults.

**Use of CBT with Older Adults with Dementia**

Core features of CBT make it adaptable to older adults both with age-related and actual memory impairment, for instance, shorter and more frequent sessions, slower therapeutic pace, repetition, multimodal training (instructions, demonstrations, practice) and memory aids (audiotapes, handouts, written assignments, notebooks).
(Kaplan and Gallagher-Thompson 1995; Zeiss and Steffen, 1996). These adaptations are important because the psychoeducational component is central to CBT and clients need to remember information from earlier sessions and conduct ‘homework’ assignments. The cognitive component emphasises active and collaborative therapist-client participation, education about connections between thoughts, behaviour and emotions, is a problem solving approach based on the present and emphasises relearning or strengthening of problem solving skills (Thompson et al, 1990). The increased use of behavioural techniques such as relaxation training and increasing daily pleasurable activities has also been recommended as particularly useful with distressed older adults (Dick and Gallagher-Thompson, 1995; Emery, 1981; Zeiss and Lewinsohn, 1986 cited in Gallagher-Thompson and Thompson, 1996). These modifications made to CBT for use with older adults have generally been applied to older adults with dementia (eg: Gallagher-Thompson and Thompson, 1996).

Additional modifications when using CBT with older people with dementia include an awareness and sensitivity to the nature of a client’s cognitive weaknesses as well as strengths, comprehensive neuropsychological testing, a structured and more directive approach, the inclusion of family members when possible, continual monitoring of the client’s comprehension of the sessions, an avoidance of overtaxing the client’s abilities and the setting of realistic goals in relation to their cognitive impairments. (Thompson et al, 1990).

The fact that older adults with dementia may not be able to fully express their emotions should not discount their suitability for psychological therapy. An older adult with dementia is in fact, more likely to be overwhelmed with anxiety and create more unrealistic sets of beliefs to account for things that they cannot make sense of. Thus making their subjective experience and reactions a good starting point for therapy (Cheston and Bender, 1999). Even seemingly trivial events may trigger a very catastrophic reaction, making the feelings, beliefs and behaviours of people with dementia less predictable to the cognitively intact. Cognitive therapy and support groups have been successfully utilised in older adults within the early and mid stages of dementia who are relatively cognitively intact (Kipling and Bailey, 1999; Noyes, Daley and French, 2000; Snyder et al, 1995) and have a degree of self-awareness and
insight (Solomon and Szwabo, 1992; Miller, 1989 cited in Cheston and Bender, 1999).
However, occasional self-awareness has been reported in later dementia (Zarit and
Zarit, 1998) and suitability may therefore be more appropriate on an individual basis.
Behavioural therapies have also been utilised with all levels of cognitive impairment
(Teri, 1994) and are generally considered more suitable in later dementia (Teri and

QUALITATIVE STUDIES OF THERAPY WITH PEOPLE WITH DEMENTIA
A general supportive foundation for the need and use of therapies such as CBT in
older adults with dementia can be found in qualitative studies. Early intervention
community-based services described by Noyes, Daley and French (2000) utilised
support programmes, CBT interventions and education for people with a diagnosis of
Alzheimer’s Disease (AD) or atypical dementia and their families. The programmes
were targeted towards relatively high functioning people in the early phases or
dementia with mild cognitive impairment and a mini mental state examination score
(MMSE: Folstein, Folstein and McHugh, 1975) of twenty-three and higher.
‘Cognitive’ and behavioural elements included education about dementia, guided
imagery, relaxation and cognitive exercises to improve memory and problem-solving.
Although not directly comparable to CBT the study indicated that the participants
were problem focused, focused on the present, able to participate, capable of
remembering previous sessions and practicing ‘homework’ tasks, despite being very
anxious. Qualitative data indicated that the participants themselves felt that the
programme had helped them to “gain hope”, “feel like I’m doing something about the
disease”, and “ be with people who know what I am talking about” (Noyes, et al,
2000). Quantitative results indicated that most people maintained or improved on
scores on the MMSE and the Geriatric Depression Scale for up to nine months.

Further support for the potential utility of CBT with older adults with dementia can be
found in Snyder et al’s, (1995) research into support groups for people with AD.
Older adults with AD and an MMSE of twenty and above were able to discuss a range
of educational topics about AD, share feelings, experiences and perspectives on their
illness and discover positive aspects of their situations and options in coping
responses. The qualitative data evidenced that through general discussion some of the
participants’ cognitions had become more adaptive during the course of the group, for instance: “Why worry about it. It won’t help will it? Let someone else worry. If you can’t do something about it, forget it” and “Don’t let it get hold of you. You have to get a hold of it. Get the think tank working. It’s the best medicine in the world” (Snyder et al, 1995).

**Effectiveness of CBT with Older Adults with Dementia**

A review of published quantitative research indicated that relatively little research has been conducted into the effectiveness of CBT with people diagnosed with dementia. However, existing literature often utilises cognitive and behavioural techniques under the rubric of CBT but without fully combining the cognitive and behavioural components into an integrated cognitive-behavioural approach (eg: Teri and Gallagher-Thompson, 1991). The identified studies mainly consist of single case studies assessing individual therapy (Haley, 1983b cited in Koder, 1998; Koder, 1998), small uncontrolled group studies with small sample sizes (Kipling and Bailey, 1999) and descriptive studies of the content of the programme with no methodological detail (Teri and Gallagher-Thompson, 1991; Teri, 1994). The effect size of the statistical analysis is often too small to determine the effectiveness of the treatment approach and studies risk claiming that minimal improvements are clinically significantly (eg: Beck et al, 1988). Furthermore, unrepresentative samples, methodological problems and the relatively uncontrolled nature of the studies generate a comparatively low level of inference from the results. However, despite the lack of rigorously controlled clinical studies, current studies do appear to offer promising outcomes for the utility of CBT with modifications, which need to be evaluated more rigorously in the future.

**CBT for Depression in Older Adults with Dementia**


Techniques used in the cognitive approach included dysfunctional thought records, challenging of automatic negative thoughts, the development of more adaptive ways of thinking and cognitive rehearsal during real life stressful situations as homework. Specific adaptations for people with dementia included simplified techniques, twice weekly and thirty-minute sessions and memory aids such as notepads and audiotapes of sessions. The behavioural treatment programme, included procedures developed by Teri and Uomoto (1986 cited in Teri and Gallagher-Thompson, 1991), which modified person-environment interactions, increased pleasant activities and decreased negative interactions. The outcome measures, administered before and after treatment, appeared to have been generated in the absence of a rigorous experimental design and no methodological details are provided. The authors however, although positive about the programmes do not make any claims about the efficacy of the treatment and do recommend rigorous evaluation of the programmes through controlled clinical trials.

Kipling and Bailey (1999) describe a small CBT group approach, based on Padesky and Mooney’s (1990 cited in Kipling and Bailey, 1999) generic cognitive therapy model to address unhelpful memory-related beliefs such as “I’m the only one that forgets X”. The sample in this group-therapy, within-subject design, consisted of three men with a diagnosis of probable dementia, whose cognitive impairments ranged from mild to moderate (MMSE score of nineteen to twenty-three). The pre and post treatment outcome measurements designed by the authors, using a seven point semantic differential scale, indicated improvements in mood, anxiety and use of relaxation skills. Qualitative data at a three-month follow-up implied that behavioural changes had been maintained, but quantitative measurements were not repeated. This uncontrolled study tentatively suggests that a small group is feasible and successful,
however no control condition was included, the sample size was small and the validity 
and reliability of the outcome measures are questionable.

**CBT for Anxiety in Older Adults with Dementia**

Akin to depression, the systematic evaluation of the outcome and effectiveness of 
cognitive behavioural therapy for anxiety in older adults with dementia has also been 
under-researched. In an analogous case study with an older adult with paranoid 
schizophrenia Haley (1983a cited in Koder, 1998) demonstrated the use of cognitive 
techniques such as cognitive challenging and rehearsal of coping self-statements to 
decrease incidents of agitation and aggression, which were maintained at a three-
month follow-up. A further case study (Haley, 1983b cited in Koder, 1998) with an 
eighty-seven year old, moderately demented lady who become anxious when left alone was described ‘CBT’ (Koder, 1998), yet the methods described were more 
comparable to a behavioural approach. For instance, techniques of simplified 
relaxation, graded exposure and environmental aids (alarm clocks, notice boards). 
This behavioural approach was useful in achieving tolerance of fifty minutes alone, 
but no systematic evaluation of the outcomes was undertaken.

Two case studies described by (Koder, 1998) again appear to place a large emphasis 
on behavioural methods although considered a ‘cognitive-behavioural’ approach by 
the author. The case study of an eighty-two year old married man with vascular 
dementia and generalised anxiety disorder, excluded the use of cognitive therapy after 
neuropsychological assessment indicated problems with concept formation and 
difficulties shifting between ideas. Nevertheless, with his wife as co-therapist, 
intervention techniques included the identification, challenging and restructuring of 
his cognitive distortions, such as; “This is not a heart attack, I am simply walking a bit 
fast and it’s a hot day. I can take my time and rest whenever I want to”, as well as 
behavioural methods of breathing retraining written on a cue card and distraction 
(Koder, 1998). Observational outcome measures indicated a temporary improvement 
in quality of life, and a complete cessation of presentations to GP, A&E and night 
awakenings. However, due to a further cerebral incident, progress was not maintained 
at a three-month follow-up.
The lack of systematic evaluation, use of non-psychometric dependent variables as outcome measures and a failure to control for non-specific factors (eg: improved marital relationship, given his history of premorbid marital difficulties or spontaneous recovery) present difficulties for this case study. The participants exclusion from cognitive therapy but the use of ‘cognitive challenging’ and ‘cognitive restructuring’ techniques raises questions about the utility and effectiveness of the cognitive component and therefore weakens the authors conclusion that the ‘role of cognitive-behaviour therapy ... is promising’. The second ‘cognitive-behavioural’ case study (Koder, 1998) only uses relaxation techniques with an older adult with alcohol induced cognitive impairment and generalised anxiety. The results were heavily confounded by the lack of baseline and outcome measures and the participants decrease in alcohol intake prior to therapy.

**CBT with Carers of Older Adults with Dementia**

Given the limited controlled research and demonstrated effectiveness of direct use of CBT with individuals with dementia, it is conceivable that conjoint therapy with the carers or CBT with the carers alone may indirectly benefit the person with dementia. Most people with dementia live in the community (Wenger, 1994 cited in Marriott, 2000 in Psige) and are cared for by spouses or children who are often elderly or have physical problems themselves (Cheston and Bender, 1999). The impact of caring for someone with dementia is well documented in the literature (Marriott, 2000) with reports of depressive symptoms twice as high than in caregivers generally (Gendron et al, 1996). Estimates of depression in caregivers of people with dementia range from forty percent (Coppel, Burton, Becker and Fiore, 1985: Gallagher, Rose, Lovett and Silven, 1986 cited in Adkins, 1999) to eighty-seven percent (Rabins, Mace and Lucas, 1982 cited in Adkins, 1999). Whilst the quality of the client-carer relationship and depressive symptoms are thought to be important mediators of distress in carers (Gillear, 1984), the rate of cognitive decline and behavioural disturbances is believed to be positively correlated with the level of stress perceived by the carer (Gallagher-Thompson, Brooks et al, 1992 cited in Kaplan and Gallagher-Thompson, 1995). The relationship between carer and client is a dynamic (James, 1999; Kitwood, 1997 cited in James, 1999) and interactive process and it is conceivable that psychological
interventions that reduce carer distress may improve the quality of the relationship (Marriott, 2000).

Despite the amount of literature on caregiver burden and stress, there are relatively few empirical studies of CBT interventions with carers of older adults with dementia. Early intervention studies by Levine, Dastoor and Gendron, (1983 cited in Gendron et al, 1996) and Gendron et al, (1986 cited in Gendron et al, 1996) have developed and indicated the usefulness of a group programme utilising CBT techniques for carers of people with dementia. Further studies have demonstrated the effectiveness of group CBT for carers on assertion and marital adjustment compared to a support group focusing on information giving and socialisation (Gendron et al, 1996) and the effectiveness of CBT for carers of longer than four years when compared to psychodynamic therapy (Gallagher-Thompson, Lovett and Rose, 1991 cited in Adkins, 1999). Furthermore, a behavioural group intervention teaching carers behavioural strategies to reduce depression in people with AD demonstrated post-treatment declines in depression in the people with dementia as well as two of the carers (Teri and Uomoto, 1986 cited in Adkins, 1999).

A subsequent controlled clinical trial on joint client and carer behavioural intervention for depression in dementia demonstrated significant levels of improvement in client and carer depression after treatment (Hamilton Depression Rating Scale) compared to the waiting list control condition (Teri, 1994). Joint therapy with clients and their carers and the indirect impact on the person with dementia when utilising CBT with the carer appear to be a relatively new research areas and only two studies on the latter (Chang, 1999; Marriott, 2000) were identified in the published research.

Marriott’s (2000) single-blind controlled treatment trial, supports the effectiveness of CBT in reducing subjective measures of anxiety and depression (General Health Questionnaire and the Beck depression Inventory) in carers of people with AD. Indirectly, the CBT approach for carers decreased behavioural disturbances for a short period immediately after intervention and increased daily living activities by follow-up in the older adults with AD. The method included fortnightly CBT sessions with a clear treatment protocol without the patient present and used cognitive and
behavioural strategies to reduce stress, coping skills training and behaviour management. Significant improvements were found between the intervention and two control groups. The results appear to be very promising for both short-term client improvements and longer-term increase in daily living activities. Unfortunately, the range of cognitive impairments in the older adults with AD was not discussed and the effect size of the statistical analysis is not mentioned, thus reducing it’s generalisability and validity.

Chang (1999) described a ‘randomised control’ trial comparing the effectiveness of a cognitive-behavioural intervention utilising videos and telephone calls with attention-only, ‘placebo’ telephone calls. However, the CBT approach described was indirect and conducted exclusively via videos and telephone calls, with a rather eclectic combination of behavioural (increasing pleasant activities, behavioural management), cognitively orientated (validation methods: Feil, 1989 cited in Chang, 1999) and cognitive-behavioural techniques (‘cognitive-reframing’ and a problem-solving) demonstrated on the videos. Although improvements in anxiety and depression were significant within the ‘CBT’ carers and maintained at follow-up, they were not significantly different to improvements in the ‘placebo’ control. Thus suggesting that videos and the elective ‘CBT’ approach had little additional benefit to general, helpful telephone conversations and indicating the presence of numerous uncontrolled and confounding variables (eg: medication, type of dementia). Measurements of the older adults with dementia only focused on their functional status and indicated significant deterioration over time. These measurements were however completed by the carers and therefore may have been biased by observed decreases in carer satisfaction over time. This study has been included because it highlights the importance of controlling for confounding variables and the negative impact that eclectic therapeutic approaches subsumed under the heading of ‘CBT’ can have on the search for effective CBT approaches with older adults with dementia.

Barriers to Effective Research with Older Adults with Dementia
Cognitive-behavioural therapies generally appear to be used with milder levels of cognitive impairment in older adults with dementia. However, this renders them highly dependent on an early differential diagnosis, the individuals’ knowledge of the
diagnosis and the reliability and validity of assessments measures with cognitively impaired older adults. Diagnosis is one of exclusion and since psychological problems such as anxiety and depression can produce similar cognitive profiles to those found in early or mild dementia ('pseudodementias') early and differential diagnosis is extremely complex (Keady, 1996 cited in Cheston and Bender, 1999). The high co-morbidity between anxiety and depression in dementia (Mintzer and Brawman-Mintzer, 1996 cited in Koder, 1998) and a general lack of reliability and validity data on measurement tools for depression in older adults above eighty-five (Scogin, 1994 cited in Kaszniak, 1996) and anxiety in older adults over the age of sixty-five years (Beck et al, 1995 cited in Kaszniak, 1996; Koder, 1998) further complicates diagnosis.

Even when a diagnosis has been made, lack of awareness about dementia and services available, and lack of physician and health provider referrals to early intervention programmes (Noyes, Daley and French, 2000) generally result in service provision targeted towards people with more advanced cognitive impairments. This process unless changed will thus, continue to limit the opportunities to conduct and evaluate the use and effectiveness of CBT techniques with milder cognitive impairments in dementia (Cheston and Bender, 1999). The additional need for controlled research to systematically evaluate the use and efficacy of CBT interventions for emotional disorders in general and across diagnostic categories dementia has been highlighted by a one-year longitudinal study data on the course of depression and anxiety in different dementias (Ballard et al, 1996). This study indicated a high rate of spontaneous resolution of depression within three months in a small sample and greater persistence in vascular dementia than AD (Burns, 1991 cited in Ballard et al, 1996).

**Conclusion**

The lack of documented therapy available to people with dementia appears to suggest a pessimistic view towards its potential clinical effectiveness. Although the range of cognitive impairments in dementia presents a challenge to psychotherapy, there is strong support for it’s value and modified use in individuals with dementia (Cheston and Bender, 1999; Thompson, 1990). Randomised control trials of CBT interventions for emotional disorders in people with dementia are extremely rare and are urgently needed in order to ascertain the effectiveness of this intervention. The existing
literature consists of case studies, single case design experiments and small group studies which generally deal with a mixture of the different diagnostic categories, a considerable and sometimes inappropriate range of definitions of CBT and relatively vague and interchangeable categories of 'mild', 'moderate' and 'severe' dementia. These present particular generalisation difficulties because people with dementia vary according to levels of cognitive impairment, sites of cognitive impairment, relative strengths and diagnostic category (Hart and Semple, 1990 cited in Woods and Bird, 1999).

Coupled with small, unrepresentative samples and inadequately designed experiments and outcome measures it is perhaps not surprising that the efficacy of CBT in this population has yet to be convincingly determined. However, the preliminary and investigational studies discussed generally do indicate that appropriate minor modifications can lead to encouraging results with mild to moderately cognitively impaired individuals, through individual, group and joint therapy with the carers (Kipling and Bailey, 1999; Teri and Gallagher-Thompson, 1991). Furthermore, an interesting and promising area for future research on the indirect impact of CBT interventions with carers on behavioural disturbances (in the short-term) and depression in people with conceivably any stage of dementia (Marriott, 2000) appears to be emerging.
REFERENCES


"In Addition to Neuropsychology, what other Knowledge and Skills are Necessary to Carry out Effective Cognitive Rehabilitation?"

Specialist Placement 1

December 2001

Year 3
In Addition to Neuropsychology, What Other Knowledge and Skills are Necessary to Carry out Effective Cognitive Rehabilitation?

'Cognitive Rehabilitation' has neither been adequately defined in the literature nor adequately studied (Carney et al, 1999), hence leaving the components of 'effective' cognitive rehabilitation very much open to debate. Cognitive rehabilitation encompasses useful conceptual frameworks and a multitude of systematic, multi-disciplinary techniques based on cognitive psychology and neuropsychology (Toglia, 1990 cited in Perna et al, 2000). However, few pre-determined treatment protocols or even general treatment approaches have been established (Sohlberg and Mateer, 1989). Traditionally cognitive rehabilitation has focused on attempting to modify the environment, implement compensatory skills or behaviours and/or restore function through direct retraining for specific impairments in intellectual, perceptual, communicative, psychomotor and behavioural skills (eg: Luria, 1948 cited in Prigatano, Glisky and Klonoff, 1996, 1963; Schacter and Glisky, 1986 cited in Prigatano, Glisky and Klonoff, 1996). However, cognitive rehabilitation is not without its limitations and more recently, the importance of psychotherapy for treating psychological and emotional consequences of brain injury in the rehabilitation process has become apparent (eg: Bennett and Raymond, 1997; Prigatano, 1989, 1999). When emotional and motivational disturbances have also become the focus of rehabilitation, improved psychosocial outcomes have been reported (eg: Ben-Yishay, Rattok, Lakin, et al., 1985; Prigatano, Fordyce, Zeiner, et al., 1984; Prigatano, Glisky and Klonoff, 1996).

Following brain injury individuals experience a wide range of physical, cognitive and emotional symptoms (eg: Ben-Yishay and Prigatano, 1990 cited in Prigatano, Glisky and Klonoff, 1996, 1999; Ponsford et al, 1995). Although emotional and personality changes could result from organic changes, depression, guilt, anxiety about the future and feelings of helplessness and hopelessness are commonly expected secondary reactions to brain injury in both the individual and their families (Prigatano, 1999).
is believed that psychotherapy can help both individuals and their families in their initial adjustment to the injury (Bennett, 1987, 1989 cited in Bennett and Raymond, 1997) and long-term adjustment to their altered roles in the broader context of their lives (Prigatano, 1991). Although, by virtue of their cognitive difficulties many individuals will have difficulties benefiting from traditional psychotherapy, important issues, knowledge, skills and modifications for effective psychotherapy with individuals with predominantly mild brain injuries are being discussed in the literature (eg: Ben-Yishay et al, 1982 cited in Prigatano, 1999; Prigatano, 1989, 1991, 1999). In providing an overview of most of the issues, attention will also be paid to pharmacological (Zafonte, et al, 1999) and substance abuse interventions (Corrigan et al, 1999) as they are also increasingly becoming the focus of attention in cognitive rehabilitation.

**INCIDENCE AND PSYCHOSOCIAL EFFECTS OF BRAIN INJURY**
The incidence of brain injury is increasing (West, 2001 cited in Folzer, 2001). Excluding milder head injuries and strokes, an (under) estimated 520 out of every 10,000 people suffer a serious head injury each year in the UK (Wenden et al, 1998 cited in Sinnakaruppan and Williams, 2001). In contrast to stroke, head injury occurs in a predominantly younger age group, 17-25 years, posing particular challenges for long-term rehabilitation, family coping and adaptation to a life time’s caring for someone who otherwise would have been independent (Flanagan, 1998 cited in Sinnakaruppan and Williams, 2001). Regardless of etiology, clients referred for cognitive rehabilitation display many and varied degrees of neuropsychological impairments, emotional responses, motivational impairments and levels of insight into their impairments (Ben-Yishay and Prigatano, 1990; Prigatano, Glisky and Klonoff, 1996). This is perhaps the central problem faced when attempting cognitive rehabilitation. Equally the course of recovery from brain injury is extremely variable among individuals and dependent on a range of mediating factors such as; age at injury, severity and location of damage, rate of improvement following injury and premorbid level of functioning (eg: socio-economic factors and external factors such substance abuse) (Sohlberg and Mateer, 1989). Spontaneous recovery is easily confounded with treatment effects, although it occurs most rapidly at the outset and
gradually slows and reaches a plateau (Brooks and Aughton, 1979 cited in McKinlay and Watkiss, 1999).

In the weeks and months following moderate-to-severe brain injury frequently reported emotional and behavioural symptoms include irritability, impatience, poor memory, slowness, mental fatigue or euphoria (eg: Ponsford, Olver, Curran, 1995 cited in McKinlay and Watkiss, 1999). The severity of cognitive impairments such as memory, slowed information processing and language and communication may decrease over time on neuropsychological testing. However, subjective reports of emotional and behavioural problems such as irritability, anxiety, depression, fatigue, mood swings, and reduced self-esteem and identity by the client and their family are more liable to increase (eg: Ben-Yishay and Prigatano, 1990 cited in Prigatano, Glisky and Klonoff, 1996; Ponsford et al, 1995). This may in part be an expression of their frustration with current limitations. As clients try to resume a normal everyday life without previous family concessions, the true impact of their cognitive and memory impairments is likely to be exposed (Bennett and Raymond, 1997). Sooner or later they experience failures and losses, which they may not understand, for example, “If only I try harder, I can make a complete recovery”, “I can’t keep up with the workload any more”, “I lost my boyfriend. He said I was too ‘childish’”. Personality change, characterised by unreasonableness, childishness, reduced self-reliance and impulsivity, is one of the most common long-term emotional-behavioural changes reported by relatives (Brooks and McKinlay, 1983 cited in McKinlay and Watkiss, 1999) and is closely associated with the degree of caregiver burden or stress (Kreutzer et al, 1994 cited in McKinlay and Watkiss, 1999).

**ROLE OF COGNITIVE NEUROPSYCHOLOGY IN REHABILITATION**

In order for cognitive rehabilitation to have a sound theoretical and empirical basis, a scientific understanding of the theories and mechanisms of recovery is crucial, as well as strong links between neurosciences, cognitive sciences and cognitive rehabilitation (Ben-Yishay and Diller, 1993 cited in Prigatano, 1996). Cognitive neuropsychology, is an approach to understanding impairments in cognitive functioning, within a model of cognitive processing (Riddoch and Humphreys, 1994). It contributes to effective rehabilitation by providing insights and knowledge into the impaired cognitive
system, how it should function, localisation of the disruption in the information processing system and what kinds of cognitive and personality changes it may produce (Perna et al, 2000). Clinically, it’s application has led neuropsychologists, occupational therapists, special educational professionals, and other rehabilitation specialists to develop cognitive rehabilitation techniques aimed at the restoration of cognitive skills such as, attentional abilities, memory, visual and auditory processing, language, spatial skills, executive functioning and problem solving. Three approaches to cognitive retraining are predominant. Firstly, the use of compensation to get around a deficit. Secondly the use of substitution to solve a brain problem that the brain is able to solve by any alternative methods and thirdly the direct retraining of specifically impaired cognitive functions through drill and practice exercises and rehearsal (Prigatano et al, 1986).

Although an understanding of the scientific theories of brain functioning, cognitive neuropsychology, learning theory and neuropsychological assessment findings are necessary for cognitive rehabilitation (Sohlberg and Mateer, 1987) the contribution of cognitive neuropsychology to rehabilitation, has not been without scrutiny and controversy. Considering that they are not traditionally models of learning or psychosocial factors (eg: motivation, adjustment), doubts about the ability of neuropsychological theories to guide intervention choice (Hillis and Caramazza, 1994) and to impact on the majority of treatment programmes have been raised (Wilson and Paterson, 1990 cited in Riddoch and Humphreys, 1994).

Limitations of ‘Cognitive’ Rehabilitation
Evidence for and against the validity and use of cognitive rehabilitation aimed at directly remediating functional brain impairments remains controversial (Prigatano, 2000). Research has generally suffered from methodological shortcomings such as, great variability in levels of severity of injury, use of non-standardised test protocols, lack of controls, lack of consistent proof of improved performance and an absence of reliable periods of follow-up (Berrol, 1990). Some authors conclude that the current evidence only shows minimal clinical improvements on certain psychometric tests (Prigatano, 1999) or is non-conclusive (Ben-Yishay and Diller, 1993 cited in Perna et al, 2000). Others report that it is at worst, negative (Pliskens et al, 1996 cited in
Perhaps a valid criticism of cognitive rehabilitation is the absence of firm evidence of a generalised effect of training to "everyday" life (Prigatano, Glisky and Klonoff, 1996). Conversely, subjective functional improvements reported by the clients, may not be evidenced on neuropsychological measures. Formal neuropsychological testing is intrinsically different from "everyday" life and hence may underestimate the impact of the neuropsychological deficits. The importance of generalisation of skills is ingrained in clinical practice, yet, an understanding of how to facilitate generalisation is essentially lacking in the field of cognitive rehabilitation (Raskin and Gordon, 1992 cited in Mateer and Raskin, 1999). Not least, because ethical implications of prospective randomised controlled trials has limited research into this area (Giles, 1999).

The true complexity of successful outcomes in cognitive rehabilitation may depend on far more than neuropsychological variables. Prigatano and colleagues (1984, 1986 cited in Prigatano and Ben-Yishay, 1999), and Ben-Yishay and colleagues (1985) provided the first empirical evidence that inclusion of psychotherapy for psychosocial factors enhances rehabilitation outcome. Cognitive rehabilitation has traditionally focused on treating the neuropsychological deficits rather than the psychosocial and emotional difficulties associated with them, yet the latter is now known to play a part in long-term problems associated with brain injury, especially vocational re-entry, burden on caregivers and social isolation (McKinlay and Watkiss, 1999). The lack of extensive experience with, or knowledge of how to define, psychosocial deficits following brain injury has been acknowledged as an inhibiting factor in both research and practice (McKinlay and Watkiss, 1999). However, minimising the degree and influence of such problems through active professional, client, and family participation is now thought to be central to effective cognitive rehabilitation.

**Efficacy of Psychotherapeutic Interventions**

General scepticism about the usefulness of psychotherapy after brain injury has prevailed for years. By virtue of their cognitive difficulties, many individuals with brain injury would have difficulty in benefiting from traditional psychotherapy, with verbal communication, abstract reasoning problems, insight and memory deficits, precluding effective psychotherapeutic outcomes (Ball, 1988; Lewis, 1986, 1991;
Prigatano, 1991 cited in Gordon and Hibbard, 1992). This is particularly true in the acute stages of recovery with severe cognitive impairments and when clients present with long-term ingrained attitudes about themselves, disabilities and life problems (Prigatano, 1999, 2000). “Client-centred” approaches typically rely on focused attention, memory within and between sessions, reasoning ability, self-insight, intrinsic motivation, initiative and problem-solving skills. Conducting traditional psychotherapy with a brain-injured individual with typical impairments in these areas could distress them and make them worse (Bennett and Raymond, 1997). Therefore, clinicians need to have a clear understanding of what they are trying to accomplish with the client from the outset and not blindly accept each referral for psychotherapy.

Although there have been no formal scientific studies evaluating the effectiveness of psychotherapy for mild brain injury, indirect clinical evidence has indicated that benefits can be obtained in the post-acute phase, when the client is returning to the community (eg: Ponsford et al, 1995, Prigatano, 1989, 1991, 1999, 2000). Benefits included a higher incidence of employability, improved interpersonal relationships, and better emotional control, (Ben-Yishay et al, 1985; Prigatano et al, 1984; Prigatano et al, 1994 cited in Prigatano, 1999). Therefore, whilst there is a lack of evidence regarding the success or otherwise of any particular psychotherapeutic approach, useful approaches have been found (Klonoff and Prigatano, 1988).

Understanding the Choice of Therapeutic Modality and Severity
Disturbances of higher cerebral functioning, which lead to failure after failure, inevitably have psychosocial consequences. Helping some clients and their families to adjust to personal losses, the problem of ‘lost normality’ and to manage interpersonal consequences through psychotherapeutic interventions is thus, an important part of effective neuropsychological rehabilitation (Prigatano, 1999). For an effective intervention the following requirements need to be met; basic awareness of cognitive impairments and behavioural problems (Prigatano, 1986 cited in Klonoff and Prigatano, 1988), some preservation of comprehension of ideas presented by the clinician and ability to express personal needs (Bennett and Raymond, 1997). The appropriateness of therapy may then be guided by knowledge of and understanding of the severity of the cognitive impairments. Clients with mild brain injury are likely to
benefit from psychotherapy as the core intervention, rather than traditional rehabilitation therapies (Cicerone, 1991 cited in Ponsford et al, 1995), and from stress inoculation training interventions (Putnam and Millis, 1994 cited in Putman and Fichtenberg, 1999). The greater the global impairment, the more pharmacological and environmental interventions (eg; behaviour modification strategies) are required. The greater the executive dysfunction, (particularly in self-regulation and response inhibition) the more structured the therapeutic sessions need to be and the more active the clinician (Putman and Fichtenberg, 1999). Although minimal verbal skills are required in expressive and insight-oriented psychotherapeutic approaches, impaired abstract reasoning and memory can pose major obstacles, as abilities to combine the information necessary to achieve insights and remember them are essential (Sohlberg and Mateer, 1989).

Cognitive-behavioural techniques tend to lend themselves quite well to therapy with individuals with mild injuries. They are well-structured, focus on concrete behaviours and thoughts, allow for the use of written aids, can be adapted to certain cognitive limitations and lend themselves to the involvement of a family member or other suitable person in the therapy process as a “co-therapist” (Ponsford et al, 1995). The usefulness of psychoanalytic concepts, particularly, the functioning of dreaming, and knowledge of physical correlates of psychoanalytic knowledge, is also being advocated (Kaplan-Solms and Solms, 2000). Knowledge and understanding of the severity of the cognitive impairments may also guide the appropriateness of group therapy. Clients with good receptive and, at least, some expressive language skills, who do not display physical aggression or psychotic symptoms may be good candidates for group therapy (Prigatano, 1986 cited in Putman and Fichtenberg, 1999). The advantage of group therapy is that clients may accept suggestions and criticisms more readily from peers and become more aware of the impact of their impairments on others. Even those who appear to be poor candidates due to low tolerance of group processes may benefit from highly structured “discussion” groups (Cicerone, 1989 cited in Putman and Fichtenberg, 1999).
Understanding the Nature and Process of Psychotherapy

The process of separating a client’s subjective feelings, affective behaviours, reactions to disability, pre-injury functioning, and current psychosocial environment from their acquired cognitive and possibly physical impairments during psychotherapy is not an easy task (Sohlberg and Mateer, 1989). Effective psychotherapy after brain injury revolves around the clinician’s understanding of the client’s pre- and post-injury personality, abilities (including their neuropsychological deficits) and emotional status (Prigatano, 1999). These factors will determine how an individual copes with their unique problems and the process of therapy. Clinicians also need to be flexible, in what perhaps may become an unusual therapeutic process, and prepared for difficulties establishing a therapeutic alliance and variable levels of motivation and cooperation (Sohlberg and Mateer, 1989). The clinician needs to have a good knowledge and understanding of brain injury as basic education about the effects of brain damage, and the purposes and goals of therapy is important. Clients who are informed about brain injury and normal effects are less likely to have severe psychological reactions one year or more after brain injury, compared to individuals with no education (Bennett and Raymond, 1997). It is also important for the clinician to understand the nature and effects of the underlying cognitive impairments in order to try and avoid reacting to, rejecting or blaming the client for seemingly irritating, inconsistent or irrational behaviour (Sohlberg and Mateer, 1989).

Psychotherapy with individuals with brain injury is essentially not about happiness, but about a process that teaches the client to better understand who they are, what their basic needs in life are, how best to get those needs and how to address areas of conflict or maladjustment (Prigatano, 1999). The inherent methodological problems of assessing the efficacy of psychotherapy are clear from Prigatano’s definition. One of the strengths of psychotherapy with individuals with brain injury is its ability to verbally assist clients in learning to control some aspect of their behaviour to facilitate adjustment. It encourages the client to observe their behavioural reactions as well as others, to recognise the importance of their feelings in maladaptive responses and to establish realistic sub-goals within therapy to reduce failure (Prigatano and Ben-Yishay, 1999). It also helps the client to achieve a sense of self-acceptance and to
ultimately forgive themselves or those who caused the injury (Klonoff and Prigatano, 1988)

**Practical Clinician Skills**

The skill of the clinician lies in the range of theoretical models that they can apply to the client, and the development of practical ways to overcome obstacles presented by cognitive impairments. Good practical skills for clinicians (Prigatano, 1999) include going slowly, exploring the client’s capacity for insight and continually sharpening their perspective on reality. The focus should be on the present whilst the contribution of past experiences (consciously or unconsciously represented) to the client’s presenting behaviour must be acknowledged. Dealing with patients’ misperceptions, angry outbursts, inappropriate behaviour, anxiety and depression, slowly, honestly and empathetically are also essential skills. The clinician may need to make ground rules about acceptable behaviours during treatment sessions. Explicit interpretations as clients may interpret everything literally and cover only one or two issues in each session in order to reduce overloading information-processing and memory abilities (Folzer, 2001). Summarizing discussions both orally and in writing, making the same point in similar or different ways, asking questions to check comprehension, understanding and retention, and having a predictable format for sessions are also helpful skills (Bennett and Raymond, 1997; Sohlberg and Mateer, 1989). The use of external representation, through sand-play (Kalff, 1980 cited in Prigatano, 1999), art, diary writing, choosing songs, and dream analysis have been cited as important methods for client’s to produce and understand how they feel internally.

According to Freud, the two major ingredients to psychological health are the capacity to work and to love (Prigatano and Klonoff, 1988). To do these things, is essentially viewed as achieving “psychological normality”. Prigatano and Klonoff (1988) therefore, suggest that focusing on activities that relate to three human and living symbols (work, love and play) can be quite helpful in the individual and family psychotherapeutic process. It is the skill of the clinician to place equal importance on all three symbols during therapy and to foster the client’s ability to work, love and play in spite of their cognitive impairments. In addition to the establishment of emotional contact or therapeutic alliance with another human being, this process is
argued to help clients to cope with suffering and establish meaning despite their losses (Prigatano, 1999). The therapeutic alliance enables the clinician to use their skills to listen to and understand the client’s phenomenological experiences of suffering and loss. Without understanding the client’s experiences, a clinician cannot work effectively in rehabilitation (Prigatano and Ben-Yishay, 1999; Prigatano, 2000).

UNDERSTANDING THE CLIENT’S EXPERIENCES

Clients naturally face a wide range of subjective experiences following brain injury, yet their phenomenological experiences regarding their cerebral functions or dysfunctions have generally been neglected in the scientific literature (Prigatano, 1999). Without an understanding of whether the client experiences the usefulness or not of rehabilitation, inappropriate rehabilitation strategies may be designed and the client may actively resist or only passively engage in rehabilitation. Effective psychotherapy begins with the establishment of a therapeutic alliance between the client and clinician, which may also have long-term benefits on outcome (Prigatano et al, 1994 cited in Prigatano et al, 1999). Both client and clinician need to first understand the implications of the impairments in the ‘big-picture’ of the client’s life, before dealing with the effects. Appropriate understanding and management of the client’s affective reactions, as well as their family’s is advocated to facilitate rehabilitation and to potentially be of equal importance (Prigatano et al, 1996).

PSYCHOTHERAPEUTIC INTERVENTION WITH THE FAMILY

It has been clearly recognised that the needs of the family of the brain-injured person must be addressed (Sohlberg and Mateer, 1989). Brain injury is a catastrophic event that affects an entire family. Family roles, communication and relationships are inevitably disrupted and family hopes for the future compromised (Sander and Kreutzer, 1999). Persistent cognitive and personality disturbances in the person with brain injury, such as poor emotional control, apathy, and difficult behaviour, have a negative impact on family functioning (Giles, 1999) and are related to high levels of stress in caregivers (Brooks and McKinlay, 1983 cited in McKinlay and Watkiss, 1999) and deterioration of global family functioning over time (Rivara et al, 1994 cited in Prigatano, 1999). Common family reactions include depression (eg: Our lives are a mess, and the future’s not going to be any better”), guilt (“it was my fault”),
anxiety ("everyday when I go to work, I wonder if Tommy and the kids will be okay when I get home") and anger ("no matter what I do, it’s never good enough for him") (Lezak, 1987 cited in Sander and Kreutzer, 1999). The question of how to help family members from a psychotherapeutic perspective is not simple, because families are as different as clients and controlled trials on the impact of family therapy on long-term adjustment are lacking. However, the results of case studies appear promising (Perlesz et al, 1989 cited in Ponsford et al, 1995) and the involvement of families in rehabilitation appears to clinically enhance outcomes (Prigatano, 1999).

In order to attempt to promote family adjustment, clinicians must understand a range of complex factors relating to the individuals and their family as a whole including: family systems functioning, family dynamics and values, role expectations, communication styles, pre-injury stressors and adjustment, social support systems, coping strategies and plans for the future (Sander and Kreutzer, 1999). Knowledge of normal life cycle changes, transitional life stages of each family member and changing sources of stress in the family are also important (Sander and Kreutzer, 1999). Another issue of importance is the magnified importance that family members and significant others take on after a brain injury and the knowledge of the enormous potential that these people have to sabotage treatment (Baird et al, 1987 cited in Sohberg and Mateer, 1989).

Family therapy should ideally facilitate the family in expressing and working through the different stages of emotional responses, including, feelings of anxiety, helplessness, hope, denial, depression, guilt, anger, loss and grief. The clinicians’ abilities to enter the family’s field of phenomenological experience, to be flexible, to understand that individuals are likely to be experiencing different responses at different times, and to balance the needs of the family members so that they are all met, are likely to be beneficial in developing efficacious long-term treatment plans (Ponsford et al, 1995; Prigatano, 1999). The clinician may also have to take an active role in helping the family to become realistic, grieve effectively, to re-structure family roles, relationships and modes of communication, and to train the family in specific behavioural and social management techniques (Sohlberg and Mateer, 1989).
Knowledge and Skills in Pharmacology

Early identification and treatment of neurological and emotional symptoms is crucial in advancing recovery and preventing an emotional and psychological “snowball” effect (Bennett and Raymond, 1997). An understanding of the psychosocial and emotional consequences of brain injury, as well as the individual’s pre-morbid personality and mood, is essential in preventing the misconception of organically based behaviours or secondary emotional reactions as more volitionally controlled or psychiatrically based problems (Sohlberg and Mateer, 1989). Despite recent interest in the potential benefits and risks of pharmacological intervention after brain injury, there have been few controlled studies exploring the efficacy of pharmacological management of problems such as depression and anxiety (Zafonte, et al, 1999). People with brain injury are often sensitive to subtle drug effects (Freeman, 1999) and may have various medical conditions that require multiple medications, making pharmacological management more complicated.

Although, pharmacology could improve learning and performance by enhancing existing abilities or decreasing the interference of unwanted behaviours, many medications may impede recovery by enhancing unwanted behaviours, inducing sedation or memory dysfunction or decreasing overall arousal. For example, some anti-hypertensives (Donovan et al, 1988 cited in Zafonte, et al, 1999) and gastrointestinal agents (Meyers, 1996 cited in Zafonte, et al, 1999) can have sedating effects and impair cognition, whilst benzodiazepines may decrease new learning and memory, induce sedation and produce increased confusion and agitation (Block and Berchou, 1984 cited in Zafonte, et al, 1999). In contrast, SSRI agents are appearing useful in treating depression, emotional liability and sleep disturbances after TBI (Zafonte, et al, 1999) and there is considerable evidence for the role of acetylcholine in memory enhancement in brain injury (Gildberg et al, 1982; Thal, 1989 cited in Zafonte, et al, 1999). Therefore, for effective rehabilitation management a full knowledge is required of the interactions and contra-indications for all prescribed medications, the potential side effects on the function of the damaged brain, the cognitive abilities of the client prior to pharmacotherapy (baseline) and the time needed for an adequate trial (Freeman, 1999). The prescribing physician must also have a clear knowledge of the symptoms of behavioural syndromes, a clear
understanding of other substances used by the client, a clear target for pharmacotherapeutic intervention and a method of determining whether the targeted behaviour has actually changed.

**Knowledge and Skills in Substance Abuse**

Post-injury substance abuse has been implicated as a major obstacle to successful rehabilitation (Corrigan et al, 1999; Sparadeo, et al, 1990 cited in Kreutzer and Sander, 1997), yet failure to assess substance abuse in rehabilitation settings is relatively common and little research has been conducted in this area (Moore and Polsgrove, 1992 cited in Corrigan et al, 1999). Prevalence studies have found that between one-third and half of people with TBI were intoxicated at the time of the injury (Harrison-Felix et al, 1996 cited in Corrigan et al, 1999), that nearly two-thirds of adults that are worked with in brain injury rehabilitation have histories of alcohol and/or other drug abuse (Corrigan, 1995 cited in Corrigan et al, 1999) and that the volume of alcohol consumption increases as time post injury increases (Kreutzer et al, 1996; Corrigan et al, 1995 cited in Corrigan et al, 1999). A review of the literature indicates that those with a history of drug use are more likely to be socially isolated and less likely to return to work one year following rehabilitation (Corrigan et al, 1997 cited in Corrigan et al, 1999). If the impact of alcohol or other drug use is not understood and minimised, the ability to prove or improve the effectiveness of rehabilitation will be severely compromised. The greatest effect on rehabilitation outcome can clinically be observed after a period of abstinence, when dramatic personality and cognitive changes are observed (Corrigan et al, 1999).

Effective prevention and intervention rehabilitation programmes are believed to offer systematic programming, routine screening for substance abuse, to consider substance abuse following brain injury as detrimental and offer at least, basic programming about substance abuse prevention and intervention (Ohio Valley Centre for Brain Injury Rehabilitation, 1997 cited in Corrigan et al, 1999). Staff educational initiatives and knowledge of the effect of a pre-existing condition on the likelihood of attaining rehabilitation goals and the consequences of use following a brain injury are also required (Moore and Polsgrove, 1992). Furthermore, the ability to use cognitive-behavioural approaches to create cognitive dissonance, recognise negative
consequences, alter expectations and improve coping and decision-making are considered important clinician skills. People with brain injury may have cognitive and behavioural deficits, which impair insight, self-reflection and abstract thought. Therefore, traditional approaches for improving readiness, such as insight-oriented therapies and confrontation, are generally ineffective (Langley et al, 1991 cited in Corrigan et al, 1999). Therefore, educational approaches that facilitate movement through the stages of change proposed by Prochaska and colleagues (1992 cited in Corrigan et al, 1999) have been recommended (Sparadeo et al, 1993 cited in Corrigan et al, 1999). Tailoring information to the client’s individual cognitive impairments and using various forms of communication media, in group formats, have also been found to be effective (Krause, 1992 cited in Corrigan et al, 1999). To ensure effective outcomes, programmes should essentially incorporate ongoing staff, client and family education (Langley et al, 1991; Sparadeo, 1993 cited in Corrigan et al, 1993), emphasise the role of the family in maintaining abstinence (particularly when other family members use substances themselves) and respect cultural, personal and ethical issues.

Cultural, Personal and Ethical Issues
Understanding the biases and philosophies of family members (eg: “a woman’s place is in the home, not at work”) is essential in rehabilitation, as well as understanding the cultural differences in family structure and interactions. For example, cultures that promote close long-term relationships between extended members may be beneficial to the recovery process as sharing and re-assignment of responsibilities are facilitated. However, adult children in Asian families may react negatively to the idea of taking a supervisory role with a revered older adult. To be most effective the clinician should utilise the family’s frame of reference in questions and feedback and avoid asserting their own values (Sander and Kreutzer, 1999). The altered integrity of “wholeness” in individual’s with brain injury (Gordon and Hibbard, 1992) and problems with lack of insight pose moral and ethical dilemmas, particularly in severe brain injury, in the course of health-care decision-making and action. The clinician needs to skilfully balance the client’s experiences, perceptions and wishes alongside the family’s,
without deciding who is right or wrong, overlooking the client's view or allowing the client to be the scapegoat for all the family's problems. Families may have experienced pre-injury sources of stress that far outweigh injury-related factors (e.g., bankruptcy, divorce, death, substance abuse), and will continue to experience external sources of stress after the injury. Clinicians therefore need to understand and carefully monitor the full spectrum of sources of stress. The clinician also needs to acknowledge the complex interface between impinging their own judgements and values on the clients, whilst doing the best for the client (Sander and Kreutzer, 1999).

Ethically, conducting traditional clinical experimental studies to determine treatment efficacy also poses a dilemma because withholding treatment for control or no-treatment group designs is not reasonable. However, single-subject designs (e.g., Gianutsos and Gianutsos, 1979; Sohlberg and Mateer, 1987 cited in Sohlberg and Mateer, 1989) and the use of matched-head-injury controls using persons on rehabilitation program's waiting lists (Sohlberg and Mateer, 1989), offer solutions in the search for knowledge and skills (other than cognitive neuropsychology) necessary for conducting effective cognitive rehabilitation.

**Conclusion**

Cognitive rehabilitation is an important intervention, particularly for individuals with mild and moderate brain injury, to improve their functional abilities and gain some control in their lives (Perna et al, 2000). Unfortunately, with overlapping and poorly defined terms, cognitive rehabilitation has previously failed to advocate a specific set of treatment protocols in the minds of professionals (Sohlberg and Mateer, 1989). Despite the traditional focus on the cognitive retraining methods such as substitution, compensation or direct retraining of cognitive impairments (e.g., Prigatano et al, 1986), the evidence for and against remediation of functional brain impairments remains controversial (Ben-Yishay and Diller, 1993; Prigatano, 2000). Widespread dissatisfaction with the efficacy of treatment approaches predominantly driven by neuropsychological and cognitive models has prompted the more recent interest in psychotherapeutic, pharmacological and substance abuse programmes for improving psychosocial outcomes (e.g: Bennett and Raymond, 1997; Prigatano, 1989; 1999; Zafonte, et al, 1999). Despite the years of pervasive scepticism regarding the use of
individual and family psychotherapy in cognitive rehabilitation, indirect clinical evidence supporting its efficacy in the post-acute, community re-integration stage is currently accumulating (eg: Ben-Yishay et al, 1984; Ponsford et al, 1995, Prigatano, 1989, 1991, 1999, 2000). At this point the initial evidence-base can therefore provide reasonably convincing data that certain knowledge and skills can make a substantial difference in psychosocial outcomes for individuals with brain injury.

In view of the myriad of cognitive, psychological and behavioural consequences faced by the individuals and their families, it is clear that no single intervention approach will be suitable for all individuals with brain injury (Ponsford et al, 1995). It is also clear that psychotherapy in the context of brain injury, with all its mediating variables, is very complex to evaluate. Hence, the very nature of brain injury and process of rehabilitation presents a problem in demonstrating efficacy according to the randomised controlled trials that have become ‘the gold standard’ for validating treatments. Nevertheless, it is apparent that in the absence of rigorous scientific data, psychotherapy (individual and family), pharmacology and substance abuse programmes are being conducted on the basis of these initial and ‘suggestive’ findings (Prigatano, 1999). For this reason alone, there is an urgent need to find ethically appropriate and scientifically acceptable solutions for systematically evaluating the impact of these interventions and establishing further guidelines on what knowledge and skills will be most helpful to individuals with brain injury.
REFERENCES


1999 - 2002

- Adult Mental Health
- People with Learning Disabilities
- Child, Adolescent and Family
- Older Adults
- Neuropsychology
- Narrative, Systemic – Adult
Core Placement 1: Adult Mental Health, Community Mental Health Centre
During my adult mental health placement I gained experience working with clients of different ages and with a range of clinical problems. These included anxiety, depression, post-traumatic stress disorder, eating disorders, anger management, phobias, asperger's syndrome and health problems. Training was received in risk assessment, eating disorders and administration of the WAIS-III and WMS-III.

I developed assessment, formulation and therapeutic skills in cognitive behavioural models and employed standardised assessment measures where appropriate; including the BDI, BAI, WAIS-III, AMIPB and WMS-R. An understanding of psychodynamic formulation and therapeutic skills was also developed. In addition, I was involved in re-designing and co-running a six-week Anxiety and Stress management group with a community psychiatric nurse. At a professional and organisational level, I attended multidisciplinary team meetings and seminars, and worked collaboratively with community psychiatric nurses and nursing staff.

Core Placement 2: People with Learning Disabilities
Over the course of my placement with learning disabilities, I worked with individuals with mild, moderate and severe learning disabilities as well as Down's Syndrome and Autism. Presenting problems included, depression, bereavement, challenging behaviours, physical aggression, health anxiety and dementia. A range of standardised and non-standardised measures including the HALO and AAPEP were utilised. In addition, I was involved in developing and co-running an Anger Management group with an assistant psychologist.

Working within behavioural and cognitive-behavioural models, I developed skills in behavioural observation, functional analysis, formulation, intervention and outcome measurement. I was also able to build upon my skills and experience in systemic models and adapting techniques to accommodate individual needs. Training in basic Makaton and communication skills was undertaken. A large amount of work involved indirect client work with day care and nursing staff, carers and families.
Core Placement 3: Child, Adolescent and Family, CAMHS
Collaboration with families, teachers and other professionals was an integral component of this placement. I worked with children and adolescents of all ages, as well as pupils at a school for Children with Developmental Disorders and Learning Difficulties. Presenting problems included anxiety, eating disorders, post-traumatic stress, attention deficit hyperactivity disorder, bereavement, sleep disorders, challenging behaviours, autism, and school refusal.

Systemic and cognitive-behavioural models of assessment, formulation and treatment were applied, and psychodynamic re-formulations developed. I also participated in family therapy as part of an observation and reflecting team, for which training was received. A range of developmental, behavioural and psychometric assessments of children with learning difficulties, head injuries and dyslexia were conducted. This included observation, functional analysis and the use of the WISC-III, WORD, WAND, and WIPPSI-R.

Core Placement 4: Older Adults
During my older adults placement I worked with clients in community, nursing home and inpatient settings. Experience with a range of clinical problems was gained including depression, anxiety, alcoholic dementia, bereavement, pain management, challenging behaviour, OCD, food refusal and personality disorder. A one-day workshop in clinical governance and risk management was also attended.

I employed psychodynamic, cognitive-behavioural and systemic approaches in the assessment, formulation and treatment of these problems. Knowledge and experience of differentiating between organic and functional pathologies using standardised neuropsychological and psychometric measures was gained. This included the MEAMS, AMIPB, CAMCOB, MMSE and WAIS-III. In addition to individual client work and systemic family work, I developed and co-run a one-day workshop on ‘managing difficult behaviour’, and a three-session course on ‘Managing Grief and Bereavement’ for nursing staff. Over the course of this placement, I became aware of specific issues facing older adults and also many of the constraints that are inherent in the services.
Specialist Placement 1: Neuropsychology

During my neuropsychology placement, I worked in a community-based outpatient setting. I became familiar with selection, administration and interpretation of a wide range of neuropsychological assessments and assessed clients with traumatic brain injury, strokes, huntington’s disease, multiple sclerosis, sub-arachnoid haemorrhage, memory problems and cerebral palsy.

In addition to assessments I carried out cognitive rehabilitation and systemic therapeutic interventions addressing various problems resulting from brain injury including adjustment difficulties, cognitive impairment, depression, behavioural problems, communication difficulties and post-traumatic stress. Consultative work was conducted with an occupational therapist and a presentation on the cognitive and emotional aspects of Multiple Sclerosis given to a multi-disciplinary community team. A review of the structure of a group for people with acquired head injury was also conducted. During this placement I acquired fundamental knowledge about psychological and pathological etiologies and their co-existence, which I believe will be extremely valuable in my future clinical work.

Specialist Placement 2: Narrative, Systemic – Adults and Families

In this placement I worked within primary care and community settings with individual adults, couples and families. Clients presented with a variety of mental health problems including depression, marital problems, sexual abuse, obesity, self-harm, anxiety, domestic violence and ADHD.

Using narrative, systemic and brief-focused solution methods, I carried out assessments, formulations and therapeutic interventions. Work was conducted as an individual therapist, in a consultative role to other health professionals and both in an observational and lead therapist role with the family therapy team. During this placement I built upon my existing knowledge in behavioural and cognitive-behavioural models and enhanced my understanding of additional therapeutic approaches such as narrative and brief-solution focused therapy. This experience has been valuable for the ongoing strengthening of my therapeutic skills and has provided a solid foundation for my future employment.
SUMMARIES OF CASE REPORTS

1999 - 2002

- Adult Mental Health
- People with Learning Disabilities
- Child, Adolescent and Family
- Older Adults
- Neuropsychology
CASE REPORT 1: SUMMARY

ADULT MENTAL HEALTH

TITLE

“Assessment and Treatment of Depression and Anxiety in a 55 year old Housewife Using a Cognitive Behavioural Approach”

Core Placement 1

March 2000

Year 1
Mrs B, a 55-year-old white woman, was referred to the community mental health team by her GP after presenting with symptoms of anxiety, agoraphobia and depression. Upon assessment it emerged that Mrs B’s anxiety symptoms (dizziness, breathlessness and disorientation) were related to a broken bone in her ear, which required urgent surgery. Her depression was characterised by regular tearfulness, suicidal thoughts and negative thoughts about being a ‘burden’ to her husband and children. Administration of the HADs (Sigmund and Snaith, 1983) indicated the presence of clinically severe anxiety and moderate depression.

Mrs B’s presenting problems were formulated within a cognitive-behavioural framework. It was suggested that her depression had developed from an array of predisposing and precipitating factors, including feeling “rejected” and “helpless” as a child, serious complications following her husband’s recent hospitalisation and her own recent health problems. Furthermore, fear of negative evaluation, negative core beliefs, cognitive distortions and avoidance were proposed as representing critical maintaining factors.

The CBT therapeutic intervention comprised of the identification and restructuring of negative automatic thoughts and thinking biases, relaxation training and pleasant activity scheduling. Following nine sessions and prior to the operation the HADs indicated that Mrs B’s anxiety had fallen from severe to mild, and her depression to within the normal range. Mrs B reported subjective improvements in anxiety and mood and was pleased with how well she coped with the operation. At follow-up the HADs scores reflected an increase in anxiety and depression. Pain management techniques, relaxation and activity pacing techniques were thus reviewed with her and her husband.
CASE REPORT 2: SUMMARY

PEOPLE WITH LEARNING DISABILITIES

TITLE

"Assessment and Intervention with a Woman with Profound Learning Disabilities and Spastic Quadriplegia"

Core Placement 2

September 2000

Year 2
Assessment and Intervention with a Woman with Profound Learning Disabilities and Spastic Quadriplegia

Miss Z was a 52-year-old white woman with profound learning disabilities who was referred for urgent assessment and intervention by a Consultant Psychiatrist. Miss Z had spastic quadriplegia, no expressive language, was non-ambulatory, and partially sighted and deaf. The referral to the Psychology services followed an increasing concern over Miss Z’s continuous removal of her clothing, which had resulted in her being denied access to group activities and day services at her group home.

Behavioural assessment consisted of a seven-week staff record of Miss Z’s behaviour and an ABC functional analysis. Staff were interviewed and Miss Z’s medical notes reviewed. Within a behavioural model, it was formulated that learning principles such as positive, negative and incidental reinforcement had been involved in the development and maintenance of Miss Z’s behaviours. Predisposing factors identified included her profound multiple disabilities, a history of institutionalisation and a lack of adequate sensory stimulation. Escalations in the frequency of her behaviours were hypothesised to be precipitated by environmental changes, boredom and pain.

The intervention consisted of nine sessions. Five sessions focused on establishing alternative preferences for sensory stimulation. The remaining four sessions used a multi-component intervention, based on behaviour interruption, external sensory stimulation, incidental learning and positive reinforcement. This aimed to teach Miss Z how to use hand movements to communicate with nursing staff and to ask for ‘more’ sensory stimulation. The nursing and day unit staff were trained in the intervention procedures. Intervention effectiveness was assessed by recording the frequency of clothing removal behaviours during alternating periods of intervention and no intervention. Following seven sessions Miss Z was consistently able to use hand movements to ask for ‘more’ sensory stimulation. This one-to-one sensory stimulation had some impact on reducing clothing removal. However, it was too early to assess the generalisation of effects to group activities and day services.
CASE REPORT 3: SUMMARY

CHILD, ADOLESCENT AND FAMILY

TITLE

“Assessment and Intervention with a Twelve year old Female Child Presenting with Post Traumatic Stress, using a Cognitive-Behavioural Approach”

Core Placement 3

March 2001

Year 2
Assessment and Intervention with a Twelve year old Female Child Presenting with Post Traumatic Stress, using a Cognitive-Behavioural Approach

Child A was a 12-year-old white girl who was referred to the Child and Family services by her GP for frequent urination during school. She reported that her frequent urination at school was linked to excessive worrying about the safety of her family. Her mother described her as irritable, controlling, argumentative, tearful, anxious and generally obsessive about safety.

During the initial assessment interview, Child A described witnessing a serious accident involving her stepbrother sixteen months earlier. She reported experiencing sleep disturbances, nightmares, concentration difficulties and flashbacks following the accident. Her symptoms and behaviours matched the criteria outlined by DSM-IV for PTSD. Administration of the Children's Impact of Events Scale, and the Spence Children's Anxiety Scale, indicated a high risk of PTSD and high levels of anxiety, respectively. The Birleson Depression Scale was above average, but non-significant.

Child A’s presenting problems were formulated within a cognitive-behavioural framework. It was suggested that PTSD had developed from an array of predisposing and precipitating factors; including a familial predisposition to anxiety and depression, parental divorce, and the suddenness and seriousness of the accident. Furthermore, guilt, negative core beliefs, cognitive distortions, tension in the family and avoidance of reminders were considered critical maintaining factors.

Ten individual sessions, four concurrent sessions with the mother and Consultant Child Psychologist, and two joint sessions with the mother were conducted. CBT focused on psychoeducation, imaginal exposure, identifying functions and triggers of her behaviours, enhancing coping skills and cognitive re-structuring of negative thoughts. At follow-up both she and her mother reported reductions in her urination at school, checking behaviours, anxiety, irritability, tearfulness and guilt. The objective measures indicated that both her risk of PTSD and anxiety had fallen to below significance. Her depression score remained non-significant.
TITLE

“Neuropsychological Assessment of a Sixty-Five year old Alcoholic Woman”

Core Placement 4

September 2001

Year 3
Neuropsychological Assessment of a Sixty-Five year old Alcoholic Woman

Mrs L. was a white, sixty-five year old Irish woman who was referred for detailed neuropsychological assessment by the Consultant Psychiatrist. She had a history of alcohol dependence and presented with symptoms of self-neglect, disorientation, visual hallucinations, psychotic features and memory impairment. A baseline neuropsychological assessment had been conducted six months previously when she was admitted to the inpatient psychiatric ward.

The assessment involved a clinical interview with Mrs L, a review of her medical notes, discussion with ward staff and neuropsychological testing. Relevant background factors included Mrs A’s history of alcoholic use and multiple family bereavements. The repeat neuropsychological assessment evaluated general intellectual functioning (premorbid and current), recall and recognition memory, language and reasoning abilities, visuo-spatial functioning and executive functioning. Assessments included the WAIS-III, NART-R, AMIPB, Trail Making test, and Hayling and Brixton test.

The results suggested that, after a six-month period of abstinence from alcohol, Mrs L. demonstrated relative improvements in orientation, abstract reasoning, executive functioning, trial and error learning and verbal and non-verbal concept formation. However, cognitive deficits appeared to persist on both verbal and visual memory acquisition, retention and retrieval, tests of psychomotor speed, perceptual-motor functioning and complex visuospatial tasks. Her overall cognitive profile was consistent with DSM-IV criteria for alcoholic dementia. The assessment findings and implications for Mrs L’s independent living were discussed with Mrs L. and recommendations for her rehabilitation and treatment were presented to all professionals involved.
CASE REPORT 5: SUMMARY

NEUROPSYCHOLOGY

TITLE

“Neuropsychological Rehabilitation with a 49 year old Woman in the Early Stages of Huntington’s Disease”

Specialist Placement 5

March 2002

Year 3
Ms. G was a forty-nine year old, white woman who was referred to the Neuropsychology services by her GP following a diagnosis of Huntington’s Disease. Ms. G presented with memory and concentration problems, anxiety and negative mood, low self-esteem, and preoccupations with food contamination and checking her bins. She requested individual support to help her adjust to the diagnosis, to assess her current cognitive functioning, to inform her of coping/rehabilitation strategies and to review her vocational prospects. She did not wish her family to be involved.

Initial assessment involved liaison with the community rehabilitation team, a clinical interview with Ms. G. and neuropsychological testing. The neuropsychological tests evaluated general intellectual functioning (premorbid and current), visual and verbal memory, information processing speed and motor speed. The results confirmed general cognitive deterioration indicative of early Huntington’s Disease.

Ms. G’s presenting problems were formulated within a cognitive rehabilitation framework, in which underlying organic changes were proposed as an etiological factor. It was also suggested that her subjective reports of anxiety and low mood following her diagnosis had possibly developed from an array of predisposing and precipitating psychological factors. These included premorbid anxiety characteristics, poor family coping, limited social support and guilt about her son’s risk of the disease.

The therapeutic intervention comprised of psychoeducation, exploration of coping in the family, improving current adaptive functioning, mediating deterioration through environmental modifications and behavioural strategies, and return to employment. Following nine intervention sessions, rehabilitation outcomes indicated increases in levels of productivity, adjustment and independence. Ms. G. reported improvements in her anxiety, mood, self-esteem and confidence. She had also widened her social support network, was utilising memory strategies and problem-solving skills, and was about to start part-time administrative employment under a supported work scheme.
• Service Related Research Project

• Literature Review

• Major Research Project
Research Supervisor: Dr. Emma Dunmore

Field Supervisor: Angela Devon, Consultant Clinical Psychologist

TITLE

“Acute Psychiatric Services: An Exploratory Evaluation of Staff Training in Cognitive Behavioural Therapy, Based on Service User Satisfaction”

AUGUST 2000

Year 1
**SERVICE RELATED RESEARCH PROJECT**

**ABSTRACT**

**TITLE:** Acute Psychiatric Services: An Exploratory Evaluation of Staff Training in Cognitive Behavioural Therapy, Based on Service User Satisfaction

**OBJECTIVES:** To conduct an exploratory evaluation into the effects of nursing staff training in cognitive-behaviour therapy (CBT) on service user satisfaction. To identify possible barriers, which inhibit the use of CBT skills and to stimulate change by feeding-back information.

**DESIGN:** A pre-post design was used to measure service user satisfaction before and after cognitive behavioural therapy training for nursing staff, run by psychologists. Interviews were conducted on two acute, psychiatric inpatient wards.

**RESULTS:** The response rates at baseline and follow-up were seventy-percent (14 participants) and sixty-two percent (10 participants), respectively. Demographic information indicated a significant difference in employment status \((p=0.003)\) at follow-up compared with the baseline sample. Overall ratings of satisfaction improved from 'dissatisfied' at baseline, to 'satisfied' at follow-up. Satisfaction with being listened to, being educated about problems, the amount of information shared and involvement in decision making also increased. There were also large increases on the scales of involvement, practical orientation and personal problem orientation. The number of participants who knew their named nurse fell by 20% at follow-up and satisfaction with named nurses fell.

**CONCLUSIONS:** The results are discussed in terms of service implications. Specific findings and service user comments suggested that benefits from the staff education were emerging after this relatively short time period. Recommendations to improve the benefits from CBT skills training were suggested. The need for a further, long-term study with a larger and more representative sample was emphasised.
Thank you to the clinicians and staff in NHS Trust who participated in this research.

Thank you to Teresa Perez, Service Leader at the Department of Psychiatry, and the Ward Managers for their assistance regards this research.

Thank you to Dr. Angela Devon, Consultant Clinical Psychologist, Trust and Dr. Emma Dunmore, Lecturer, University of Surrey for their supervision.
THE NEED FOR CHANGE IN ACUTE PSYCHIATRIC WARDS

In recent years, political and managerial attention has focused on developing strategies to modernise relatively neglected acute mental health services (DOH, Modernising Mental Health Services, 1999) and evaluate service effectiveness (DOH, The New NHS – Modern. Dependable, 1998). Concern has also grown about the diversity of education required by mental health nurses (Higgins, Hurst and Wistow, 1999). Gradual changes in patient mix have increased demands for a broader range of nursing skills into areas such as; management of anger, hallucinations and relapse prevention (Higgins et al, 1999). Nursing education is however, still dominated by the medical model of checking symptoms and signs of illness and has generally been slow to encompass counselling and psychotherapeutic skills, despite its’ importance (DOH, Modernising Mental Health Services, 1999; Ministry of Health, 1968 cited in Higgins et al, 1999). Consequently, many qualified staff have felt unprepared to work on psychiatric wards (Higgins et al, 1999).

PSYCHOTHERAPEUTIC SKILLS IN PSYCHIATRIC WARDS

There is good evidence for the effectiveness of psychological therapies in relieving symptoms of mental illness (Parry and Richardson, 1996 cited in DOH, 1999) particularly for well-established, structured therapies such as cognitive behaviour therapy (CBT) (eg: Beck, 1976), which alleviate depression and anxiety, and reduce relapse in schizophrenia (DOH, 1999). More specifically there are also promising results that suggest a modest efficacy for CBT with depressed psychiatric inpatients alone and in combination with antidepressant treatment (Stuart and Bowers, 1995). CBT offers principles that promote a broader biopsychosocial model of care and rely on effective service user-professional interactions. CBT has furthermore been suggested as a potentially useful and under-researched tool for enhancing nursing skills and communication with service users (Moon and Liu, 1998).
**PATIENT SATISFACTION AS A MEASURE OF EFFECTIVENESS**

Poor communication between users and professionals has been a substantial problem for the NHS (The Mental Health Act Commission, 1998) and is considered an important determinant of user dissatisfaction (Beckman et al, 1989 cited in Moon and Liu, 1998). Although psychiatric inpatients provide valuable views (Wykes and Carroll, 1993), there is mixed evidence concerning whether demographics and clinical diagnoses confound measures of satisfaction (Carr-Hill, 1992 cited in Greenwood et al, 1999). There is some support for men (Gjerden, 1997), younger people (Hansson, 1989; Rosenheck, Wilson and Meterko, 1997), and employed people (Holcomb et al, 1998) being more satisfied with psychiatric inpatient wards. Relatively consistent findings also indicate that involuntary patients are significantly less satisfied with their care than voluntary patients (Svensson and Hansson, 1994; Leavey et al, 1997 cited in Greenwood et al, 1999) and both substance abuse (Lebow, 1983) and schizophrenia (Svensson, 1994) have also been related to lower satisfaction (Svensson, 1994). However, Gjerden (1997) found no relation between voluntary status and satisfaction and Holcomb et al (1998) found no relations with depression, anxiety, schizophrenia or other psychotic disorders.

**THE CURRENT RESEARCH**

The research explored one of two developments prioritised by staff and service users through the Mental Health Acute Inpatient Practice Development Network set up by the King’s College in 1999. Service users’ views were regarded as a valuable measurement in this study and an important determinant of validity (Wykes and Carroll, 1993). The second development, reconfiguration of day unit services, was taken into account during the research.

The need for a nursing training programme on the psychiatric wards (Appendix 1) was supported by the Psychology Departments’ initial investigation, which highlighted a lack of post-qualification training and psychotherapeutic knowledge amongst nurses. Due to the lack of previous research into the integration of psychological models of treatment into acute psychiatric inpatient settings (Granello, Granello and Lee, 1999), the intent of this research was exploratory at this stage.
**RESEARCH AIMS**

The research was designed to gather information to inform ongoing service development and hoped to address two aims:

- Firstly, to determine the effect of staff training in CBT on service user satisfaction.

- Secondly, to explore possible factors that may have helped or hindered the success of the education programme and make recommendations to help improve its' effectiveness.

Any improvements in satisfaction were expected to be small due to a short, four month, follow-up period. Staff levels and morale were relatively low during this period and changes to the day services led to building work and disruptions to daily activity programmes.

**SETTING**

The research was set in two, low security, acute psychiatric inpatient wards and the day unit at the Department of Psychiatry. The target population was male and female adult mental health patients, ranging from eighteen to sixty-five years old.
METHOD

DESIGN
A pre-post design was used. Baseline satisfaction measurements were taken two weeks prior to the commencement of staff training and day unit changes and repeated after 4 months (after the first block of staff training).

PARTICIPANTS (Appendix 5)
A total of fourteen people participated at baseline and ten at follow-up. Ages ranged from 26 to 67. Approximately 70% of participants were female at both times, all participants were Caucasian and all spoke English.

ETHICAL CONSIDERATIONS AND EXCLUSION CRITERIA
Ethical approval was obtained by the Department of Psychiatry, Epsom District General Hospital. The following exclusion criteria were implemented:

1. Admission within the previous 24 hours.
2. Inability to give informed consent judged by the Consultant Psychiatrists.
3. Illness too severe as judged by the Ward Managers on day of interview.

The research was explained to each individual and written information was provided (Appendix 2). Participation was voluntary, responses were confidential and did not affect treatment. Written consent was obtained from participants (Appendix 3).

INTERVIEW DEVELOPMENT (APPENDIX 4)
The content of the interview was determined in consultation with the Psychology Department and the Department of Psychiatry. It contained five sections including demographic details, user-professional contact, activities, the Ward Atmosphere Survey (WAS; Moos and Houts 1968), and the General Satisfaction Questionnaire (CSG; Nyguyen, Attkinson and Stegner, 1983 cited in Granello et al, 1999). Satisfaction was generally measured using closed questions with a five-point Likert scale and a neutral or 'neither/nor' category. Open-ended questions were used to probe beyond global responses and to identify problems. Item non-response was
minimised by conducting the survey as an interview. The interview was piloted with service users and subsequent amendments helped to ensure it was meaningful.

CONFounding VARIABLES
Potential differences in demographics and clinical diagnoses were identified through the demographic section. Concurrent changes to the day services were also expected to affect satisfaction. Therefore, a behavioural observation was conducted in the areas that users spent most of their time (wards at baseline and day unit at follow-up) to help identify differences in environment, changes in staff-user interaction and changes in activities.
MEASURES

The General Satisfaction Questionnaire (CSQ-8: Nyguen, Attkinson and Stegner, 1983)

This is a short, general scale with eight-items that measures user satisfaction with a specific treatment programme (Pascoe, Attkinson and Roberts, 1983 cited in Granello et al, 1999). The CSQ-8 has good psychometric properties, well-validated scales (Lebow, 1983) and internal consistency values of .92 (Derogatis and Spencer, 1982 cited in Granello et al, 1999) and .93 (Attkisson and Zwick, 1982 cited in Granello et al, 1999). However, no norms are provided for the CSQ.

The Ward Atmosphere Survey (WAS; Moos and Houts, 1968)

The WAS measures different dimensions of the atmosphere of psychiatric wards and has reasonable psychometric properties. Factor analysis of the responses of psychiatric inpatient volunteers has supported the 10 subscales measuring ward atmosphere (Moos and Schwartz, 1972 cited in Alden, 1978) but some claim that the subscales could be collapsed (Alden, 1978).

PROCEDURE

Interviews were administered over three days, in a quiet room, with standardized instructions. The interviews took approximately thirty-to-forty minutes and breaks were permitted. The interviews were conducted by an independent researcher and placed in a sealed envelope to ensure confidentiality on the ward. Ward managers provided information about primary diagnosis (according to DSM-IV criteria), status under the mental health act, duration of mental illness and length of stay.
RESULTS

THE DATA
The data for the two wards were combined, given the small sample size. An apriori power analysis (Erdfelder et al, 1996) indicated the number of participants needed to provide sufficient power to detect significant differences. A two-tailed T-Test, with an alpha level of 0.05, power level of 0.7 and effect size of 0.5, indicated that 102 participants would be required for meaningful inferential statistics. Neither a power level below 0.7, nor a compromise power analysis was considered acceptable for this research. A descriptive analysis of the data was conducted and the major findings discussed.

Response Rates
The overall response rate at baseline, of those considered eligible to participate, was 70% and for the follow-up was 62% (Appendix 5, Tables 1 and 2). Two people were excluded, due to the presence of thought intrusions and unreliability. Non-participants were generally more acutely ill and found it harder to engage.

Participants (Appendix 6)
There were few differences between baseline and follow-up samples in age (Appendix 6, Tables 3 and 4), education (Tables 5, 6), gender (Tables 7, 8), ethnic origin (Tables 9, 10), marital status (Tables 11, 12), previous admissions (Table 15, 16), voluntary status (Tables 17, 18), number of days on ward (Tables 19, 20), primary clinical diagnosis (Tables 21, 22) and years since first admission (Tables 23, 24). However, the follow-up sample had a significantly higher percentage of unemployed participants (p=0.003) (Tables 13, 14) and slightly more were admitted voluntarily and reported substance abuse.
**Client Satisfaction Questionnaire (Table A)**

The percentage of satisfied participants increased on most items at follow-up compared to baseline, particularly with range of activities. However, the percentage of participants that were dissatisfied with their named nurse listening to and understanding their problems increased by 18.6%.

Table A: Client Satisfaction Questionnaire

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline (n=14)</th>
<th>Follow-Up (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Reception when first arrived</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Could not be worse and dissatisfied</td>
<td>3 (21.4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Satisfied and could not be better</td>
<td>11 (78.6%)</td>
<td>10 (100%)</td>
</tr>
<tr>
<td><strong>Are you receiving the service you want</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5 (35.7%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Yes</td>
<td>9 (64.3%)</td>
<td>8 (80%)</td>
</tr>
<tr>
<td><strong>Recommend the ward to a Friend</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>5 (35.7%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Yes</td>
<td>9 (64.3%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td><strong>Named nurse listens to and understands your problems</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3 (21.4%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Yes</td>
<td>11 (78.6%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td><strong>Would you return to this ward</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>3 (21.4%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Yes</td>
<td>11 (78.6%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td><strong>Range of activities</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>9 (64.3%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>(Very) satisfied</td>
<td>5 (35.7%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td><strong>Staff team work</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>3 (21.4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>11 (78.6%)</td>
<td>10 (100%)</td>
</tr>
<tr>
<td><strong>Extent Staff have met needs</strong> n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None/a few</td>
<td>4 (28.6%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>almost/most</td>
<td>10 (71.4%)</td>
<td>8 (80%)</td>
</tr>
</tbody>
</table>
Named Nurses and Contact with Staff (Table B)

At follow-up, the number of participants who knew their named nurse decreased by 20%, to a total of 30%. Of those who actually knew their named nurse, fewer met their named nurse on the day of arrival and meetings were less frequent compared to baseline. At follow-up, the frequency with which participants spoke to other staff about their problems increased, as demonstrated by the ‘sometimes’ category, which almost doubled.

Table B: Contact With Named Nurses and Staff

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline (n=14)</th>
<th>Follow-Up (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of named nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (50%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td>7 (50%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>First meeting with named nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Day of arrival</td>
<td>5 (35.7%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Day after arrival</td>
<td>1 (7.1%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>More than a week</td>
<td>1 (7.1%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>7 (50%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Frequently of seeing named nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Whenever nurse is on shift</td>
<td>4 (28.6%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Every now and then</td>
<td>3 (21.4%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Rarely</td>
<td>0 (0%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Not Applicable</td>
<td>7 (50%)</td>
<td>7 (70%)</td>
</tr>
<tr>
<td>Frequency of speaking to other staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N (%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>2 (14.3%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Hardly Ever</td>
<td>6 (42.9%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>3 (21.4%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Always</td>
<td>3 (21.4%)</td>
<td>2 (20%)</td>
</tr>
</tbody>
</table>
Satisfaction with Communication (Table C and Appendix 7)

At follow-up increases were observed in the percentage of participants that were satisfied and very satisfied with being listened to (2.9%) (Appendix 7, Graph 1), being educated about their problems (37.1%) (Appendix 7, Graph 3), information sharing (17.1%) (Appendix 7, Graph 4) and overall treatment (15.7%) (Appendix 7, Graph 6), compared to baseline. The number of participants satisfied with their involvement in decision-making fell slightly by 4.3% (Appendix 7, Graph 5) and more participants were dissatisfied with the education of their relatives (Appendix 7, Graph 2).

Table C: Satisfaction with Communication

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline (n=14)</th>
<th>Follow-Up (n=10)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Staff listening to problems</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>8 (57.1%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Neither Satisfied nor Dissatisfied</td>
<td>2 (14.3%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>4 (28.6%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td><strong>Education about problems</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>6 (42.9%)</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>5 (35.7%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>3 (21.4%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td><strong>Education of relatives</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>5 (35.7%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>5 (35.7%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>4 (28.6%)</td>
<td>4 (40%)</td>
</tr>
<tr>
<td><strong>Shared Information</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>6 (42.9%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>3 (21.4%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>5 (35.7%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td><strong>Involvement in decision making</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>9 (64.3%)</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>1 (7.1%)</td>
<td>3 (30%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>4 (28.6%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td><strong>Overall satisfaction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Very) Satisfied</td>
<td>9 (64.3%)</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>Neither/nor</td>
<td>2 (14.3%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>(Very) Dissatisfied</td>
<td>3 (21.4%)</td>
<td>0 (0%)</td>
</tr>
</tbody>
</table>
Nature of Communication
The proportion of brief comments in the day unit increased by 21% compared to the wards at baseline (Appendix 9, Table 26). This was reflected by a 30% increase in the number of times participants reported that staff introduced activities at follow-up (Appendix 8, Table 25). The proportion of general conversations however, fell by 18% (Appendix 9, Table 26). The number of communications initiated by users in the day unit fell by 7% and the proportion of communications lasting between one to six minutes fell by 29.7% (Table 27). Approximately 85% of communications between staff and users at baseline and at follow-up were one-to-one (Table 28).

Ward Atmosphere Scale (Appendix 10, Table 29, Graph 7)
Most scales demonstrated better ratings at follow-up. The greatest increases occurred in the three areas of Involvement, Practical Orientation and Personal Problem Orientation, with scaled score increases of 13, 14 and 15, respectively. The rating for Order and Organisation remained unchanged and Staff Control was rated similar over time. Moderate increases were observed in Autonomy and Program Clarity and a moderate decrease was observed in Anger and Aggression.
**DISCUSSION**

The two aims of the research were firstly, to determine the effect of staff training in CBT on service user satisfaction. Secondly, to identify recommendations to help improve the benefits from staff education in CBT.

**Changes in Overall Satisfaction**

Although the general increases in satisfaction may have resulted from improved staff-user communication (Beckman et al, 1989), the mixed evidence-base for relationships between patient characteristics and satisfaction (Carr-Hill, 1992) made it difficult to determine the precise influence of the demographic differences. An increase in satisfaction was anticipated because the follow-up sample had a slightly higher (although not significant) percentage of voluntary admissions (Hansson, 1989; Leavey et al, 1997 cited in Greenwood et al, 1999) and mean age was also slightly higher (Hansson, 1989; Rosenheck, Wilson and Meterko, 1997). However, the significantly higher rate of unemployment (Holcomb et al, 1998) at follow-up, anticipated an increase in dissatisfaction.

**Satisfaction with Staff Contact**

The named nurse system was expected to facilitate the use of staff CBT skills, but only thirty percent (3/10) of participants knew their named nurse at follow-up and less were satisfied with their named nurse listening to their problems. Accessibility and time pressures on nursing staff appeared to be a considerable problem, particularly after changes to the day unit. One participant explained that, "*It is hard to get hold of staff (named nurses). You are expected to be in the day unit most of the time and are not allowed upstairs (to the ward). When you are upstairs nurses are too busy with ward rounds and medication*."

Despite apparent shortcomings of the named nurse system, more participants at follow-up appeared to be satisfied with being educated about their problems, with being listened to, information sharing, staff orientation towards personal problems and overall treatment. Specific participant comments made at follow-up about one-to-one support provided by nursing staff, suggested that these improvements may have been
caused by benefits from staff education. For instance, "I am encouraged to do relaxation when panicking", "(nursing) staff help me to see things differently" and "staff give helpful suggestions (on coping)".

Impact of Reconfiguration of Day Services

Although range of activities, practical orientation (skills development and future planning) and involvement evidenced some of the largest improvements, these were generally felt to reflect changes in the day unit services. Whether these changes alone were accountable for the overall increase in satisfaction is debatable. Continued dissatisfaction with the day services was evident. Participants complained that the décor of the day room was "cold", "uninviting" and the furniture "uncomfortable" and that service users tended to "creep upstairs" to the wards. Participants felt that the day unit generally inhibited communication because there was "no opportunity, time or privacy to talk to staff". This was supported by the observational analysis, which indicated that the number of general and longer conversations between staff and service-users decreased. The number of brief contacts increased due to register taking.

Limitations

In using satisfaction questionnaires it should be acknowledged that the occurrence of ‘socially desirable’ responses might lead to over-estimation of results and decrease face validity (Huxley and Mohamad, 1991-1992). Amalgamation of the data in this research also increased the risk of removing individual differences between the two wards and the small sample size generated a higher chance of sample-bias. The sample was too small for accurate generalisation of the findings and lacked a control group, where staff received no training. Due to cross-over of staffing working on the two wards and in the day unit, it was not possible to utilise one ward as a control. Further research in this area could utilise a longer data collection period to increase the sample size and enable analyses between the two wards and use a control group. It is important for continued evaluation of this education programme, in order to allow staff time to consolidate their new skills and help determine its’ overall effectiveness.
RECOMMENDATIONS

The findings, supported by service users’ comments, appeared to indicate that weaknesses in the named nursing system were limiting the opportunities for staff to apply their new skills.

Service users suggested that they should meet their named nurse on the day of arrival, every time the nurse works and have a written reminder of their nurse’s name. Service users felt that changes to the day services predominantly contributed to the decline in contact at follow-up and felt that unrestricted access to their named nurses was essential for recovery. Perceived helpfulness of staff also appeared to vary. Service users commented both at baseline and at follow-up that some staff were “better than others” because they were more educated about mental health problems and “more approachable” on a personal level. Ensuring that all staff attend the education programme may be difficult but essential for broadening staff skills (Higgins et al, 1999), enabling a uniform and consistent approach and increasing staff confidence for working on psychiatric wards (Higgins et al, 1999).

The findings and recommendations were fed-back to the Department of Psychiatry and considerable changes to the Named Nurse system are being developed as a result.
REFERENCES


APPENDICES

Appendix 1: Education Programme for Nursing Staff

Appendix 2: Information Leaflet

Appendix 3: Consent Form

Appendix 4: Interview

Appendix 5: Response Rates

Appendix 6: Participant Demographics

Appendix 7: Satisfaction with Communication

Appendix 8: Nature of Communication

Appendix 9: Behavioural Observation

Appendix 10: Ward Atmosphere Scale

Appendix 11: Confirmation of Project Presentation
Minimum Training Attended by All Staff

1. Introduction to Cognitive Behavioural Therapy (3 x 1 hour sessions).
   Counselling Psychologist.

2. Introduction to Counselling Skills (3 x 1 hour sessions).
   Counselling Psychologist.

Additional Training

3. Introduction to Cognitive Behavioural Therapy (2 hours).
   Clinical Psychologist.

4. Cognitive Behavioural Therapy for Psychosis (3 days).
   Consultant Clinical Psychologist.

5. Cognitive Behavioural Therapy for Personality Disorders (1 hour).
   Clinical Psychologist.

6. Observation of Anxiety Management Group.

7. Observation of Depression Group.
We are undertaking a study to determine the best way of helping people who, like you, are currently suffering problems and are spending some time in hospital. The Trust is a member of the National Mental Health Acute inpatient Practice Development Network, which is organised by the centre for mental health services Development (CMHSD) and the Division of Nursing and midwifery, King’s College London.

The aim of the network is to improve care for mental health service users in inpatient units and the experience of staff working in these units. To achieve these aims a series of initiatives will be planned by a project development group in this Trust in collaboration with the project team at King’s College. They will be implemented by the Trust over the next two years.

It is crucial for the views of service users to assist these local initiatives and so we need your help. We would be grateful if you would complete this questionnaire to give us an accurate picture of what service users need at this time. This should take about 25 minutes and there should be someone available to assist you.

We do hope that you will agree to help us by completing the questionnaire, although you are not obliged to. Participation or non-participation in this project will in no way affect the care you receive. The identification number on the questionnaire reveals only which Trust and ward you are currently in. Your name is not needed and the information you give will be treated in confidence and remain anonymous. The questionnaires will be analysed and a summary of the findings will be made available to the project team in you Trust to inform inpatient care initiatives. Your personal views will be identifiable and not made available to anyone on the ward or any member of the hospital staff.

If you have any questions about this initiative, please speak to:

Service leader for Acute Services
Department of Psychiatry

Thank You For Your Time
CONSENT FORM

I...................................................of
(ward).............................................agree to participate in the
research in relation to the above project. The nature and purpose
have been explained and are acceptable to me.

I understand that I am entering this project of my own free will
and I am free to withdraw at any time, without necessarily
giving any reasons and that me participation or non-participation
in this project will in no way affect the care I receive.

I understand that all information will be kept in the strictest
confidence and my identity will not be revealed to anyone.

Participants signature ..............................................................

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

Witnessed by..............................................................

Date..............................................................
SECTION 1: BACKGROUND INFORMATION

1.1 Age ............. years.

1.2 Male  Female

1.3 Ethnic Origin:
- White UK
- White Eire
- White Other
- Black Caribbean
- Black African
- Black Other
- Indian
- Pakistani
- Chinese
- Other (please specify) .................................................................

1.4 Is English your main language? Yes □  No □  If no, please specify...........

1.5 What age did you leave school/education ..............................................

1.6 Are you: single □  married □  divorced/separated □  with a partner □

1.7 Do currently have a job?  Yes □  No □

1.8 Have you been a patient on this ward before?  Yes □  No □

1.9 Are you a Voluntary Patient □  Involuntary Patient □

INFORMATION GATHERED FROM STAFF:

1.10 Number of days patient has been on the ward ..................................

1.11 Diagnosis ......................................................................................

1.12 Age at onset of illness .................................................................
Section 2: Patient Contact with Staff

2.1) Would you change anything about the way in which you were admitted to the ward?

2.2) Do you have a Named Nurse? Yes □ No □ Don’t Know □

IF NO, GO TO QUESTION 2.7

2.3) When did you first meet your Named Nurse?
On the day I arrived □ The day after I arrived □
A couple of days after I arrived □ I haven’t met them yet □
Other________

2.4) How often do you see your Named Nurse?
Daily □ Whenever they are working □ Occasionally □
Rarely □ Not at all □
Other____________________________________

2.5) How easy is it to talk to your Named Nurse?

2.6) How often do you speak to other staff about your problems?
Never □ Hardly Ever □ Sometimes □ Always □

2.7) How friendly and helpful are the staff?

2.8) How satisfied are you about the way in which the staff listen to and understand your problems? (Please Circle)

1 Very Satisfied  2 Satisfied  3 Neither Satisfied Nor Dissatisfied  4 Dissatisfied  5 Very Dissatisfied

2.9) How satisfied are you with the way in which the staff have helped you to understand and deal with your problems? (Please circle)

1 Very Satisfied  2 Satisfied  3 Neither Satisfied Nor Dissatisfied  4 Dissatisfied  5 Very Dissatisfied
APPENDIX 4

2.10) How satisfied are you with the way in which the services have helped your relatives to understand your problems? (Please circle)

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Satisfied</td>
<td>Satisfied</td>
<td>Neither Satisfied</td>
<td>Dissatisfied</td>
<td>Very Dissatisfied</td>
</tr>
</tbody>
</table>

2.11) How satisfied are you with the way staff share information with you?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Satisfied</td>
<td>Satisfied</td>
<td>Neither Satisfied</td>
<td>Dissatisfied</td>
<td>Very Dissatisfied</td>
</tr>
</tbody>
</table>

2.12) How satisfied are you with the way in which you are involved in decisions about your own treatment?

<table>
<thead>
<tr>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Satisfied</td>
<td>Satisfied</td>
<td>Neither Satisfied</td>
<td>Dissatisfied</td>
<td>Very Dissatisfied</td>
</tr>
</tbody>
</table>

2.13) Overall, how satisfied are you with your treatment and care in this ward?

<table>
<thead>
<tr>
<th></th>
<th>5</th>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Very Satisfied</td>
<td>Fairly Satisfied</td>
<td>Neither Satisfied</td>
<td>Very Dissatisfied</td>
<td>Don’t Know</td>
</tr>
</tbody>
</table>

Section 3: Activities

3.1) Since you have been on the ward, have you been told what activities are available and where to go to join in with them?

Yes □ No □ Don’t know □

3.2) How often do the staff encourage you to join in with activities?

Never □ Hardly Ever □ Sometimes □ Always □

3.3) Is there anything you would change about the activities available? (prompt: what kind of activities would you like to do?)

3.4) What have you enjoyed or found particularly helpful about your treatment here?

3.5) Is there anything you would change about your overall treatment?
Section 4: Client Satisfaction Questionnaire

4.1) How do you feel about your reception when you first met the ward staff?

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Could not be better</td>
<td>Satisfied</td>
<td>Dissatisfied</td>
<td>Could not be worse</td>
</tr>
</tbody>
</table>

4.2) Are you getting the kind of service you want?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, definitely not</td>
<td>No, not really</td>
<td>Yes, generally</td>
<td>Yes, definitely</td>
</tr>
</tbody>
</table>

4.3) If a friend were in need of similar help, would you recommend the ward to him or her?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, definitely not</td>
<td>No, I don’t think so</td>
<td>Yes, I think so</td>
<td>Yes, definitely</td>
</tr>
</tbody>
</table>

4.4) Are you satisfied that your Named Nurse listens to and understands your problem?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, definitely not</td>
<td>No, I don’t think so</td>
<td>Yes, I think so</td>
<td>Yes, definitely</td>
</tr>
</tbody>
</table>

4.5) If you were to seek help again, would you come back to this ward?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td>No, definitely not</td>
<td>No, I don’t think so</td>
<td>Yes, I think so</td>
<td>Yes, definitely</td>
</tr>
</tbody>
</table>

4.6) How satisfied are you with the range of activities available to you in this ward?

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>Satisfied</td>
<td>Dissatisfied</td>
<td>Very dissatisfied</td>
</tr>
</tbody>
</table>

4.7) How satisfied are you with the way staff in the ward seem to work together as a team?

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Very satisfied</td>
<td>Satisfied</td>
<td>Dissatisfied</td>
<td>Very dissatisfied</td>
</tr>
</tbody>
</table>

4.8) To what extent have ward staff met your needs?

<table>
<thead>
<tr>
<th>4</th>
<th>3</th>
<th>2</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Almost all of my needs have been met</td>
<td>Most of my needs have been met</td>
<td>Only a few of my needs have been met</td>
<td>None of my needs have been met</td>
</tr>
</tbody>
</table>
Section 5: Ward Atmosphere Scale

Please answer true or false to the following statements about the atmosphere on the ward.

<table>
<thead>
<tr>
<th>Statement</th>
<th>True</th>
<th>False</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1) Patients put a lot of energy into what they do on the ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.2) Doctors have very little time to encourage patients</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.3) Patients tend to hide their feelings from one another</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.4) The staff act on patients’ suggestions</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.5) New treatment approaches are often tried on this ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.6) Patients hardly discuss their sexual lives</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.7) Patients often moan</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.8) Patients’ activities are carefully planned</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.9) The patients know when the doctors will be on the ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.10) The staff very rarely punish patients by restricting them</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.11) This is a lively ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.12) The staff know what the patients want</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.13) Patients say anything they want to doctors</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.14) Very few patients have responsibility on the ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.15) There is very little emphasis on developing patients’ practical skills</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.16) Patients tell each other about their personal problems</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.17) Patients often criticise or joke about ward staff</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.18) This is a very well organised ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.19) Doctors don’t explain what treatment is about to patients</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.20) Patients may interrupt a doctor when he is talking</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.21) The patients are proud of this ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.22) Staff are interested in following-up patients after they leave hospital</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.23) It’s hard to tell how patients are feeling on this ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.24) Patients are expected to exercise their initiative on the ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.25) Patients are encouraged to plan for the future</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.26) Personal problems are openly talked about</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.27) Patients on this ward rarely argue</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.28) The staff make sure that the ward is always tidy</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.29) If a patient’s medication is changed, a nurse or doctor always tells them why</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.30) Patients who break the ward rules are punished for it</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.31) There is very little group spirit on the ward</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.32) Nurses have very little time to encourage patients</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.33) Patients are careful about what they say when staff are around</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.34) Patients here are encouraged to be independent</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.35) There is very little emphasis on what patients will be doing after they leave</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.36) Patients are expected to share their personal problems with each other</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.37) Staff sometimes argue with each other</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.38) The ward sometimes gets very messy</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.39) Ward rules are clearly understood by patients</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>5.40) If a patient argues with another patient s/he will get into trouble with the staff</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
## RESPONSE RATES

### Table 1: Percentage of Ward Capacity Available for Survey

<table>
<thead>
<tr>
<th></th>
<th>Baseline (pre)</th>
<th>Follow-Up (post)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of service users on ward</td>
<td>29</td>
<td>33</td>
</tr>
<tr>
<td>Number of service users excluded by psychiatrists</td>
<td>6</td>
<td>9</td>
</tr>
<tr>
<td>Number of service users on leave</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Number of service users Absent Without Leave</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Total number of people eligible to participate</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Percentage of users eligible to participate</td>
<td>69% of ward capacity</td>
<td>48% of ward capacity</td>
</tr>
</tbody>
</table>

### Table 2: Response Rate

<table>
<thead>
<tr>
<th></th>
<th>Pre</th>
<th>Post</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of users available for interview</td>
<td>20</td>
<td>16</td>
</tr>
<tr>
<td>Declines to participate</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Excluded*</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Total number of participants in research</td>
<td>14</td>
<td>10</td>
</tr>
<tr>
<td>Response Rate (of users approached)</td>
<td>70%</td>
<td>62%</td>
</tr>
</tbody>
</table>

* Evidence of mental illness made responses unreliable and were therefore excluded
PARTICIPANT DEMOGRAPHICS

Table 3: Age

<table>
<thead>
<tr>
<th>Time</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean (1dp)</th>
<th>Standard Deviation (1dp)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre (n=14)</td>
<td>26</td>
<td>67</td>
<td>41.4</td>
<td>11.8</td>
</tr>
<tr>
<td>Post (n=10)</td>
<td>23</td>
<td>65</td>
<td>46.7</td>
<td>12.4</td>
</tr>
</tbody>
</table>

Table 4: Non-Parametric T-Test Comparing Age Across Time

Test Statistics

<table>
<thead>
<tr>
<th>Test Statistic</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>52.000</td>
</tr>
<tr>
<td>Wilcoxon W</td>
<td>157.000</td>
</tr>
<tr>
<td>Z</td>
<td>-1.056</td>
</tr>
<tr>
<td>Asymp. Sig. (2-tailed)</td>
<td>.291</td>
</tr>
<tr>
<td>Exact Sig. [2*(1-tailed Sig.)]</td>
<td>.312</td>
</tr>
</tbody>
</table>

a Not corrected for ties.
b Grouping Variable: Time of measurement

Table 5: Number of Years in Education

<table>
<thead>
<tr>
<th>Time</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean (1dp)</th>
<th>Standard Deviation (1dp)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre (n=14)</td>
<td>11</td>
<td>16</td>
<td>12.3</td>
<td>12.3</td>
</tr>
<tr>
<td>Post (n=10)</td>
<td>9</td>
<td>19</td>
<td>12.4</td>
<td>12.4</td>
</tr>
</tbody>
</table>

Table 6: Non-Parametric T-Test Comparing Number of Years in Education

Test Statistics

<table>
<thead>
<tr>
<th>Test Statistic</th>
<th>Number Of Years In Education</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>66.500</td>
</tr>
<tr>
<td>Wilcoxon W</td>
<td>171.500</td>
</tr>
<tr>
<td>Z</td>
<td>-.224</td>
</tr>
<tr>
<td>Asymp. Sig. (2-tailed)</td>
<td>.823</td>
</tr>
<tr>
<td>Exact Sig. [2*(1-tailed Sig.)]</td>
<td>.841</td>
</tr>
</tbody>
</table>

a Not corrected for ties.
b Grouping Variable: Time of measurement
Table 7: Gender

<table>
<thead>
<tr>
<th>Time</th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>28.6%</td>
<td>71.4%</td>
</tr>
<tr>
<td>Count</td>
<td>4/14</td>
<td>10/14</td>
</tr>
<tr>
<td>Post</td>
<td>30%</td>
<td>70%</td>
</tr>
<tr>
<td>Count</td>
<td>3/10</td>
<td>7/10</td>
</tr>
</tbody>
</table>

Table 8: Chi-Square Comparing Gender Across Time

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordinal by</td>
<td>Kendall's τ^b</td>
<td>-0.015</td>
<td>0.205</td>
</tr>
<tr>
<td>Ordinal</td>
<td>tau-b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N of Valid</td>
<td></td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Cases</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* a Not assuming the null hypothesis.
* b Using the asymptotic standard error assuming the null hypothesis.

Table 9: Ethnic Origin

<table>
<thead>
<tr>
<th>Time</th>
<th>White UK</th>
<th>White Eire</th>
<th>White Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>85.7%</td>
<td>7.1%</td>
<td>7.1%</td>
</tr>
<tr>
<td>Count</td>
<td>12/14</td>
<td>1/14</td>
<td>1/14</td>
</tr>
<tr>
<td>Post</td>
<td>90%</td>
<td>0%</td>
<td>1%</td>
</tr>
<tr>
<td>Count</td>
<td>9/10</td>
<td>0/10</td>
<td>1/10</td>
</tr>
</tbody>
</table>

Table 10: Chi-Square Comparing Ethnic Origin Across Time

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordinal by</td>
<td>Kendall's τ^b</td>
<td>-0.052</td>
<td>0.197</td>
</tr>
<tr>
<td>Ordinal</td>
<td>tau-b</td>
<td></td>
<td></td>
</tr>
<tr>
<td>N of Valid</td>
<td></td>
<td>24</td>
<td></td>
</tr>
<tr>
<td>Cases</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* a Not assuming the null hypothesis.
* b Using the asymptotic standard error assuming the null hypothesis.
## Table 11: Marital Status

<table>
<thead>
<tr>
<th>TIME</th>
<th>Single</th>
<th>Married</th>
<th>Divorced/Separated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>42.9%</td>
<td>57.1%</td>
<td>0%</td>
</tr>
<tr>
<td>Count</td>
<td>6/14</td>
<td>8/14</td>
<td>0/14</td>
</tr>
<tr>
<td>Post</td>
<td>40%</td>
<td>40%</td>
<td>20%</td>
</tr>
<tr>
<td>Count</td>
<td>4/10</td>
<td>4/10</td>
<td>2/10</td>
</tr>
</tbody>
</table>

## Table 12: Chi-Square Comparing Marital Status Across Time

**Symmetric Measures**

- **Ordinal by Kendall's tau-**
  - Value: .132
  - Asymp. Std. Error: .203
  - Approx. T: .641
  - Approx. Sig: .521

- N of Valid Cases: 24

---

a Not assuming the null hypothesis.
b Using the asymptotic standard error assuming the null hypothesis.

## Table 13: Employment

<table>
<thead>
<tr>
<th>TIME</th>
<th>Employed</th>
<th>Unemployed</th>
<th>Retired</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>50%</td>
<td>50%</td>
<td>0%</td>
</tr>
<tr>
<td>Count</td>
<td>7/14</td>
<td>7/14</td>
<td>0/14</td>
</tr>
<tr>
<td>Post</td>
<td>10%</td>
<td>70%</td>
<td>20%</td>
</tr>
<tr>
<td>Count</td>
<td>1/10</td>
<td>7/10</td>
<td>2/10</td>
</tr>
</tbody>
</table>

## Table 14: Chi-Square Comparing Employment Across Time

**Symmetric Measures**

- **Ordinal by Kendall's tau-**
  - Value: .474
  - Asymp. Std. Error: .140
  - Approx. T: 3.009
  - Approx. Sig: .003

- N of Valid Cases: 24

---

a Not assuming the null hypothesis.
b Using the asymptotic standard error assuming the null hypothesis.
Table 15: Previous Admissions

<table>
<thead>
<tr>
<th>Time</th>
<th>None</th>
<th>Present Ward</th>
<th>Present Ward &amp; Other Wards</th>
<th>Only Other Hospital Wards</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>28.6%</td>
<td>21.4%</td>
<td>35.7%</td>
</tr>
<tr>
<td></td>
<td>Count</td>
<td>4/14</td>
<td>3/14</td>
<td>5/14</td>
</tr>
<tr>
<td>Post</td>
<td>%</td>
<td>0%</td>
<td>20%</td>
<td>30%</td>
</tr>
<tr>
<td></td>
<td>Count</td>
<td>0/10</td>
<td>2/10</td>
<td>3/10</td>
</tr>
</tbody>
</table>

Table 16: Chi-Square Comparing Previous Admissions Across Time

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Ordinal by Kendall's</th>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordinal tau-b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a Not assuming the null hypothesis.
b Using the asymptotic standard error assuming the null hypothesis.

Table 17: Status

<table>
<thead>
<tr>
<th>TIME</th>
<th>Voluntary</th>
<th>Involuntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>71.4%</td>
<td>28.6%</td>
</tr>
<tr>
<td>Count</td>
<td>10/14</td>
<td>4/14</td>
</tr>
<tr>
<td>Post</td>
<td>90%</td>
<td>10%</td>
</tr>
<tr>
<td>Count</td>
<td>9/10</td>
<td>1/10</td>
</tr>
</tbody>
</table>

Table 18: Chi-Square Comparing Voluntary Status Across Time

**Symmetric Measures**

<table>
<thead>
<tr>
<th>Ordinal by Kendall's</th>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordinal tau-b</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>N of Valid Cases</td>
<td>24</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

a Not assuming the null hypothesis.
b Using the asymptotic standard error assuming the null hypothesis.
### Table 19: Number of Days on Ward

<table>
<thead>
<tr>
<th>Time of measurement</th>
<th>N</th>
<th>Mean Rank</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>pre</td>
<td>14</td>
<td>11.14</td>
<td>156.00</td>
</tr>
<tr>
<td>post</td>
<td>10</td>
<td>14.40</td>
<td>144.00</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 20: Non-Parametric t-Test Comparing Number of Days Across Time

**Test Statistics**

<table>
<thead>
<tr>
<th></th>
<th>Number of Days on Ward</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>51.000</td>
</tr>
<tr>
<td>Wilcoxon W</td>
<td>156.000</td>
</tr>
<tr>
<td>Z</td>
<td>-1.113</td>
</tr>
<tr>
<td>Asymp. Sig. (2-tailed)</td>
<td>.265</td>
</tr>
<tr>
<td>Exact Sig. [2*(1-tailed Sig.)]</td>
<td>.285</td>
</tr>
</tbody>
</table>

*a* Not corrected for ties.

*b* Grouping Variable: Time of measurement

### Table 21: Primary Clinical Diagnosis

<table>
<thead>
<tr>
<th>TIME</th>
<th>Depression</th>
<th>Substance Abuse</th>
<th>Anxiety Disorder</th>
<th>Schizophrenia</th>
<th>Personality Disorder</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
<td>%</td>
</tr>
<tr>
<td>Pre</td>
<td>35.7%</td>
<td>7.1%</td>
<td>21.4%</td>
<td>28.5%</td>
<td>1%</td>
</tr>
<tr>
<td>Count</td>
<td>5/14</td>
<td>1/14</td>
<td>3/14</td>
<td>4/14</td>
<td>1/14</td>
</tr>
<tr>
<td>Post</td>
<td>40%</td>
<td>20%</td>
<td>0%</td>
<td>40%</td>
<td>0%</td>
</tr>
<tr>
<td>Count</td>
<td>4/10</td>
<td>2/10</td>
<td>0/10</td>
<td>4/10</td>
<td>0/10</td>
</tr>
</tbody>
</table>

### Table 22: Chi-Square Comparing Primary Clinical Diagnosis Across Time

**Symmetric Measures**

<table>
<thead>
<tr>
<th></th>
<th>Value</th>
<th>Asymp. Std. Error</th>
<th>Approx. T</th>
<th>Approx. Sig.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ordinal Kendall's tau-b</td>
<td>.080</td>
<td>.191</td>
<td>.416</td>
<td>.678</td>
</tr>
</tbody>
</table>

*a* Not assuming the null hypothesis.

*b* Using the asymptotic standard error assuming the null hypothesis.
Table 23: Number of Years Since First Admission

<table>
<thead>
<tr>
<th>Time of measurement</th>
<th>N</th>
<th>Mean Rank</th>
<th>Sum of Ranks</th>
</tr>
</thead>
<tbody>
<tr>
<td>pre</td>
<td>14</td>
<td>10.75</td>
<td>150.50</td>
</tr>
<tr>
<td>post</td>
<td>10</td>
<td>14.95</td>
<td>149.50</td>
</tr>
<tr>
<td>Total</td>
<td>24</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 24: Non-Parametric t-Test Comparing Number of Years Since First Admission Across Time

<table>
<thead>
<tr>
<th>Test Statistics</th>
<th>Number of Years Since First Admission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mann-Whitney U</td>
<td>45.500</td>
</tr>
<tr>
<td>Wilcoxon W</td>
<td>150.500</td>
</tr>
<tr>
<td>Z</td>
<td>-1.437</td>
</tr>
<tr>
<td>Asymp. Sig. (2-tailed)</td>
<td>.151</td>
</tr>
<tr>
<td>Exact Sig. [2*(1-tailed Sig.)]</td>
<td>.154</td>
</tr>
</tbody>
</table>

\[a\] Not corrected for ties.
\[b\] Grouping Variable: Time of measurement
SATISFACTION WITH COMMUNICATION

GRAPH 1

Percentage of Participants Satisfied with Staff
Listening to Problems

Satisfaction

GRAPH 2

Percentage of Participants Satisfied with Education About their Problems

Satisfaction
**Graph 3**

Percentage of Participants Satisfied with Education of their Relatives

**Graph 4**

Percentage of Participants Satisfied with Information Shared about their Care
**Graph 5**

Percentage of Participants Satisfied with
**Involvement in Decision Making**

![Bar chart showing percentage of participants satisfied with involvement in decision making.](chart1)

**Graph 6**

Percentage of Participants Satisfied with
**Overall Treatment**

![Bar chart showing percentage of participants satisfied with overall treatment.](chart2)
### Table 25: Communication About Activities

<table>
<thead>
<tr>
<th>Variable</th>
<th>Baseline</th>
<th>Follow-Up</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Introduction to activities by staff</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n (%)</td>
<td>7 (50%)</td>
<td>8 (80%)</td>
</tr>
<tr>
<td>Yes</td>
<td>6 (42.9%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>No</td>
<td>1 (7.1%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Don’t Know</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Encouragement by staff to join in with activities</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>1 (7.1%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Hardly Ever</td>
<td>3 (21.4%)</td>
<td>2 (20%)</td>
</tr>
<tr>
<td>Sometimes</td>
<td>5 (35.7%)</td>
<td>1 (10%)</td>
</tr>
<tr>
<td>Always</td>
<td>5 (35.7%)</td>
<td>7 (70%)</td>
</tr>
</tbody>
</table>
APPENDIX 9

BEHAVIOURAL ANALYSIS

BASELINE OBSERVATION – TWO WARDS

Observers: A & B
Date: Wednesday 17th November 1999

Time Observation Commenced: 10.00am
Time Observation Finished: 12.00pm
Place of Observation: Nursing station on both wards overlooking the lounge areas
Number of Staff on Duty: 4 + nursing student on each ward
Number of Patients: 12 on Delius, 17 on Elgar
Number of Emergencies: 0
Weather: Sunny but very cold.
Activities Available: Cooking 10am – 12.00pm
Number of Ward Rounds: 1 (Delius)

FOLLOW-UP OBSERVATION – DAY UNIT

Observer: A
Date: Wednesday 22nd March 2000

Time Observation Commenced: 10.00am
Time Observation Finished: 12.00pm
Place of Observation: Day Unit Lounge
Number of Staff on Day Unit: 2
Number of Patients: 13
Number of Emergencies: 0
Weather: Sunny but cold
Activities Available: Cooking 10am – 12.00pm
Number of Ward Rounds: 1 (Delius)

Observation Criteria

Whether contact initiated by staff or patients
Nature of contact (general conversation, therapeutic, activity, reprimanding)
Duration of Contact
Number of people involved in contact
Staff Attitude
Patient Attitude
### Table 26: Tally Score of Nature of Contact Initiated by Staff and Service Users

<table>
<thead>
<tr>
<th>Nature of Contact</th>
<th>Wards (Baseline) 17.11.99</th>
<th>Total Baseline</th>
<th>Day Unit (Follow-Up) 22.3.00</th>
<th>Total (Follow-Up)</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Staff to User</td>
<td>User to staff</td>
<td>Staff to User</td>
<td>User to staff</td>
<td>Staff to User</td>
</tr>
<tr>
<td>Brief Comment</td>
<td>6</td>
<td>3</td>
<td>9 (25%)</td>
<td>15</td>
<td>4</td>
</tr>
<tr>
<td>Conversation</td>
<td>4</td>
<td>8</td>
<td>12 (33%)</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Caring/Concern</td>
<td>4</td>
<td>3</td>
<td>7 (19.5%)</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Task Orientated</td>
<td>5</td>
<td>2</td>
<td>7 (19.5%)</td>
<td>5</td>
<td>8</td>
</tr>
<tr>
<td>Reprimanding</td>
<td>1</td>
<td>0</td>
<td>1 (3%)</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Total</td>
<td>20</td>
<td>16</td>
<td>36</td>
<td>26</td>
<td>15</td>
</tr>
</tbody>
</table>

- Increase in brief comments and <1 minute durations (in Day Unit) due to staff taking a register (4 occasions)

### Table 27: Length of Contact Between Staff and Service Users

<table>
<thead>
<tr>
<th>Duration</th>
<th>Wards, Tally Score (Baseline) 17.11.99</th>
<th>Maximum Total in Minutes (Baseline)</th>
<th>Day Unit, Tally Score (Follow-Up) 22.3.00</th>
<th>Maximum Total in Minutes (Follow-Up)</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>Up to 1 min</td>
<td>21</td>
<td>21 mins (35%)</td>
<td>34</td>
<td>34 mins (49%)</td>
<td>+14%</td>
</tr>
<tr>
<td>1-2 mins.</td>
<td>9</td>
<td>18 mins (30%)</td>
<td>4</td>
<td>8 mins (12%)</td>
<td>-18%</td>
</tr>
<tr>
<td>2-3 mins.</td>
<td>4</td>
<td>12 mins (20%)</td>
<td>0</td>
<td>0</td>
<td>-20%</td>
</tr>
<tr>
<td>3-4 mins.</td>
<td>1</td>
<td>4 mins (7%)</td>
<td>1</td>
<td>4 mins (6%)</td>
<td>-1%</td>
</tr>
<tr>
<td>4-5 mins.</td>
<td>1</td>
<td>5 mins (8%)</td>
<td>0</td>
<td>0</td>
<td>-8%</td>
</tr>
<tr>
<td>5-6 mins.</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>6-10 mins.</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>10 mins (14%)</td>
<td>+14%</td>
</tr>
<tr>
<td>13 mins.</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>13 mins (19%)</td>
<td>+19%</td>
</tr>
<tr>
<td>Total contacts</td>
<td>36</td>
<td>60 minutes</td>
<td>41 contacts</td>
<td>69 minutes</td>
<td></td>
</tr>
</tbody>
</table>

- Increase in brief comments and <1 minute durations (in Day Unit) due to staff taking a register (4 occasions)
### Behavioural Analysis

Table 28: Number of People Involved in Communications

<table>
<thead>
<tr>
<th>Number of People</th>
<th>Wards (Baseline) 17.11.99</th>
<th>Day Unit (Follow-Up) 22.3.00</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 staff, 1 User</td>
<td>31 (86%)</td>
<td>35 (85%)</td>
<td>- 1%</td>
</tr>
<tr>
<td>1 staff, 2 Users</td>
<td>2 (6%)</td>
<td>2 (5%)</td>
<td>- 1%</td>
</tr>
<tr>
<td>1 staff, &gt;2 Users</td>
<td>0</td>
<td>4 (10%)</td>
<td>+ 10%</td>
</tr>
<tr>
<td>2 staff, 1 Users</td>
<td>3 (8%)</td>
<td>0</td>
<td>- 8 %</td>
</tr>
<tr>
<td>2 staff, 2 Users</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>2 staff, &gt; 2 Users</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>36</strong></td>
<td><strong>41</strong></td>
<td></td>
</tr>
</tbody>
</table>
WARD ATMOSPHERE SCALE

TABLE 29: STANDARDISED SCORES ON THE WARD ATMOSPHERE SCALE, PRE AND POST SERVICE RECONFIGURATION

<table>
<thead>
<tr>
<th>Time</th>
<th>Involvement</th>
<th>Support</th>
<th>Spontaneity</th>
<th>Autonomy</th>
<th>Practical Orientation</th>
<th>Personal Problem Orientation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>34</td>
<td>40</td>
<td>45</td>
<td>38</td>
<td>18</td>
<td>39</td>
</tr>
<tr>
<td>Post</td>
<td>47</td>
<td>42</td>
<td>48</td>
<td>47</td>
<td>32</td>
<td>54</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Time</th>
<th>Anger and Aggression</th>
<th>Order and Organisation</th>
<th>Program Clarity</th>
<th>Staff Control</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre</td>
<td>49</td>
<td>57</td>
<td>45</td>
<td>44</td>
</tr>
<tr>
<td>Post</td>
<td>42</td>
<td>57</td>
<td>54</td>
<td>43</td>
</tr>
</tbody>
</table>

GRAPH 7: WARD ATMOSPHERE SCALE PROFILE AT BASELINE AND FOLLOW-UP

Ward Atmosphere Scale Profile

Subscales
Psychology Department,
University of Surrey,
Guildford,
Surrey.

Dear Sirs,

I am writing to confirm that Gemma Dold has presented her service related research project to the Inpatient Development Network Meeting, at the Department of Psychiatry, General Hospital, on 27th September 2000.

Yours faithfully,

[Signature]
Senior Nurse

Teresa Perez
Service Leader - Acute & MDO
"Critical Review of Psychosocial Factors in the Psychological Adjustment of Children with Chronic Illnesses and their Mothers"

AUGUST 2001

YEAR 2
Critical Review of Psychosocial Factors in the Psychological Adjustment
of Children with Chronic Illnesses and their Mothers

A recurrent definition of chronic illnesses used across research into psychological adjustment is that offered by Pless and Pinkerton (1975 cited in Wallander and Thompson, 1995), in which a “chronic physical condition” is defined as interfering with daily functioning for more than three months, causing more than one month's hospitalisation in a year, or is thought to do either at the time of diagnosis. Examples of chronic physical conditions include, asthma, cerebral palsy, cystic fibrosis, sickle cell diseases, congenital heart disease, spina bifida and leukaemia. Prevalence estimations of chronic childhood illnesses range from ten (Cadman et al, 1987 cited in Tansella, 1995) to twenty-percent (Pless and Nolan, 1991 cited in Bradford, 1997) due to a number of definitions used across the literature as a whole. With advances in medical technology prevalence rates have slowly increased and consequently, more children and families have to learn to adapt to the changes that chronic childhood illnesses cause and the physical, social and psychological problems that may result from these changes (Tansella, 1995). Although epidemiological and clinical studies indicate that children with chronic physical conditions and their mothers are at increased risk for poor psychological adjustment (Lavigne and Faier-Routman, 1993; Wallander and Thompson, 1995), very little is understood about the processes involved in the long-term adjustment of children and their families (Kazak and Barakat, 1997).

The study of chronic illnesses and the need to delineate variables associated with good and poor psychological adjustment is becoming of increasing interest to healthcare providers and therefore is the focus of this review. Dissatisfaction with past research described as generally descriptive, subjective and confounded (Bradford, 1997) has prompted researchers to develop conceptually based models which are helping to guide research to delineate psychosocial processes (Thompson, 1985), or ‘risk’ and ‘resistance’ factors (Wallander et al, 1989a). These mediate child and maternal psychological adjustment and identify suitable targets for clinical intervention (eg:
Thompson, 1985; Wallander et al, 1989b). The considerable lack of research into paternal adjustment means that this highly selective and by no means exhaustive critical review focuses on a series of articles that examine the relationship between maternal and child adjustment (eg: Thompson et al, 1992, 1993, 1994, 1999; Wallander et al, 1989a, 1989b, 1989c) and form the evidence-base for the development of current models of adjustment to chronic illnesses, which will not be discussed in detail. Articles with outcome measurements that cannot be quantified and inadequate information on research methodology have been excluded. The implications of this critical review will be discussed in relation to future directions for research into this area.

**HISTORICAL BACKGROUND**

Historically, research into the psychosocial impact of chronic physical illnesses was driven by the unsupported theoretical assumptions that maladjustment was common and reactions of families uniform (Bradford, 1997). Early research focused on investigating illnesses according to disease-specific aetiology, characteristics and severity and has largely been criticised for using anecdotal evidence and uncontrolled conditions, and failing to support direct relationships between chronic illnesses and psychosocial adjustment (Wallander and Thompson, 1995). Increasing dissatisfaction also developed with the inability of earlier approaches (eg: Knowles, 1971; Kellerman et al, 1980 cited in Bradford, 1997) to explain both the considerable variation in psychological adjustment and the findings that many children and families have no significant adjustment problems (eg: LaVigne and Faier-Routman, 1993; Wallander, Varni, et al 1988b).

Psychosocial adjustment to chronic illnesses was subsequently, re-conceptualised as a composite construct including emotional, social and behavioural problems, self-concept, physical and mental health status, satisfaction with life and quality of life (Tansella, 1995). Researchers have also progressively moved towards a non-categorical approach (Stein and Jessop 1982, 1984a cited in Wallander and Thompson, 1975), which emphasises that there are considerable commonalities in the challenges of different childhood illnesses, such as diagnosis acceptance, assessment and treatment procedures, that distinguish them from other children and families.
These commonalities have been found to be relatively independent of diagnosis (Pless and Perrin, 1985 cited in Bradford 1997; Varni and Wallander, 1988).

The progression of research from a descriptive to an analytic stage has been characterised by the formulation, testing and refining of coherent conceptual models such as the transactional stress and coping model (Thompson, 1985), and an integrated model of adjustment (Wallander et al, 1989b). Such models attempt to provide a rationale for including and organising specific child and maternal processes that mediate psychosocial adjustment and to provide a framework for theoretically driven research. Common to both these models is an underlying systems theory perspective of chronic illness as a potential stressor to which the family system endeavours to adapt, and the emphasis on identifying 'adaptational' (Thompson, 1985; Thompson, Gustafson et al, 1992a) or 'risk' and 'resistance' factors (Wallander et al, 1989b).

In common with the general consensus in the literature, the models also assume that children with chronic illnesses and their families are at risk of psychological adjustment problems. For example, mothers of physically disabled children were found to be at higher risk of developing mental health problems such as depression anxiety and distress than control subjects (Davis et al, 1998; Wallander et al, 1989a; 1989c). Furthermore, a mediating influence of the mother-child relationship on children's psychological adjustment has also been supported (DeMaso et al, 1991). For example, studies have found relationships between parental anxiety and children's distress during hospitalisation (eg: Cameron, Bond and Pointer, 1996 cited in Whelan and Kirby, 2000) and maternal anxiety in mother-reported child behaviour in sickle cell disease and cystic fibrosis (Thompson et al, 1992b; 1993b). The series of studies investigating the impact of various psychosocial factors by Thompson and Wallander and colleagues will be considered alongside independent research.

**IMPACT OF ILLNESS ON PSYCHOLOGICAL ADJUSTMENT**

**Condition Type**

Studies of chronic illnesses that do not involve brain pathology tend to demonstrate a lack of significant associations between specific condition types and psychological adjustment (Pless and Perrin, 1985; Thompson et al 1992, 1993, 1994, 1999), but
studies involving the brain and neurological disorders have found that children
demonstrate more emotional and behavioural problems and poorer social functioning
(Rutter et al, 1970 cited in Bradford, 1997). Although children with chronic illnesses,
such as, juvenile diabetes, spina bifida, juvenile rheumatoid arthritis, and cerebral
palsy, have been found to be at greater risk of psychological problems in comparison
to healthy peers, these difficulties are not directly associated to the child’s condition
type (Wallander, Varni et al, 1988).

Severity
There are considerably mixed findings over the contribution of illness severity to
psychological adjustment, which may be caused by the lack of a ‘gold standard’ to
measure severity in most chronic illnesses and the use of different ‘objective’ criteria
across research studies (Wallander and Thompson, 1995). The use of objective criteria
makes studies less comparable and future studies should attempt to develop
quantifiable parameters of disease severity.

Similar to the findings of a meta-analysis of the literature (LaVigne and Faier-
Routman, 1993), children’s illness severity was found to account for a significant
amount of variance in the anxiety of mothers of children with cystic fibrosis at
baseline (Thompson et al, 1992a) and after twelve months (Thompson, Gustafson et
al, 1994a). However, individual studies of sickle cell disease (Thompson and
Gustafson, 1992a, 1994b, 1999), non-referred children (Thompson, Merritt et al,
1993), congenital heart disease (Davis et al, 1998) and cerebral palsy and spina bifida
(Wallander et al, 1989a, 1989c) have demonstrated a lack of relationship between
severity and child or maternal psychological adjustment. The latter is consistent with
Pless and Pinkerton’s (1975) non-categorical approach to the study of adaptation of
chronically ill or handicapped children, in which the character of the chronic physical
illness is alleged to be secondary. Significant associations have also not been found
between child and maternal psychological adjustment and the presence of a child’s
learning difficulty, functional independence, medical problems and bowel and bladder
a relationship may not be direct, but instead mediated by the mother’s or child’s
subjective health beliefs and illness theories.
Impact of Demographic Factors

In the series of studies evaluating the transactional stress and coping model, no significant differences were found between good and poor adjustors on demographic parameters in cross-sectional studies of sickle cell disease (Thompson and Gustafson, 1992a; 1993a), cystic fibrosis (Thompson, Gil et al, 1993b), non-referred children (Thompson, Merritt et al, 1993) and mothers of children with congenital heart disease (Davis et al, 1998). However, longitudinal studies indicate that relationships between demographic factors and adjustment may be complex. For example, in the longitudinal study of mothers of low birth weight infants, distress at time of birth was not a function of either illness or demographic parameters, but six months later, mothers who reported higher distress had significantly lower Peabody IQ scores (Thompson, Oehler, et al, 1993). Studies investigating the impact of gender have also reported mixed findings, with no gender differences between parent and teacher-reported behaviour problems (eg: Thompson, Gustafson et al, 1992a), but increased behaviour problems in boys (Perrin et al, 1993 cited in Wallander and Thompson, 1995) and increased self-reports of distress in girls (eg: Thompson, Gustafson et al, 1992).

Studies investigating the impact of age on behaviour problems and self-esteem appear to be fairly consistent across a number of chronic illnesses (Wallander and Thompson, 1995). Although in contrast, age of onset has demonstrated mixed results. Whilst, late onset diabetes evidenced more behaviour problems in boys and poorer self-reported concept in girls (Rovet et al, 1987; Ryan and Morrow, 1986 cited in Wallander and Thompson, 1995), other studies have found no relationships (Hanson et al, 1990 cited in Wallander and Thompson, 1995). Furthermore, children’s age and the use of passive adherence pain coping strategies demonstrated a significant positive relationship in children with sickle cell disease (Gil et al, 1991). The finding that lower socio-economic status (SES) was associated with stable poor mother and child-reported adjustment in cystic fibrosis in the longitudinal study (Thompson, Gustafson, et al, 1992b) is consistent with findings across the literature. However, the use of measures of SES across studies is not, which explains the failure to find a relationship in studies investigating sickle cell disease (Thompson, Gil et al, 1993a, 1993b),
mothers of low birth weight infants (Thompson, Oehler et al, 1993) and congenital heart disease (Davis et al, 1998).

**CHILD PARAMETERS**

**Child Mediational Processes**

Although a range of cognitive processes have been investigated for their relationship with child adjustment the limited number of studies investigating each process mean that the findings are only preliminary. General self-worth has been related to perceived social support in children with cancer (Varni et al, 1989a cited in Wallander and Thompson, 1995) and adjustment problems in cystic fibrosis (Thompson, Gustafson et al, 1992b). Stability of the latter relationship over a one year period has been found as well as the relative contribution of self-worth to overall adjustment over and above that of illness and demographic parameters (Thompson, Gustafson et al, 1992a). Furthermore, perceived classmate social support has been related to the psychological adjustment of children with newly diagnosed cancer (Varni et al, 1994). Findings of perceptions of health locus of control across condition types have generally been mixed. Although mother and child reports of psychological adjustment of children with cystic fibrosis were not found to be related to health locus of control (Thompson, Gustafson et al, 1992b), mother-reported internalising behaviour problems in children with sickle cell disease were related to the child’s perceptions of the health locus of control of “powerful others” (Thompson, Gil et al, 1993b).

Research into the use of palliative or instrumental coping methods in children has also demonstrated inconsistent findings. For example, the use of palliative or instrumental coping methods in children with diabetes was not found to be related to self-reports of psychological distress (Kovacs et al, 1986) or to maternal reports of child adjustment problems in sickle cell disease (Thompson, Gil et al, 1993b). However, the use of negative thinking in children with sickle cell disease did account for a significant proportion of variance in the child’s self-reported psychological adjustment (Thompson, Gil et al, 1993b; Gil et al, 1991). It is likely that such inconsistent findings are directly attributable to the lack of empirically developed ways to measure coping methods in children.
CHILD ADJUSTMENT
In studies of chronic illness, mother-reported measures of child adjustment such as the Child Behaviour Checklist (CBCL: Achenbach and Edelbock 1983 cited in Wallander et al, 1989b) and the Missouri Children’s Behaviour Checklist (MCBC; Sines et al, 1969 cited in Thompson, Gustafson et al, 1992b) are used. It is perhaps not surprising that significant associations have been found between mothers’ perceptions of children’s behaviour problems and mothers’ self-reports of anxiety and depression (Thompson, Gil et al, 1993b, Thompson, Gustafson et al, 1992b), which remain stable over time (Thompson et al, 1999). The direction of causality has not yet been determined and either a mothers’ own psychological adjustment or the child’s adjustment could equally have a confounding influence on mother’s perceptions of their children. Determining directional causality in future studies would, for instance, contribute to an explanation for the finding that child adjustment significantly contributed to maternal adjustment in the cystic fibrosis group (Thompson, Gustafson et al, 1992b), but not in the sickle cell disease group (Thompson, Gustafson et al, 1994a).

MATERNAL PARAMETERS
Maternal Mediational Processes
The literature generally supports relationships between psychosocial/mediational processes, such as; stress appraisal, methods of coping, and family functioning and maternal adjustment, over and above that explained by illness and demographic parameters (eg: Thompson et al 1999). Nevertheless, some support has been found for different patterns of associations across chronic illnesses.

Cognitive Processes
Analyses of the contribution of mediational processes to adjustment in longitudinal designs found that maternal appraisals of concurrent daily hassles in studies of cystic fibrosis (Thompson, Gustafson et al, 1994a), sickle cell disease (Thompson, Gustafson et al, 1994b), a range of physical disabilities (Wallander, Pitt and Mellins, 1990) and low birth weight infants (Thompson, Oehler et al, 1993) accounted for a significant amount of variance in maternal adjustment. Stress and lower perceived efficacy expectations in relation to illness tasks was also found to be related to maternal
psychological adjustment in a range of physical disabilities (Wallander, Pitt and Mellins, 1990), including cystic fibrosis (Thompson, Gustafson et al, 1992a) and adults with sickle cell disease (Thompson, Gil et al, 1993a). In contrast to these studies, daily hassles did not reach significance in a study of mothers of children with congenital heart defects (Davis et al, 1998) and expectations of health locus of control were not associated with maternal adjustment in studies of children with congenital heart defects (Davis et al, 1998) and cystic fibrosis (Thompson, Gustafson et al, 1992a).

Coping Methods
A series of longitudinal studies studying cystic fibrosis and sickle cell disease indicate that lower levels of palliative coping methods in relation to adaptive coping and lower levels of daily stress are significantly related to stable good adjustment over a period of one year (Thompson et al, 1994a; 1994b, 1994c, 1999). In addition, coping strategies used by parents were associated with children’s use of coping strategies (Gil et al, 1991) and a greater use of palliative coping (self-blaming, avoidance of negative emotions) was found to be significantly predictive of a mother’s adaptation to children with sickle cell disease (Thompson, 1993a) cystic fibrosis (Thompson, 1992a) and congenital heart defects (Davis et al, 1998).

Family Functioning
Family functioning is one of the most frequently studied socio-ecological processes in psychological adjustment in chronic illness and has commonly been conceptualised in terms of Moos and Moos’s (1981 cited in Wallander and Thompson, 1995), dimensions of cohesion, expressiveness, organisation, independence and control (Family Environment Scale). The role of family functioning in child and maternal psychological adjustment has been supported across a number of illnesses (Wallander and Thompson, 1995; Wallander, Varni et al, 1989), although there is conflicting evidence. Family cohesion was found to make a particular contribution to social functioning in a mixed illness sample (Wallander, Varni et al, 1989) and to be a risk factor for poor maternal adjustment in families experiencing non-malignant life-threatening illnesses (Mastroyannopoulou et al, 1997) and child adjustment in paediatric cancer (Varni et al, 1996 cited in Mastroyannopoulou et al, 1997). In
contrast, no significant support for a mediational role of family functioning processes on maternal adjustment was found in mothers of children with congenital heart disease (Davis et al, 1998) and with sickle cell disease (Thompson, 1993a, 1993b). Unfortunately, in several other studies processes of family functioning such as lower family supportiveness and higher family conflict (Thompson et al, 1992), higher family control (Thompson et al, 1993a) and increasing family conflict and decreasing supportiveness (Thompson, Oehler et al, 1993) were indicated as risk factors but failed to reach statistical significance. Methodological weaknesses, discussed later, could be responsible for these findings.

**STABILITY OF CHILD AND MATERNAL PSYCHOLOGICAL ADJUSTMENT OVER TIME**

Although longitudinal studies offer a unique opportunity to assess the stability and change of psychosocial adjustment and mediational processes in adjusting to chronic illness over time, relatively few studies have been conducted. Even so, the generally prevailing view has been that psychological adjustment problems in children (without brain impairment) and mothers tend to decrease over time (eg: Kovacs, et al, 1990b). However, the series of studies examining the transactional stress and coping model indicate a somewhat different pattern. Whilst a significant decrease was observed over time in depression, anxiety and psychological adjustment problems for mothers in the cystic fibrosis group (Thompson et al, 1994b, 1994c, 1999), this was not evident in mothers in the sickle cell disease group (Thompson et al, 1994a, 1994c, 1999). Equally, despite a general decline in children’s self-reported adjustment problems there was relatively little stability in the diagnostic classification of individuals over time, particularly in the children’s self-reports (Thompson et al, 1999). Thus, on an individual basis, considerable variability in children’s and mother’s experiences of chronic illnesses exist over time. This considerable variability could be attributed to the high rates of multiple diagnoses found in individuals and the fact that the self-reported Child’s Assessment Schedule (CAS: Hodges et al, 1982 cited in Thompson, Gustafson et al, 1992b) is not a specific measure for chronic illness.

**EVALUATION OF RESEARCH METHODOLOGY**

The main series of studies researching relationships and mediating processes of child and maternal adjustment were specifically conducted by Thompson and Wallander
and colleagues in order to empirically test their own models. Although it is understandable that each researcher has a vested interest in validating their own conceptual model, a review of the research indicates that several predictions made by the models have not been substantiated or only tentatively supported. It now remains to be seen whether the models will be reformulated in order to improve their predictive validity or the research methodology altered.

Sample
It is interesting to note that even though the general consensus is that condition type does not appear to directly mediate psychological adjustment (eg: Lavigne and Faier-Routman, 1993), differences in mediational processes have been found across different condition types. Consequently, studies that draw samples from a range of chronic illnesses (eg: Wallander, Pitt and Mellins, 1990) without controlling for indirect mediational effects of condition type considerably run the risk of underestimating the importance of differences in experiences across conditions. The wide age ranges of samples are also of concern. For example, six to eleven years (eg: Wallander et al, 1989a, 1989b, 1989c) and seven to seventeen years (eg: Gil et al, 1991; Thompson et al, 1992, 1993, 1994, 1999). Not only are children’s understandings of illnesses likely to vary as a function of their developmental status (eg: Bibace and Walsh, 1980), but also patterns of family functioning (Minuchin et al, 1975 cited in Bradford, 1997). A narrower age range would therefore be more beneficial in controlling for age-related developmental differences.

Representativeness
The series of studies undertaken by both Thompson and Wallander and colleagues primarily limit the representativeness of their samples to the population by drawing upon participants from one clinical centre. Although argued to be representative of the clinic populations in terms demographic factors, the relative healthiness of the children (eg: Thompson et al, 1994c, 1999) indicates that the extent to which the samples represent the general population of children with chronic illnesses is unknown. Furthermore, the relatively high rates of child and maternal psychological adjustment problems also question sample representativeness. By using research volunteers, the researchers do acknowledge the possibility that levels of psychological
distress may have influenced participation and biased the sample (eg: Thompson, Gustafson et al, 1994c). With generally white and middle-classed samples, studies such as Davis et al (1998) demonstrating some cultural diversity are essential for broadening our understanding of adjustment to chronic illnesses. Failure to acknowledge the importance of cultural influences within studies may already have contributed to conflicting support across studies for processes such as family functioning. For example, ways of conceptualising family functioning, family support and the notion of “family” may vary considerably between white, middle-class mothers and African-American mothers.

**Power**

Due to the difficulty of obtaining participants in a relatively low incidence population (Davis, et al, 1998) the vast majority of studies have relatively small sample sizes. In addition, these samples suffer from attrition in longitudinal studies (eg: Thompson et al, 1999). Quantitative statistical analyses is not only prevented by small sample sizes but, if conducted, can lead to the obscuring of significant effects or relationships that may have otherwise occurred in a larger sample, for examples see family functioning. Thus, hampering the ability to determine potential indicators of stable good or poor adjustment over time and misinforming researchers. It is notable that all the studies considered in the literature review have conducted quantitative statistical analyses, but failed to report the power of their analyses.

**Design**

The analyses provided by Thompson et al’s (1994a, 1994b, 1994c, 1999) longitudinal studies have provided valuable insights into the continuing nature of maternal and child adjustment and the contribution of mediational processes one and two years after baseline. However, the longitudinal studies do not actually represent discrete time-sampling but instead continuous assessment, rendering the comparability of the results both within and across illness groups less reliable. For example, the “two-year” follow-up was conducted immediately after the “one-year” follow-up and between sixteen to twenty-five months after baseline in the cystic fibrosis group but a surprisingly long nineteen to forty-one months after baseline in the sickle cell disease group (Thompson et al, 1999). In order to improve the meaningfulness and
comparability of follow-up assessments future studies will need to incorporate considerably shorter assessment periods and more uniform time brackets across illnesses.

**Methods of Measurement**

Self-report measures were employed by all the studies of maternal and child psychological adjustment to chronic illnesses, despite several inherent limitations. Firstly, exclusive reliance on self-report measures overlooks the need for independent verification. Although a mother may perceive her family and child’s functioning in a particular way, it is likely that a father or the children themselves may perceive very different patterns of relationships and strengths. The low congruence between mother-reported child adjustment and child self-reported adjustment in sickle cell disease demonstrates relatively large differences in perspectives (Thompson et al 1993b). This, secondly, also highlights the difficulties of questionnaires to accurately assess the intricacies of processes such as family life and patterns of interactions. Even when considering maternal perceptions in their own right, self-report measures are likely to overestimate diagnosable adjustment disorders and their objectivity essentially makes comparison across individuals difficult (O’Hara, Neunaber and Zekoski, 1984 cited in Thompson, Oehler et al, 1993).

The lack of measures developed specifically for use in chronic illness is a particular problem and has resulted in an over-reliance on measures developed in the mental health field (Bradford, 1997). These measures naturally hold considerably less theoretical relevance to child and maternal adjustment to chronic illnesses and are primarily psychopathology based eg: the Child Behaviour Checklist, (CBCL; Achenbach and Edelbrock, 1983 cited in Wallander et al, 1989a) the Missouri Children’s Behaviour Checklist (MCBC; Sines et al, 1969 cited in Thompson, Merritt et al, 1993) and the Symptom Checklist 90-Revised (Derogatis, 1983 cited in Thompson, Gustafson et al, 1992a). Norms of these are based on psychiatric or healthy populations without physical illnesses and thus pathologise processes in children with chronic illnesses and their mother’s, which may otherwise be adaptive or at least appropriate in their circumstances (Meijer and Oppenheimer, 1995). They also include items, which tap directly into physical health problems thus, artificially
inflating the scores of a child with a chronic illness in comparison to healthy peers (Perrin et al, 1991 cited in Bradford, 1997).

The use of measures such as the CBCL, MCBC and the SCL-90-R in studies of chronic illness have also been heavily criticised for their insensitivity to mild adjustment problems (Perrin et al, 1991). These measurements were principally designed to identify significant emotional and behavioural problems within the mental health field, thus overlooking individuals with problems that are still of concern but have not yet reached the statistical threshold. These measures therefore do not support the "preventative" ethos of health psychology and future research will therefore need to considerably adapt or develop measures that are appropriate and relevant to issues faced by children with chronic illnesses and their families. This should include reducing emphasis on physical symptoms and incorporating items relevant to health problems such as compliance and distress during treatment.

**Relationships Among Variables**

The studies reviewed have mainly conducted correlational analyses on the data collected by self-report measures. The researchers accordingly, appear to have drawn upon the value of the relationships identified by the analyses and withheld from making inferences about causality. The use of hierarchial regression analyses has furthermore strengthened the study of the causal priorities of specific variables over and above other variables (eg: Thompson et al, 1992, 1993, 1994, 1999). However, the use of correlational methods to develop linear relationships should only be considered as one aspect of the emerging multivariate relationships between maternal and child mediational processes and overall adjustment (Wallander, Pitt and Mellins, 1990). In view of the large individual variability in maternal and child adjustment over time, it is important to note that the use of correlational methods to compare group change obscures case-by-case variations and potentially value information about individuals (Chaney et al, 1997). Furthermore, correlations between variables may also have been artificially elevated by the use of self-report measures to reflect both mediational processes and psychological adjustment. Future research will therefore need to increase the focus on prospective longitudinal or time-series studies.
and develop multivariate relationships to improve the understanding of the roles of specific mediational processes and causality.

**Clinical Implications**
The clinical implications of relationships identified between mediational processes and adaptation have been discussed by Thompson and colleagues. For example, enhancing adaptive coping skills in mothers (eg: Davis et al, 1998), self-efficacy in children (eg: Thompson, Gustafson et al, 1992b), decreasing maternal daily stress (eg: Davis et al, 1998), reducing negative thinking in sickle cell disease with cognitive-behaviour therapy (Thompson, Gil et al, 1993b) and generally increasing family supportiveness and decreasing family conflict (Thompson, Gustafson et al, 1994b) have been proposed. The next step is thus, to experimentally evaluate the efficacy of the proposed treatment interventions in order to confirm and validate causality between mediational processes and psychological adjustment.

**Future Directions**
Common to the literature in this field and despite efforts to delineate all variables involved in child and maternal adjustment, there appears to be a large amount of unaccounted for variance in both. For example, variance accounted for in maternal adjustment ranged from thirty percent (Thompson, Oehler et al, 1993) to a maximum of fifty-five percent (Thompson, Gil et al, 1993a). Maximum variance accounted for in maternal reports of behaviour problems was forty-nine percent (Thompson, Gil et al, 1993b) and child self-reported adjustment was seventy-five percent (Thompson, Gustafson et al, 1994c). Considerable proportions of variance therefore remain unexplained, suggesting that methodological problems may be hampering research and that additional child, maternal and environmental processes may need to be identified and incorporated into models. For example, family patterns of interaction, the nature of ‘doctor-patient’ communication, the health care environment and health beliefs and theories of illness (Bradford, 1997). Methods of measurements need to be developed for use in chronic illnesses, to include more family members and to be expanded to involve measurements such as, direct observations, structured interviews and analyses of records (Wallander and Thompson, 1995). The delineation of mediational processes involving paternal adjustment, in particular, is required in order
to develop the concept of psychosocial adjustment by placing the experiences of chronic illnesses directly within the family system, rather than just within the mother-child relationship.

It is evident that the studies on samples with mixed illness groups have considerably failed to support several predictions (e.g., Wallander et al., 1989c). In view of the general variability in outcomes and mediating processes across studies (Lavigne and Faier-Routman, 1993; Wallander and Thompson, 1995), there may be significant individual responses as well as illness specific responses that studies investigating mixed samples obscure. Efforts in general must therefore be made to enrol illness-specific and larger samples, across multiple sites and to target under-researched populations such as ethnic minorities and economically less advantaged in order to enhance the analyses of the results. Furthermore, the ability of individual processes to act as risk or resistance factors and thereby mediates whether other processes are associated with adjustment need to be delineated. For example, the role of maternal daily stress in child-reported adjustment appeared to vary as a function of the presence of absence of certain coping skills (Thompson, Merritt et al., 1993). Researchers such as Thompson and colleagues do indeed acknowledge that the transactional stress and coping model is only the beginning point in delineating processes that mediate child and maternal psychological adjustment in chronic illnesses.

Finally, the progression of children through developmental stages needs to become a more salient feature in the conceptualisation of children's adjustment. More complex models need to be proposed that incorporate child development and move research forward from the evaluation of simple bivariate relationships towards more multivariate relationships; including interpersonal correlates of adjustment such as temperament, and broader family and social contexts (Wallander and Thompson, 1995). More specifically, theories of illness and health beliefs need to be incorporated (Bradford, 1997) in order to place the study of psychological adjustment to chronic illnesses more securely within the field of physical health rather than mental health.
CONCLUSION

This selective review of the literature indicates that a number of variables have demonstrated relationships with child and maternal adjustment including coping methods, cognitive processes and family functioning (LaVigne and Faier-Routman, 1993; Wallander and Thompson, 1996). Despite the preliminary nature of the cross-sectional and longitudinal studies, findings do appear to converge in three areas. Firstly, that child and maternal psychosocial mediational processes are better predictors of psychological adjustment than illness and demographic factors, secondly that these processes include the socio-ecological factors of family support and distress, and thirdly that there are some differences in mediational processes across illnesses types (eg: LaVigne and Faier-Routman, 1993, Thompson, Gil et al, 1993a; Wallander et al, 1990, 1989). However, when considering each type of variable and classes of variables, it is notable that the total number of studies devoted to each is considerably limited and that many other possible variables have not yet received much attention; for instance, child temperament, parental styles and pre-existing symptomatology (Lewis et al, 1988 cited in LaVigne and Faier-Routman, 1993). The former may considerably account for the varied research findings and the latter for the considerable amount of unaccounted for variance in models of child and maternal adjustment to chronic illness. Furthermore, the concept of psychosocial adjustment is, in general, currently limited to self-report measures that are unable to reflect the systemic nature of interaction-connections between people, environments and different systems (Bradford, 1997).

There is no doubt that psychological adjustment of children with chronic illnesses and their families is a very complex and multi-level concept, which is continually influenced by the child’s development, the family life-cycle and possibly the disease itself (Tansella, 1995). Despite the valuable contribution of the preliminary findings, the literature is unfortunately dominated by dependence on uni-dimensional self-report measures from the mental health field and a failure to develop ‘ecologically valid’ methods of measurement. This domination is perhaps indicative of a broader conceptualisation of psychosocial adjustment as tantamount to the absence of mental health difficulties. If this is indeed the case, then considerable effort must first be directed towards the development of the concept of psychosocial adjustment to
chronic illness, before the development or replacement of existing methods of measurement (Bradford, 1997). Simultaneously, this development also needs to reflect the identified variability in individual psychosocial adjustment over time through the expansion of research objectives to include the identification of processes associated with transitions into or out of good adjustment (Thompson et al, 1999). The identification of such processes is not only essential in indicating possible targets for clinical intervention but also, through the empirical evaluation of the efficacy of these interventions, essential for driving future research, further refining proposed models of adjustment and verifying the proposed direction of effects.
REFERENCES


Research Supervisor: Dr. James Murray

Field Supervisor: Mary John

TITLE

"THE PSYCHOLOGICAL ADJUSTMENT OF MOTHERS AND CHILDREN TO ENCOPRESIS."

July 2002

Year 3

17,043 WORDS

DEPARTMENT OF PSYCHOLOGY, UNIVERSITY OF SURREY
This study aimed to investigate the relative utility of components of the transactional Stress and Coping model (Thompson et al, 1992, 1999) in determining the psychological adjustment of mothers to enencopretic children. The stress and coping model predicts that cognitive representations will account for significant amounts of variance in maternal adjustment, over and above that of illness and demographic parameters. This model was developed for the study of chronic illness and indicates a relationship between maternal and child adjustment. Within this framework, a cross-sectional survey design was utilised with 52 mothers to investigate maternal illness representations and child adjustment, and the impact of these variables on maternal psychological adjustment. Previously developed self-report measures of illness representations and maternal adjustment, and proxy-reports of child adjustment were used. The data obtained indicated that illness representations and child adjustment each explained significant proportions of variance in maternal adjustment, over and above that accounted for by illness and demographic parameters. Furthermore, child adjustment was found to have a more active role in mediating maternal adjustment than previously conceptualised by the stress and coping model. Contrary to the hypotheses of the Stress and Coping model, socio-economic status was found to mediate the amount of distress produced by the presence of psychological symptoms and significant differences were not observed in maternal adjustment after encopretic symptoms had ceased. The possible insight this offers into maternal adjustment to a child’s encopresis, the implications for clinical interventions and future research directions are considered.
I would like to thank all those who have helped and supported me throughout this project.

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# CONTENTS

<table>
<thead>
<tr>
<th>CHAPTER 1: INTRODUCTION</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>..................................................</td>
<td>201</td>
</tr>
<tr>
<td>1.1 Encopresis Epidemiology</td>
<td>202</td>
</tr>
<tr>
<td>1.1.1 Aetiology and Clinical Features of Encopresis</td>
<td>203</td>
</tr>
<tr>
<td>1.1.2 Treatment and Outcome</td>
<td>204</td>
</tr>
<tr>
<td>1.2 Psychological Adjustment</td>
<td>205</td>
</tr>
<tr>
<td>1.3 Parental Adjustment and it's Importance</td>
<td>206</td>
</tr>
<tr>
<td>1.3.1 Maternal-Child Adjustment</td>
<td>208</td>
</tr>
<tr>
<td>1.4 Child Psychological Adjustment</td>
<td>209</td>
</tr>
<tr>
<td>Behavioural and Familial Characteristics</td>
<td>210</td>
</tr>
<tr>
<td>Depression, Anxiety and Aggression</td>
<td>211</td>
</tr>
<tr>
<td>Self-Esteem</td>
<td>211</td>
</tr>
<tr>
<td>The Importance of Child Adjustment</td>
<td>212</td>
</tr>
<tr>
<td>1.5 Illness Perceptions</td>
<td>213</td>
</tr>
<tr>
<td>1.6 Models and Maternal Adjustment</td>
<td>216</td>
</tr>
<tr>
<td>Figure 1: The Stress and Coping Model</td>
<td>217</td>
</tr>
<tr>
<td>Cognitive processes in the Stress and Coping Model</td>
<td>219</td>
</tr>
<tr>
<td>1.7 Aims of this Study</td>
<td>220</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CHAPTER 2: METHOD</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.0 Procedure</td>
<td>223</td>
</tr>
<tr>
<td>2.1 Participants</td>
<td>224</td>
</tr>
<tr>
<td>2.2 Sample Description</td>
<td>224</td>
</tr>
<tr>
<td>2.3 Measures</td>
<td>225</td>
</tr>
<tr>
<td>2.4 Statistical Analysis</td>
<td>227</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>CHAPTER 3: RESULTS</th>
<th>PAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>3.1 Hypothesis 1</td>
<td>228</td>
</tr>
<tr>
<td>3.2 Hypothesis 2</td>
<td>228</td>
</tr>
<tr>
<td>3.3 Hypothesis 3</td>
<td>229</td>
</tr>
</tbody>
</table>
CHAPTER 3: RESULTS (cont.)

3.4 Hypothesis 4 ................................................................. 231
3.5.1 Hypothesis 5 ............................................................... 233
3.5.2 Hypothesis 6 ............................................................... 233
3.6 Hypothesis 7 ................................................................. 235
3.7 Causal Attributions .......................................................... 239

CHAPTER 4: DISCUSSION

4.1 Levels of Maternal and Child Psychological Adjustment ................. 241
4.2 Maternal Psychological Adjustment and Illness and Demographic Variables ............................................................... 242
4.3 Maternal and Child Psychological Adjustment .................................. 245
4.4 Predicting Psychological Adjustment from Illness Representations and Perceived Child Adjustment ............................................................... 247
4.5 Perceived Causes of Encopresis ...................................................... 249
4.6 Limitations and Future Research Directions ..................................... 250
4.7 Conclusions ........................................................................... 252

REFERENCES ............................................................................ 253

APPENDICES .............................................................................. 263

Appendix 1: Ethics Approval .......................................................... 264
Appendix 2: GP Letter .................................................................... 267
Appendix 3: Initial Letter ............................................................... 268
Appendix 4: Information Sheet .......................................................... 270
Appendix 5: Consent Form ............................................................... 271
Appendix 6: Second Letter ............................................................... 272
Appendix 7: Reminder Letter ............................................................ 273
Appendix 8: Questionnaire Booklet ..................................................... 274
Appendix 9: Brief Symptom Inventory .................................................. 282
Appendix 10: Transformed Data .......................................................... 284
Appendix 11: Summary Statistics for Illness and Demographic Variables... 285
1. INTRODUCTION

Adjustment to encopresis in children and their families appears to be poorly understood, considerably under-researched and generally disputed in the literature. By the very nature of the problem, a child with encopresis presents as one of the more complex conditions confronting health care professionals (Buchanan, 1992). Despite consistent management, remission rates and relapse are high and nearly twenty percent of cases continue to have soiling 'accidents' (Levine and Bakow, 1976; Young, Brennen, Baker and Baker, 1995). In the scant literature focusing on treatment outcome, 'adjustment' has traditionally been defined in terms of the presence or absence of behavioural and social problems. In the case of encopresis it would thus be defined as the absence of 'soiling accidents'. This narrow definition however, clearly neglects the broader emotional, psychological and social impact of the condition on both the child and their family.

Implicit in research into encopresis is the assumption that co-morbid psychological problems observed during treatment will spontaneously resolve following successful treatment (eg: Levine et al, 1980), (Buchanan, 1990 cited in Buchanan, 1992). This tenet however, has not gone unchallenged (Buchanan, 1990 cited in Buchanan, 1992) and evidence has been emerging for a sub-group of children with more serious behavioural and social difficulties (Abrahamian and Lloyd-Still, 1984; Friman et al, 1988; Gabel et al 1988; Loening-Baucke et al 1987). Nevertheless, encopresis is still rarely discussed, frequently misunderstood and if not resolved quickly is believed to have a detrimental effect on the child and on parent-child relationships (Young, Brennen, Baker and Baker, 1995).

Developments within the broader field of children with chronic health conditions have begun to focus on the mother-child relationship. Research preference is given to mothers because it is believed that they are still more likely to be the primary caretaker and take the child to medical appointments (Havermans, and Eiser, 1991 cited in Mastroyannopoulou et al, 1997). It has been postulated that parental
perceptions of the illness (Daniels, Moos, Billings and Miller, 1987; Whelan and Kirkby, 2000) and maternal psychological adjustment (Compas et al, 1989; Thompson et al, 1992b, 1993b, 1994b; Whelan and Kirkby, 2000) are influential factors in a child’s psychological adjustment, and vice versa (Lavigne and Faier-Routman, 1993; Thompson et al, 1994b). Understanding the factors that contribute to a mother’s adjustment may therefore assist in the identification of those at risk of poorer adjustment. Prevention and intervention techniques targeted at improving maternal adjustment could then be developed, which may also indirectly influence the child’s adjustment. This could be extremely important in a condition such as encopresis in which parental distress, anger, guilt and shame towards the child is commonly encountered (Buchanan, 1992; Levine et al, 1980; 1982).

The present study aimed to explore the psychological adjustment of mothers with an encopretic child, and the interaction of their cognitive perceptions of their child’s illness and adjustment. A brief overview of encopresis - its epidemiology, aetiology, clinical features and treatment – is followed by a discussion of the concept of psychological adjustment and a review of evidence which has identified factors that may mediate maternal and child psychological adjustment to encopresis. In addition, research relating to illness representations will be evaluated, with a description of the principal components of illness representations and their influence on psychological adjustment. Finally, Thompson et al’s (1992, 1993, 1994, 1999) stress and coping model will be introduced, including an outline of the model and a brief summary of research findings. In accordance with the stress and coping model, the hypotheses to be addressed in this study will be presented and aimed towards determining the role of illness representations and perceived child adjustment in predicting maternal psychological adjustment to the encopresis.

1.1 **Encopresis Epidemiology**

Encopresis is a generically used term to describe any kind of voluntary or involuntary passage of faeces into inappropriate places (eg: clothing or floor) (DSM-IV; American Psychiatric Association, 1994). According to the DSM-IV encopresis is diagnosed after the age of four, with symptoms occurring at least once a month, with a three
month history, and in the absence of any physical disorder (eg: Hirschsprung's Disease, spina bifida) or developmental delay (eg: autism). Prevalence estimates range from 1.5% to 7.5% (Bellman, 1966; McGrath, Mellon and Murphy, 2000). These estimates however, are not thought to be reliable because fluctuations in incidence vary according to the definitions employed and the age ranges sampled. The prevalence of encopresis is furthermore believed to be underreported because parents fail to seek help and frequently attribute the condition to the child's laziness or blame themselves (Levine, 1982). Encopresis appears to decrease slowly with age to almost nothing at sixteen (Bellman, 1966). A higher frequency of encopresis in boys, compared to girls, has consistently been supported in the literature ranging from a ratio of 3:1 to 6:1 (Anthony, 1957 cited in Quay and Werry, 1986; Bellman, 1966; Levine, 1975). In relation to the relative importance of demographic parameters, there is no evidence that encopresis is related to family size, ordinal position of the child in the family or parental age (Levine, 1982). However, the evidence related to socio-economic status are mixed, with some researchers finding little or no relationship with social class (Buchanan, 1992; Levine, 1982) and others finding that families from lower socio-economic backgrounds are more likely to be affected (Lask and Fosson, 1989; Taitz et al, 1986 cited in Buchanan, 1992).

1.1.1 Aetiology and Clinical Features of Encopresis
The primary cause for encopresis remains obscure, even though various etiological theories have been proposed (Quay and Werry, 1986). Biological models focus on impairments of sensory feedback from the bowel and motor function, which lead to an inability to control the sphincter muscle. This latter is believed to be responsible for overflow incontinence ('accidents') - the passage of soft faeces around the impacted constipation (eg: Berg and Jones, 1964; Levine, 1982). These biological abnormalities are hypothesized to be associated with genetic and constitutional factors, or developmental delay (Buchanan, 1992). Dietary factors such as insufficient roughage, a bland diet, insufficient fluid intake and lactose intolerance have also been suggested as predisposing and maintenance factors in encopresis (Christophersen and Rapoff, 1992). The DSM-IV subdivides encopresis into constipation with and without overflow incontinence. Research studies however, generally do use these subdivisions
as many cases commonly fluctuate over time (Levine, 1981). Encopresis may also occur with or without enuresis (urinary incontinence), as an uncomplicated one-symptom presentation or as part of a wider set of adjustment problems related to a chaotic, stressful or abusive psychosocial environment (Carr, 1999).

Encopresis is more commonly classified according to primary and secondary types. Primary encopresis indicates that satisfactory bowel control has never been achieved, whilst secondary encopresis indicates that bowel control was achieved but has regressed (Carr, 1999). Family theorists have suggested that primary encopresis may arise through a chaotic family environment, whilst secondary encopresis may arise from stressful life events and family lifecycle transitions (Loening-Baucke et al, 1987; White, 1984 cited in Carr, 1999). Behavioural theories have emphasised the lack of positive reinforcement for successful toileting and the association of aversive events such as pain with toileting in both the development and maintenance of encopresis (eg: Quay and Werry, 1986). Finally, psychodynamic theorists have more traditionally hypothesised the influence of underlying psychopathological problems (Buchanan, 1992) and unconscious conflicts stemming from negative parent-child relationship and coercive toilet training (eg: Anthony, 1957 cited in Quay and Werry, 1986).

1.1.2 Treatment and Outcome
Although considerable developmental importance has been placed on the task of bowel control, controlled treatment trials of medical and behavioural interventions appear to be limited in the case of encopresis (Buchanan, 1992; McGrath, Mellon and Murphy, 2000). Evaluating the effectiveness of the various treatments is therefore not easy. Small sample case reports and anecdotal, rather than empirical, studies are more common in the literature. This makes it difficult to generalise findings and to control for the affects of type and severity of encopresis, associated psychopathology, learning difficulties and poor compliance. It is conceivable that the cultural taboo surrounding encopresis and its relative lack of importance compared to health priorities of heart disease, cancer etc. have contributed to the scarcity of this literature.

A recent review of behavioural and medical treatments for encopresis failed to identify any well-established interventions but did highlight several medical,
biofeedback and combined medical-behavioural treatments that met criteria for
efficacy (McGrath, Mellon and Murphy, 2000). Anecdotal success of the effect of
psychotherapy alone has been reported as fewer than 50% in several case studies
(Doleys, 1978). However, many cases were referred to psychology suggesting that
they were probably biased towards increased severity and treatment resistance.
Despite a general lack of research into joint paediatric and psychological intervention
programmes, preliminary findings have indicated successful outcomes in 77% to 87%
of children (Buchanan, 1992; Stark et al, 1990; Stark et al, 1997). ‘Successful
outcomes’ were defined in terms of a reduction or cessation of soiling and increased
parental management of encopresis. Interestingly, a single study has demonstrated
that successful outcomes do not lead to symptom substitution (Levine, Mazonson and
Bakow, 1980). This finding potentially undermines etiological theories based on
encopresis as a symptom of underlying conflict and a means of conveying distress.

Recommended components of combined psychological and pediatric programmes
include psycho-education about the pathophysiology of encopresis, clearing the faecal
mass and bowel retraining (Carr, 1999). The latter includes the use of laxatives in
combination with regular toileting programmes, relaxation to manage anxiety, reward
charts, a high fibre diet and increased exercise. Nevertheless, almost 20% of cases
continue to have accidents despite consistent management and little is known about
why this occurs (Levine and Bakow, 1976; Young, Brennen, Baker and Baker, 1995).

1.2 Psychological Adjustment

‘Psychological Adjustment’ is a composite construct and difficult to define (Bradford,
1997). Consequently, there is little consensus in the literature regarding what
constitutes adjustment. In fact, the vast majority of studies actually appear to fail to
provide a definition of precisely what they set out to measure. Within the literature,
psychological adjustment has variably been used to indicate, for example; a lack of
psychopathology, a lack of sickness behaviour, the extent to which an individual
functions ‘normally’ in everyday life and the extent to which an individual arrives at a
realistic acceptance of a condition and the limitations it imposes (Bradford, 1997).
Such definitions that rely on the absence of certain behaviours are however, generally
considered inadequate.
No clear attempts have been made to define psychological adjustment in relation to encopresis although it would appear that it has been implicitly assumed to relate to the presence or absence of behavioural, social and psychological problems. In keeping with previous research and the stress and coping model investigated in this study (discussed later), psychological adjustment will therefore be taken to be equivalent to the absence of psychopathology on subjective measures of emotional, social and behavioural well-being. However, when considering the nature of adjustment in a socially isolating condition such as encopresis it should be borne in mind that the emotional, social and behavioural changes needed for good adjustment may themselves have an adverse impact on adjustment. That is, significant changes in lifestyle caused by adherence to dietary changes, regular medication and toileting routines may have further detrimental impact on the child (Buchanan, 1992). Furthermore, cognitive changes to causal attributions may leave a parent feeling anxious and guilty, particularly if they blamed the child for being lazy, (Levine, 1982). The uncertain nature of encopresis, its relative resistance to treatment and a mixed approach to treatment also complicates the process of adjustment to encopresis (Buchanan, 1992). The current research available on parental and child psychological adjustment to encopresis will now be reviewed.

1.3 Parental Adjustment and Its Importance

Research into parental adjustment to child health conditions has indicated that approximately one third of parents met the criteria for poor adjustment (Chaney et al, 1997; Sawyer et al, 1998; Thompson et al, 1992a; Thompson et al, 1993; Thompson et al, 1993a). Most interventions for encopresis require substantial time and effort by the parents. Treatment success and long-term outcome is therefore hypothesised to be influenced by the parents' perceptions of the child's condition, adjustment, coping and management style (eg: Bernard-Bonnin, Haley, Belanger and Nadeau, 1993). However, research specifically addressing these hypotheses with encopresis appears to be scarce. Predicting who will fail and who will succeed in treatment on the basis of parental adjustment thus remains a difficult task. Only one study has suggested the possibility of an association between maternal adjustment and outcome. This study indicated that poorer treatment outcome was associated with a combination of having a ‘very tense’ mother and a present or past history of constipation (Buchanan, 1990).
cited in Buchanan, 1992). Maternal tension was specifically found to be related to the frequency of the child’s soiling. Having a ‘very tense’ mother without a history of constipation also appeared to affect outcome, but did not reach significance in this study (Buchanan, 1990). A relatively small sample size may have influenced this finding.

Drawing on the literature from the broader field of chronic health problems in children, it could be predicted that at least some parents would be at risk of poor adjustment. For example, there is evidence supporting the fact that attending outpatients or the prospect of a child undergoing medical procedures can be highly stressful for some parents (eg: Whelan and Kirkby, 2000). Furthermore, the personal impact of the child’s diagnosis and consequent treatment has been found to precipitate symptoms of post-traumatic stress in parents of children with cancer, even up to 2 years after treatment (eg: Kazak and Barakat, 1997). Although encopresis is not life threatening, this finding suggests that the distress of some parents may not be alleviated through medical treatment alone.

Only a few studies have specifically focused on associations between parental reaction to, and involvement with, encopresis and treatment outcome (Gabel, Chandler and Shindledecker, 1988; Landman, Levine and Rappaport, 1983; McGrath, Dunn-Geier, Cunningham et al, 1985 cited in Stark et al, 1990; Stark et al, 1990). To date, no significant differences have been found in the parents’ use of appropriate behavioural strategies, consistency and coping style when comparing children who responded to treatment versus those who did not. Surprisingly, poor motivation in parents was not found to be associated with treatment failure (no change) although it may have influenced the length of treatment (Buchanan, 1990 cited in Buchanan, 1992). This may indicate the isolating nature of encopresis on the child, although a small sample size is likely to have contributed to this finding. A parent’s active undermining of the child’s efforts was however, found to be strongly associated with limited or no treatment success (Buchanan, 1990 cited in Buchanan, 1992). This suggests that family dynamics may be responsible for the maintenance of encopresis in some children.
A study into parents’ perceived causes of encopresis (Bernard-Bonnin et al, 1993) appeared to provide a little insight into predicting who may succeed or fail in treatment although the relatively small sample size limits generalisation. The most important causes by the parents were considered to be intestinal dysfunction and painful defecation and the most helpful interventions to be dietary changes and a behavioural programme of regular toileting. However, despite the establishment of a clear understanding of the pathophysiology of encopresis through education, almost eleven percent of parents still thought that their child soiled on purpose. This negative belief expressed in one or both parents was more likely to lead to treatment failure (Bernard-Bonnin et al, 1993). Given that more than half of the parents in the treatment success group initially expressed the same negative belief, the ability to change this view either independently or in response to the treatment was considered as the most significant factor.

The apparent lack of attention to maternal adjustment to encopresis in the literature presents a valuable opportunity to advance the knowledge about encopresis. Toilet training has been identified as one of the largest parental concerns about preschool children and is known to lead to unrealistic expectations in some parents and pressure from schools (Christophersen and Rapoff, 1992). Consequently, unsuccessful toileting (encopresis) has been reported to lead to considerable frustration, anger, resentment, lifestyle constraints and conflict within the family, as well as attribution of the condition to the child’s laziness, poor hygiene, aggression and ‘attention-seeking’ (Levine, 1981, 1982; Buchanan, 1992). The potential negative impact of this condition and its relative resistance to treatment warrants further investigation into the growing area of associations between maternal and child adjustment to chronic health conditions.

1.3.1 Maternal-Child Adjustment
Research into the relationship between maternal and child adjustment to encopresis does not appear to have been conducted. Therefore, research from the wider field of chronic health problems will be drawn upon. It is believed that the emotional state of the parents can influence that of a child’s (Whelan and Kirkby, 2000). Empirical studies have related key determinants of a child’s adjustment (eg: anxiety, distress) to
parental perceptions of the condition (Daniels, Moos, Billings and Miller, 1987; Whelan and Kirkby, 2000), parental emotional state (Melnyk, 1995) and parental ability to cope with the psychological stress caused by diagnosis (Chang, 1991 cited in Larson, Wittrock and Sandgren, 1994).

More specifically, child adjustment to a variety of chronic health conditions, such as sickle cell disease, cystic fibrosis and juvenile rheumatic disease, has been related to maternal adjustment (Lavigne and Faier-Routman, 1993; Thompson et al, 1994b), maternal depression (Daniels, Moos, Billings and Miller, 1987) and maternal anxiety (Thompson et al, 1992b; Thompson et al, 1993b). Very few, if any, studies have focused on a relationship between paternal and child adjustment or compared maternal, paternal and child adjustment. Findings from research into maternal adjustment cannot be generalised to fathers as some gender differences in the degree of distress have been identified. For example, mothers appear to report higher levels of depression, anxiety and obsessive-compulsiveness than fathers (eg: Magni et al, 1983, 1986b, 1988 cited in Larson, Wittrock and Sandgren, 1994).

The proposed links between maternal and child adjustment presents an appealing prospect because through the identification of mothers at risk of poorer adjustment interventions could be developed to improve their adjustment and indirectly contribute to the child’s improvement (Whelan and Kirkby, 2000).

1.4 Child Psychological Adjustment

Compared to other child health problems, the understanding of the psychological impact and the adjustment of encopretic children is very much in its infancy. Although historically it has been suggested that psychological problems such as family and personal distress cause encopresis (eg: Levine, 1975), treatment outcomes tend to be characterised according to objective criteria such as the absence of soiling. Whilst clearly the aim of treatment it neglects the social, emotional and psychological impact of the condition on both the child and their family. It is also often implicitly assumed that successful treatment of encopresis will lead to spontaneous improvements in other areas. Whilst support for spontaneous improvement of behavioural problems has been found (Levine et al, 1980), it is not consistent. One
study found that thirty-three percent of children still had some form of behavioural problem at the end of standard paediatric treatment (Buchanan, 1990 cited in Buchanan, 1992). However, when the alleviation of behavioural difficulties was specifically targeted, only three-percent had behaviour problems at the end of treatment (Buchanan, 1990 cited in Buchanan, 1992). High relapse and remission rates (Levine and Bakow, 1976; Young, Brennen, Baker and Baker, 1995) have perhaps contributed to the inconsistent findings concerning psychological characteristics of encopretic children (Bellman, 1966; Landman, Rappaport, Fenton et al, 1986; Friman, Mathews, Finney et al, 1988; Levine, Mazonson and Bakow, 1980).

**Behavioural and Familial Characteristics**

Several studies have supported the hypothesis that children with encopresis have significantly more emotional, behavioural and social problems, although not necessarily to the degree found in children referred to child mental health services (Friman et al, 1988; Gabel, Hegedus, Wald et al, 1986; Gabel et al, 1988; Owens-Stively, 1987). Anecdotal and observational evidence has indicated that children with encopresis have less adequately functioning family systems compared to a non-clinical contrast group (Young, Brennen, Baker and Baker, 1995) and more punitive family backgrounds (Bellman, 1966). However, some of the researchers have argued that the incidence is not high enough to suggest a causal relationship between the two, to differentiate them from a normative sample, or to interfere with treatment outcome (Friman, et al, 1988; Gabel, Hegedus, Wald et al, 1986; Loening-Baucke et al, 1987). Furthermore, a study comparing differences in psychological functioning between children with encopresis and their siblings also failed to find significant differences (Ling, Cox, Sutphen et al, 1996). However, the findings of the latter study appear ambiguous because it is unclear whether psychological difficulties would be unique to the child with encopresis per se, or to the family as a whole.

The lack of consensus could, at least partially, be explained by a range of methodological weaknesses of the studies. The majority of studies fail to systematically classify the type of encopresis or bowel problem and thus generally mix several disorders into the same study. The majority also rely on small, un-randomised samples and fail to indicate the power of their statistical analysis. Control
or comparison groups are frequently not matched, not random themselves, not clinically referred or not used at all. Despite these limitations, there does however, appear to be some consensus in the literature regarding the presence of a sub-group of children with encopresis, between fifteen and twenty percent, with more serious behavioural and social difficulties (Abrahamian and Lloyd-Still, 1984; Frieman et al, 1988; Gabel et al 1988; Loening-Baucke et al 1987). These problems are believed to be secondary to the encopresis, rather than casually related and some evidence has been found for their resolution following successful treatment of the encopresis (Bellman, 1966; Fritz and Armbrust, 1982). This brings into question the etiological role of emotional, behavioural and family problems.

**Depression, Anxiety and Aggression**

Limited data are available pertaining to general levels of depression, anxiety, aggression and self-esteem amongst children with encopresis, compared to normative samples. Assessment measures have heavily relied on parent rated-questionnaires and anecdotal evidence rather than self-report. Validity is thus reduced and may contribute to the lack of consensus in the literature (Bellman, 1966; Landman, Rappaport, Fenton et al, 1986; Levine, Mazonson and Bakow, 1980). A general tendency to become withdrawn depressed, anxious and aggressive has been observed in encopretic children (Levine, 1981; Levine, Mazonson and Bakow, 1980). Attempts have been made to study gender differences, but the findings are inconsistent. In one study boys were described as more anxiety prone, to lack self-assertion, to have low tolerance for demands and difficulties handling aggression when compared to a normative sample (Bellman, 1966). Yet, in a later study girls rather than boys, were found to be characterised as socially withdrawn, delinquent and aggressive (Loening-Baucke et al, 1987). The findings and generalisations from both studies are limited, by relatively small sample sizes and a lack of randomisation.

**Self-Esteem**

Two studies have specifically focused on self-esteem in children with encopresis (Landman, Rappaport, Fenton and Levine, 1986; Owens-Stively, 1987). Although using different measures, both studies utilised children’s self-report questionnaires and found similar results. Children with encopresis exhibited significantly lower self-
esteem when compared to a normative control group (Owens-Stively, 1987) and to a comparison group with other "low severity high prevalence" disorders, such as recurrent abdominal pain, enuresis and chronic headaches (Landman, Rappaport, Fenton and Levine, 1986). Lower self-worth was associated with a diminished sense of self-efficacy and a greater desire to change and be different (Landman et al, 1986). Furthermore, a study of parents found that parents perceived their child's reduced self-esteem as one of the most important consequences of encopresis (Bernard-Bonnin et al, 1993; Gabel et al, 1986). Although lower self-esteem was found to improve after successful treatment and not to affect treatment compliance (Owens-Stively, 1987), the results of this study should be interpreted with extreme caution as the sample size was extremely small and all children were rated as successful in treatment. Thus, it remains unclear whether negative feelings about the self are causally related or secondary to the encopresis.

The Importance of Child Adjustment
Attempts to identify children who are at risk of failing treatment have generally focused on the child's history or favoured physiological over behavioural factors (Landman et al, 1983; Levine and Bakow, 1976; Loening-Baucke, Cruikshank and Savage, 1987). No differences between children who succeeded or failed at treatment have been found on the basis of the child's age, school functioning, socio-economic status, infant feeding and bowel problems, toilet phobic behaviour, somatic complaints, behavioural problems or parental attribution of aetiology at their initial presentation. Children, who failed however, were more likely to have accidents at school indicating difficulties at generalising or maintaining treatment outcome in the classroom (Levine and Bakow, 1976). Attempts to relate child adjustment to treatment outcome have yielded few significant findings. So far, the ability to overcome a child's resistance to treatment and motivate the child has been found to be the best predictor of positive outcome (Buchanan, 1992; Kaplan and Busner, 1993 cited in Carr, 1999). Poor prognosis has also been found in cases characterised by highly coercive or intrusive parent-child interaction (Kelly, 1996 cited in Carr, 1999). This however, may equally relate to the child's characteristics or the parents' perceptions about the child's condition.
1.5 ILLNESS PERCEPTIONS
Throughout the literature many different terms have been used for cognitions about illness: illness perceptions, cognitive models or “schemata”, implicit models or beliefs, common-sense representations/lay cognitive models, illness concept and illness representations (Scharloo et al, 1998). Illness models tend to view illness-related adjustment as the result of an ongoing process in which an individual integrates information about their illness into existing cognitive frameworks (e.g: Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984; Papadopoulos et al, 2001). Illness representations (Weinman et al, 1996; Weinman, Petrie et al, 2000) are thought to derive from and change in accordance with the individual’s personal characteristics, experiences of symptoms, information from the medical system, illness progression, response to treatment and from the broader culture. If the illness information is incompatible with what the individual already believes, it is often ‘tailored to fit’ leading to distorted interpretations of the illness (Papadopoulos et al, 2001). Consequently, the nature and psychological impact of the illness on an individual develops out of the meaning they place on their illness.

Despite the range of terminologies, methodologies and different chronic conditions the following dimensions for the representations of illness have consistently been supported; identity, timeline (acute/chronic and cyclical), personal and treatment control, consequences, illness coherence, emotional representations and cause. These have been used in the most recent studies of illness perceptions in chronic health conditions (Weinman et al, 1996; Weinman, 2001).

Illness identity refers to the individuals’ beliefs about the diagnosis or illness label and their knowledge of the symptoms associated with it. A strong illness identity has been associated with perceptions of the illness lasting longer and having more serious consequences (Weinman et al, 1996) and worse outcomes on measures of psychological and social functioning (Scharloo et al, 1998). Doubt about diagnostic label has also been associated with adjustment difficulties (Kemp, Morley and Anderson, 1999). Agreement on the identity scale between patients and significant others has been found to vary considerably (Weinman et al, 1996).
Individuals' expectations about the duration of the illness are divided into the dimensions of *acute/chronic timeline* and *cyclical timeline*. Individuals who perceive their illness as longer lasting are less likely to perceive their illness as controllable or curable, more likely to believe in serious consequences and a chronic time-line, and are less likely to comply with treatment (Hampson et al, 1994 cited in Heijmans and de Ridder, 1998; Moss-Morris, Petrie and Weinman, 1996; Weinman et al, 1996). Subsequently, they score worse on outcome measures of psychological adjustment and social functioning (Scharloo et al, 1998; Weinman et al, 1996). A *cyclical timeline* refers to an individuals' expectations about the characteristic course of the illness. Beliefs that the illness will be intermittent or discontinuous appear to be associated with more positive outcomes (Hampson, Glasgow and Zeiss, 1994 cited in Scharloo et al, 1998; Petrie, Wienman, Sharpe and Buckley, 1996 cited in Scharloo et al, 1998).

The extent to which illness is believed to be controllable by the individual is referred to as *personal control* (Turk et al, 1986 cited in Heijmans and Ridder, 1998). High scores on perceptions of internal personal control have been associated with a favourable course of illness (eg: Schussler, 1992 cited in Scharloo et al, 1998). Personal responsibility has been found to correlate positively with manageability (Heijmans and de Ridder, 1998). However, for chronic fatigue clients, personal responsibility did not show a significant relationship with adjustment (Heijmans and de Ridder, 1998). *Treatment control* refers to the extent to which the illness is believed to be controlled by the treatment. Beliefs in controllability/cure have been significantly related with better functioning (Scharloo et al, 1998). Furthermore, people who hold strong beliefs about the efficacy of medical control have fewer thoughts about doing something extra to control their illness (Heijmans and de Ridder, 1998).

The dimension of *consequences* reflects the individual’s beliefs about illness severity and the likely impact on physical, psychosocial and economic functioning. Beliefs in more serious consequences have been associated with worse outcome on disease-specific measures of functioning, general role and social functioning (Scharloo et al, 1998). The dimension of *illness coherence* is an indicator of how helpful the
individuals’ model of illness is to the individual and the extent to which they find the illness/symptoms puzzling. This illness perception arose from a recent study with Rheumatoid Arthritis clients (Weinman, 2001, unpublished).

The final two dimensions of illness representations are emotional representations, the emotional impact of the illness, and causes, the individuals’ ideas about the original cause of the illness. Depression, measured as an emotional representation, has been found to correlate significantly with negative views of the consequences of the illness and personal control (Murphy et al, 1999). Furthermore, increases in depression over time were associated with increased perceptions of personal responsibility for the illness (Schiaffino, Shawaryn and Blum, 1998). Finally a favourable course of illness is associated with high doctor-client agreement on ‘causes’ as well as ‘identity’ (eg: Millard, Wells and Thebarge, 1991 cited in Scharloo et al, 1998). Beliefs of an external cause have been found to be positively correlated with serious consequences and negatively related to belief in controllability (Heijmans and de Ridder, 1998). Furthermore, a biological cause can be associated with higher levels of impairment (Heijmans and de Ridder, 1998).

These illness representations, and the ongoing process of illness-related adjustment, are also believed to apply to other people close to the individual (eg: parent, spouse), particularly if they have a caring role. Studies investigating the attributions of significant others have found a similarity between their types of attributions and those of the individual. Attributions of the significant other and individual have also both demonstrated relatively stability over time (eg: Affleck et al, 1987a, 1987b cited in Weinman, et al, 2000; Weinman, et al, 2000). The investigation of illness representations may therefore play an informative role in understanding maternal adjustment to a child with encopresis and associations between maternal and child adjustment. A useful conceptual framework for understanding maternal and child adjustment to chronic illness has been suggested by Thompson et al, 1992, 1993, 1994, 1999).
1.6 Models and Maternal Adjustment

A single conceptual model (Figure 1) delineating transactions of biomedical, developmental and psychosocial processes on maternal and child adjustment has been developed by Thompson and his colleagues (1992a, 1992b, 1993a, 1993b, 1994a, 1994b, 1994c, 1999). Within a systems theory perspective, the Stress and Coping model aims to identify both illness-specific and general processes of importance to the outcome, maternal and child psychological adjustment. The choice of adaptational processes included in the model was guided by the theoretical work of Lazarus and Folkman (1984 cited in Thompson et al, 1992). The model primarily focuses on within-group variability in adjustment of children with chronic illness and thus does not include comparison with children who are not chronically ill (Thompson, 1999). For a critical review of the stress and coping model and the psychosocial factors in the psychological adjustment of children with chronic illnesses and their mothers, the reader is directed towards the current authors Literature Review.

The stress and coping model, depicted in Figure 1, views chronic childhood illness as a potential stressor to which the child and family systems attempt to adapt. The relationship between psychological adjustment and the chronic health condition is hypothesized to be a function of illness and demographic parameters, and psychosocial or mediational processes. Illness parameters include the severity of the child’s illness reflected in overall clinical status, whilst the demographic parameters include child age, gender and socio-economic status. However, the model predominantly focuses on the hypotheses that mediational processes will account for significantly greater amounts of the variance in maternal and child psychological adjustment than illness and demographic parameters (Thompson et al 1992; Wallander and Thompson, 1995).
**Figure 1: The Stress and Coping Model of Adjustment**

*(Thompson et al., 1992; 1999)*

- **Maternal Adaptational Processes**
  - Illness Parameters: Type, Severity
  - Demographic Parameters: Child gender, Child age, SES
  - Methods of Coping: Palliative, Adaptive
  - Family Functioning: Supportive, Conflicted, Controlling

- **Child Adaptational Processes**
  - Cognitive Processes: Self-esteem, Health locus of control
  - Methods of Coping

- **Outcome**
  - Maternal Adjustment
  - Child Adjustment
Three types of maternal, mediational processes were included in the basic model. Firstly, maternal cognitive processes are associated with appraisals of stress (Lazarus and Folkman, 1984 cited in Thompson et al, 1992a) and expectations. Outcome measurements focus on the assessment of daily hassles and illness tasks, and perceived efficacy and health locus of control, respectively. Secondly, illness coping methods were included to assess the use of palliative and/or adaptive methods of coping and thirdly, social support in terms of supportive, conflicted, and/or controlling family functioning. Although the basic model was developed to delineate maternal adjustment (Thompson, Gustafson et al, 1992a) it was subsequently expanded to delineate the processes associated with child psychological adjustment (Thompson, Gustafson et al, 1992b). This reflected the hypothesis that child adjustment affects, and is affected by, levels of stress and symptoms experienced by other family members, particularly maternal adjustment (Compas et al, 1989). Child mediational variables included cognitive processes associated with child self esteem and health locus of control, and methods of coping associated with pain coping strategies in specific chronic health conditions.

Path relationships between the illness and demographic parameters and the mediational processes have not yet been established, due to insufficient empirical bases (Thompson et al, 1999). The focus is thus on assessing individual and collective contributions of the parameters and hypothesised mediational processes to maternal adjustment. Research using the conceptual framework of the stress and coping model has now tested the hypotheses in several studies of children with different chronic physical conditions (eg: Gil et al, 1991; Thompson et al 1992, Thompson et al, 1993, Thompson et al 1999). Mediational processes such as stress appraisal, methods of coping and family functioning have been related to maternal adjustment to children with cystic fibrosis, sickle cell disease, congenital heart defects and low birth weight babies (Thompson et al, 1992b, Thompson et al, 1993a, Thompson et al, 1999). Furthermore, most of these studies have found an association between maternal distress and child adjustment. Some support has also been found for different patterns of association between mediational processes and adjustment across illness groups and for little stability in the adjustment classification of individual children in terms of specific behaviour problems and diagnoses (Thompson et al, 1999).
stress and coping model proposed by Thompson and colleagues has however, not been investigated with encopresis.

**Cognitive Processes in the Stress and Coping Model**

In order to investigate the utility of this model in encopresis and the influence of illness perceptions, the hypothesised mediational role of cognitive processes on maternal adjustment was targeted. Analysis of the contribution of mediational cognitive processes utilised in the stress and coping model suggested that it was the least supported component of the model. The variables chosen to represent maternal cognitive processes, maternal appraisals of stress (daily hassles and illness tasks) and maternal expectations (perceived efficacy and health locus of control), appear to have been derived from different conceptual and theoretical backgrounds. Maternal appraisals of daily hassles have been found to account for a significant amount of variance in maternal adjustment in a variety of physical illnesses (Thompson, Gustafson et al, 1994a; Thompson, Gustafson et al, 1994b; Wallander, Pitt and Mellins, 1990; Thompson, Oehler et al, 1993). However, there is no supportive evidence for the relative influence of maternal appraisal of illness tasks on maternal adjustment. Furthermore, only one study has supported a significant association between perceived efficacy and adjustment, in mothers of low birth weight babies (Thompson et al, 1993). No significant associations have been found for perceived efficacy in other studies of mothers of children with a range of other paediatric problems (eg: Davies et al, 1998; Thompson et al, 1992; Thompson, 1993a; Thompson et al, 1999). There is also no supportive evidence for the mediational role of health locus of control on maternal adjustment.

In view of the relatively scant support for the variables that represent maternal cognitive processes within this model of adjustment, this study aimed to investigate the utility of measuring more specifically, health-related cognitions in the form of illness representations. Research within the broader field of health and illness perceptions has led to theoretically driven research and support for several components of illness representations (discussed previously). These have been developed from a single conceptual framework and include the general concepts of perceived efficacy and locus of control investigated by Thompson and colleagues, as well as additional components worth investigating.
1.7 AIMS OF THIS STUDY

The present study aimed to explore the relationships between maternal psychological adjustment, child psychological adjustment and cognitive processes within the framework of the Stress and Coping Model (Thompson et al, 1992a, 1992b, 1999). This model aims to delineate illness parameters and psychosocial processes involved in maternal and child adjustment to chronic health conditions and its utility have been investigated with a range of conditions. In addition to illness and demographic parameters, coping methods, family functioning, child adjustment and cognitive processes are believed to mediate maternal psychological adjustment. It is this latter aspect of the model – maternal cognitive processes –, which was the focus of the study.

The cognitive components in the Stress and Coping model focus on appraisals of stress related to daily hassles and chronic illness tasks, expectations of efficacy, and health locus of control. These measures were not all exclusively designed for use within a health setting and have been disappointing in their general inability to account for significant increments in maternal adjustment within this model. This study therefore aimed to explore the utility of focusing on illness representations within the cognitive component of the model. Illness representations are more commonly associated with Leventhal’s self-regulation model (Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984). One specific measure assessing the distinct components of illness representations, the Illness Perception Questionnaire (IPQ), has been developed for use with a generic range of illnesses (Weinman, Petrie, Moss-Morris and Horne, 1996; Weinman, 2001). Illness specific amendments were made to the identity and cause items (Weinman, Petrie, Moss-Morris and Horne, 1996), according to the literature on encopresis (particularly Buchanan, 1990; 1992).
Hypotheses were formulated around the following variables and their relationships:

1) **Maternal Psychological Adjustment**
   It has been found that some parents who regularly attend outpatients experience the process as highly stressful (Whelan and Kirkby, 2000); mothers of children with chronic health problems such as cystic fibrosis (Thompson et al, 1992a; Thompson et al, 1999), insulin-dependent diabetes (Chaney et al, 1997), sickle cell disease (Thompson et al, 1993a; Thompson et al, 1999) and congenital heart disease (Davis et al, 1998). Therefore, it was predicted that some mothers of children with encopresis would report levels of distress that meet the criteria for poor psychological adjustment (Hypothesis 1). It was also predicted that some mothers would report their children as exhibiting levels of distress that meet the criteria for poor psychological adjustment (Hypothesis 2). In accordance with a basic tenet of Thompson’s stress and coping model, it was also hypothesised that ‘poor’ and ‘good’ maternal psychological adjustment subgroups would not differ significantly in terms of illness or demographic parameters, but would differ in terms of cognitive processes and perceived child adjustment (Hypothesis 3).

2) **Child Adjustment and Maternal Adjustment**
   It has been suggested that child adjustment to chronic health conditions is related to maternal psychological adjustment (Lavigne and Faier-Routman, 1993; Thompson et al, 1994b), maternal depression (Daniels, Moos, Billings and Miller, 1987) and maternal anxiety (Thompson et al, 1992b; Thompson et al, 1993b). Therefore, it was predicted that maternal adjustment, anxiety and depression would be related to child adjustment (Hypothesis 4).

3) **Illness Representations and Maternal Adjustment**
   In general, beliefs in controllability have been significantly related with better functioning (Scharloo et al, 1998). Therefore, it was hypothesised that perceptions of illness controllability would be related to better psychological functioning (Hypothesis 5). As previously discussed, a strong illness identity, perceptions of the illness lasting longer and beliefs in more serious consequences are generally
psychological adjustment (Scharloo et al, 1998; Weinman et al, 1996). In view of this it was hypothesised that illness representations incorporating a strong illness identity, chronic timeline and increased seriousness would be associated with depression and poorer psychological adjustment (Hypothesis 6).

Finally, it has been suggested that illness representations (Moss-Morris, Petrie and Weinman, 1996), as well as child adjustment (Lavigne and Faier-Routman, 1993; Thompson et al, 1994b) exert a direct effect on maternal psychological adjustment. Therefore, it was hypothesised that illness representations and child adjustment would predict a significant amount of the variance in measures of psychological adjustment, over and above that of illness and demographic parameters (Hypothesis 7).

Hypotheses 1 to 3 conceptualised maternal adjustment as a dichotomous variable. Although this fundamentally splits the concept of 'psychological adjustment' into two groups, this method of analysis was utilised in order to replicate previous research into the stress and coping model. Hypotheses 4 to 7 essentially addressed the same issues, but focused on maternal adjustment as a continuous variable. The latter approach was used in order to enable a broader analyses of the concept of adjustment and was considered more appropriate.
2. Methods/Procedures

2.0 Procedure

Ethical approval for the study was gained from the relevant local research ethics committees (see Appendix 1).

Families attending a hospital outpatient, paediatric clinic were approached by letter with permission from their Consultant. An explanatory letter was also sent to their GP (Appendix 2). An initial letter (see Appendix 3) was posted to the families, including an Information Sheet (see Appendix 4) explaining the aims and purpose of the study. A freepost envelope was provided for families to opt-out. A second letter (Appendix 6) was sent to the mother’s willing to participate, including the same Information Sheet, a Consent Form (see Appendix 5) a sixteen page Questionnaire Booklet (see Appendix 8) and the Brief Symptom Inventory (see Appendix 9). A freepost envelope was again provided for the return of the questionnaire booklet and signed consent form. A reminder letter (Appendix 7) was sent prior to and following the closing date.

In addition to the aforementioned psychometric measures, a range of demographic and medical background details were collected. These included child age, gender, history of the soiling problem, current frequency of symptoms and method treatment. Information pertaining to the family included ethnic background, occupation and number of household members (see Appendix 5). Finally, mothers were welcomed to comment on their experiences of coping with their child’s enuresis.

Following the return of the completed questionnaires, the questionnaires were individually scored, the results collated and statistical analysis conducted.
2.1 PARTICIPANTS
Prospective participants were recruited from a paediatric, constipation and soiling clinic at a district general hospital. Inclusion criteria consisted of the child being aged over four years old, with a primary diagnosis of encopresis with more than three months duration. Exclusion criteria consisted of children with a co-morbid chronic medical disorder (e.g., spina bifida, cerebral palsy, Hirschsprung’s disease), learning difficulty or autistic spectrum disorder. A total of 207 families attending the clinic were asked to participate in the study.

2.2 SAMPLE DESCRIPTION
Ninety (43%) out of the 207 families approached actively participated in the study and returned their questionnaires booklets. A total of fifty-two (25%) met the inclusion criteria and had completed all the questionnaires. Thirty-eight were excluded because the child had an autistic spectrum disorder, a co-morbid medical disorders or the mothers had not fully completed all the questionnaires. The mothers’ ages ranged from twenty-five to fifty-two, with a mean age of 37.8 years (SD: 6.47). The sample was almost exclusively from a white-UK background, with only one family from a white-American background. This represented the overall clinic population. The children’s ages ranged from four to sixteen years, with a mean age of 7 years 9 months (SD: 3 years). Of the sample 32 (62%) were male and 20 (38%) were female. SES was assessed using the four-factor index of social position (Hollingshead, 1975). The sample distribution generally followed a normal distribution, it was as follows: I (high), n = 2 (4%), II, n = 8 (15%), III, n = 28 (54%), IV, n = 9 (21%), V (low), n = 5 (10%).

Basic demographic data about the children (gender and age) was collected for all 207 prospective participants, enabling some comparison between the final sample and non-responders/those excluded. Similar to the final sample, the children’s ages in the non-responders/excluded group ranged from four to seventeen years and males and females were similarly distributed, with 93 (60%) males and 62 (40%) females. The non-responders/excluded group were significantly older (t=−2.676, p<0.01) with a mean age of 9 years 5 months (SD: 3 years 8 months). However, the mean age in the non-responders/excluded group was elevated by the presence of several older children in the paediatric clinic who had problems other than encopresis.
2.3 MEASURES
Copies of the measures are provided in Appendices.

2.3.1. PSYCHOLOGICAL ADJUSTMENT

i) The Mood and Feelings Questionnaire (MFQ: Costello and Angold, 1988)
The MFQ is a 32-item depression scale, which is either self or parent-rated. It covers the DSM-III-R criteria for major depressive disorder and is designed for six to seventeen year olds (Kent, Vostanis and Feehan, 1997). Symptoms are rated for the past two weeks as “true” (2), “sometimes true” (1) or “not true” (0), yielding a maximum score of 64. Cut off scores and classification are as follows, less than 20 (low), 20-34 (medium) and 35 and over (high) (Cooper and Goodyer, 1993). The MFQ parent version has high internal consistency, acceptable reliability (Wood et al, 1995) and good criterion validity (Costello and Angold, 1988).

ii) Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)
The SDQ is a 25-item, brief behavioural screening questionnaire. It covers both positive and negative attributes and is based on the child’s behaviour over the last six months. It is designed for children and adolescents aged between four and sixteen years and has a self- and informant-rated version. The SDQ is divided into five scales, with five items each covering DSM-IV criteria for conduct problems, hyperactivity, emotional symptoms, peer problems and pro-social behaviour. All but the latter are summed to generate a total difficulties score. Respondents using a 3-point Likert scale, using ‘not true’, ‘somewhat true’ or ‘certainly true’. Cut-off scores are based on a normative sample of 403, UK children (Goodman, 1997). The SDQ has demonstrated satisfactory face validity, internal consistency, inter-rater agreement and test-retest reliability (Goodman, 1997; Goodman and Scott, 1999; Goodman, 1999; Goodman, 2001). Factor analyses have confirmed the predicted five-factor structure (Goodman, 2001).

iii) Brief Symptom Inventory (BSI: Derogatis, 1993).
The BSI is a brief 53-item adult, self-report symptom scale developed from the Symptom Checklist-90-Revised (SCL-90-R; Derogatis, 1975). It is designed to assess normal adults as well as psychiatric and medical patients. Respondents rate their experience over the past seven days on a 5-point likert scale from not at all (0) to
extremely (4). Raw scores are converted to standardized T-scores. The normative sample consisted of 719 non-patient, UK adults aged over nineteen years of age. The BSI consists of nine primary symptom dimensions; somatisation, obsessive-compulsive, interpersonal-sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. In addition to the nine primary symptoms, three global indices assess global severity (GSI), positive symptom distress (PSDI) and positive symptom total (PST). The global severity index (GSI) has been identified as the single best predictor of current distress levels (Derogatis and Melisaratos, 1983). The BSI has quite high internal consistency and test-retest reliability (Derogatis and Melisaratos, 1983), high convergent validity and good construct validity (Derogatis, Rickles and Rock, 1976).

2.3.2. Illness Representations


The IPQ-R was developed to measure cognitive representations in adults and has a significant other/carer version (Weinman et al, 1996). The original scale consisted of five scales, which had been found in a range of different chronic health populations and subsequently developed into a nine-item scale (Weinman et al, 2000). The nine scales are divided into three sections. The first section relates to illness identify and is a 14-item checklist concerned with symptoms the respondents have noticed since the onset of the illness and those that they associate with the illness. The second section consists of 38 items and deals with respondents’ views about the timeline (acute versus chronic), consequences, personal control, treatment control, illness coherence, timeline (cyclical) and emotional representations. All items are scored on a 5-point likert scale ranging from strongly agree to strongly disagree. Some items are reverse scored. The third section deals with the respondent’s perceived causes of the illness. Items in the first and third section can be modified to include items specific to a particular illness group.

The reliability and validity of the IPQ has been found in a range of different chronic illness populations including diabetes, rheumatoid arthritis, multiple sclerosis, pain, asthma (Weinman et al, 1996) chronic fatigue (Heijmans and de Ridder, 1998) and
vitiligo (Papadopoulos, Bor, Walker and Legg, 2001). Good criterion validity and good internal reliability has been found for the IPQ-R (Weinman et al, 2000).

2.3.3 Additional Comments
A section for additional comments was included at the end of the questionnaire booklet. The qualitative information provided by the mothers was used to support the quantitative findings. Qualitative analysis was not conducted because the methodological procedures were not structured to facilitate this.

2.4 Statistical Analysis
The data represented a cross-sectional survey design. A priori power analyses (Erdfelder et al, 1996) indicated that a minimum of 32 participants were required for the Mood and Feelings Questionnaire ($r = 0.8$, $\alpha = 0.05$, power = 0.8). Out of the remaining questionnaires, the highest number of participants required was a minimum of 52. All data were checked for assumptions of normality and homogeneity of variance prior to statistical analyses. Data that did not meet these criteria were transformed to produce normality (Tibachnik and Fiddell, 2000) (Appendix 10). The final sample of 52 participants was found to be similar with respect gender to those who did not respond or had been excluded. However, age was significantly different ($t = -2.676$, $p = 0.008$). The sample is thus, biased towards younger children. Socio-economic status of the sample followed a normal distribution, but ethnic origin was exclusively white. This was representative of the geographical location of the clinic.

In accordance with the tenets of descriptive statistics for group means, differences between the two subgroups of ‘poor’ and ‘good’ maternal adjustment on demographic, illness and psychological factors were investigated using independent samples t-tests. Chi-squared analyses were used for categorical data. In order to move away from the categorical approach utilised in the stress and coping model, the associations between individual variables and maternal adjustment were also investigated using Pearson’s Product Moment Correlation. Finally, the predictive power of the model was assessed using hierarchical regression procedures. Regression equations were calculated in order to establish the relative influence of perceived child adjustment and maternal illness representations on maternal psychological adjustment as a continuous variable.
3. RESULTS

The data are presented according to the three proposed variables and their relationships described in the introduction: maternal psychological adjustment, child adjustment and maternal adjustment, and illness representations and maternal adjustment. Descriptive statistical information relating to these variables is provided, together with the results of independent samples t-tests, correlation and regression analyses. Summary statistics for illness and demographic variables can be found in Appendix 11. Specific hypotheses previously defined will be addressed.

3.1 Hypothesis 1: Some mothers of children with encopresis will report levels of distress that meet the criteria for poor psychological adjustment.

To address hypothesis 1, the brief measure of maternal symptoms classified adjustment as 'good' or 'poor' in accordance with the established criteria for "caseness" (Derogatis, 1993). That is, poor adjustment was defined as a global severity index (GSI) score, or any two primary dimension scores, greater than or equal to a T score of 63 (ie: above the 90th percentile). A total of 38 mothers (73%) reported good adjustment, whilst 14 (27%) reported poor adjustment. The 14 mothers who reported poor adjustment scored significantly higher (p < .0001) on the GSI and each of the nine BSI primary symptom dimensions, than the 38 mothers who reported good adjustment. Therefore, hypothesis one was supported.

3.2 Hypothesis 2: Some mothers will report their children as experiencing levels of distress that meet the criteria for poor psychological adjustment.

Although no children fell into the 'high' risk category of the mood and feelings questionnaire 6 (17%) children did fall into the 'medium' category (n=35). According to the strengths and difficulties questionnaire 8 (16%) children fell within the 'borderline' category and 7 (14%) fell within the 'abnormal' category (n=52). In relation to those children for whom both questionnaires had been completed, six children (17%) were consistently rated on both the SDQ and MFQ as meeting the criteria for poor psychological adjustment. Hypothesis two was also supported.
3.3 *Hypothesis 3*: Poor and Good maternal psychological adjustment subgroups will not differ significantly in terms of illness or demographic parameters, but will differ in terms of perceived child adjustment and psychological processes.

**Illness and Demographic Parameters**

To address hypothesis 3, independent samples t-tests were conducted on parametric data to assess differences between good and poor maternal adjustment subgroups on the demographic parameters, illness parameters and mediational processes of the stress and coping model. Chi-squared analyses (with Fisher’s Exact test if >25% of cells have expectancies of 5 or less) were used for categorical data and independent samples t-tests for parametric data. As hypothesised, there were generally no significant subgroup differences on demographic and illness parameters according to the Stress and Coping Model, with one exception. Consistency, whether or not the encopresis had ever disappeared, did demonstrate significant subgroup differences ($X^2 = 6.60, p = 0.011$). That is, the good adjustment subgroup had significantly higher numbers of children who had experienced periods of remission.

There were no significant maternal adjustment subgroup differences according to child age, gender, SES, length of clinic attendance, parental marital status or the method of treatment (i.e., with new drug movicol or not). There were also no differences according to whether or not the child was premature, had the condition since birth, experienced enuresis (wetting), had been potty trained, had a secondary paediatric problem or lived in a reconstituted family. In addition, there were no significant subgroups differences on symptom presence or absence, whether they had been discharged from the clinic or not, and whether or not they perceived their child’s symptoms to have improved in the previous month. The first part of Hypothesis three, was therefore not supported.

**Perceived Child Adjustment and Psychological Processes**

There were no significant maternal adjustment subgroup differences on the total child MFQ and SDQ scores (Table 1a). The second part of Hypothesis three was therefore also not supported.
Table 1a: Comparison of Good Adjustment and Poor Adjustment Maternal Subgroups on Measures of Perceived Child Adjustment and Illness Representations

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Good Adjustment</th>
<th>Poor Adjustment</th>
<th>t</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>MFQ (n=35)</td>
<td>0.90 0.34</td>
<td>1.16 0.21</td>
<td>-2.018</td>
<td>.052</td>
</tr>
<tr>
<td>SDQ - Total</td>
<td>3.04 0.84</td>
<td>3.43 0.67</td>
<td>-1.549</td>
<td>.128</td>
</tr>
</tbody>
</table>

For interest, further analysis of subgroup differences on the subscales of the IPQ-R and the SDQ was conducted using independent samples t-tests (Table 1b). A Bonferroni t Correction for the number of t-tests was applied which, yielded a corrected significance level of 0.004. No significant subgroup differences were demonstrated.

Table 1b: Comparison of Good Adjustment and Poor Adjustment Maternal Subgroups on Measures of Perceived Child Adjustment and Illness Representations

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Good Adjustment</th>
<th>Poor Adjustment</th>
<th>t</th>
<th>Sig. (2-tailed)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SDQ - pro-social</td>
<td>.35 .31</td>
<td>.39 .23</td>
<td>-.514</td>
<td>.610</td>
</tr>
<tr>
<td>- hyperactivity</td>
<td>3.29 1.74</td>
<td>3.93 2.34</td>
<td>-1.069</td>
<td>.290</td>
</tr>
<tr>
<td>- emotions</td>
<td>1.91 .58</td>
<td>2.12 .56</td>
<td>-1.176</td>
<td>.245</td>
</tr>
<tr>
<td>- conduct</td>
<td>.38 .25</td>
<td>.40 .31</td>
<td>-.200</td>
<td>.842</td>
</tr>
<tr>
<td>- peer</td>
<td>.34 .31</td>
<td>.43 .31</td>
<td>-.889</td>
<td>.378</td>
</tr>
<tr>
<td>IPQ-R - identity</td>
<td>5.18 2.95</td>
<td>6.00 2.48</td>
<td>-9.21</td>
<td>.362</td>
</tr>
<tr>
<td>-time (acute/chronic)</td>
<td>20.21 4.71</td>
<td>20.36 4.20</td>
<td>-.102</td>
<td>.919</td>
</tr>
<tr>
<td>- consequences</td>
<td>19.13 4.13</td>
<td>19.79 4.61</td>
<td>-.491</td>
<td>.625</td>
</tr>
<tr>
<td>- personal control</td>
<td>18.42 4.93</td>
<td>19.93 3.97</td>
<td>-1.026</td>
<td>.310</td>
</tr>
<tr>
<td>- treatment control</td>
<td>19.71 3.44</td>
<td>18.93 1.94</td>
<td>.802</td>
<td>.427</td>
</tr>
<tr>
<td>- illness coherence</td>
<td>14.92 3.45</td>
<td>14.86 3.53</td>
<td>.059</td>
<td>.953</td>
</tr>
<tr>
<td>- time (cyclical)</td>
<td>12.71 2.24</td>
<td>12.64 2.37</td>
<td>.095</td>
<td>.925</td>
</tr>
<tr>
<td>- emotional</td>
<td>18.61 4.97</td>
<td>18.43 5.23</td>
<td>.112</td>
<td>.911</td>
</tr>
<tr>
<td>representation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
3.4 Hypothesis 4: Maternal adjustment, anxiety and depression would be related to child adjustment.

Bivariate correlation analyses using Pearson’s Product Moment correlation were calculated to investigate the relationship between maternal adjustment and perceived child adjustment (Table 2). A Bonferroni Correction for the number of correlations was not applied because of the exploratory nature of this study.

The findings were consistent with this hypothesis. Overall maternal adjustment was found to be associated with the child’s perceived mood and feelings \((r = .476, p < 0.01)\), and overall strength’s and difficulties \((r = .380, p < 0.01)\) (Table 3). The number of positive symptoms (PST) reported by the mothers was associated with maternal perceptions of the child’s mood and feelings \((r = .425, p < 0.05)\), and overall strength’s and difficulties \((r = .401, p < 0.01)\). The distress the positive symptoms caused was found to be related to the child’s perceived mood and feelings (MFQ) \((r = .341, p < 0.05)\).

Maternal anxiety was found to correlate positively with both measures of child adjustment; the child’s mood and feelings \((r = .399, p < 0.05)\) and strength’s and difficulties \((r = .303, p < 0.05)\). Maternal depression was found to correlate even more strongly with the child’s mood and feelings \((r = .509, p < 0.01)\) and strengths and difficulties \((r = .356, p = 0.01)\). Hypothesis four was supported.

<table>
<thead>
<tr>
<th>Maternal Adjustment (BSI)</th>
<th>Perceived Child Adjustment</th>
<th>Perceived Child Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MFQ Total (n=35)</td>
<td>SDQ Total (n=52)</td>
</tr>
<tr>
<td><strong>BSI Total</strong></td>
<td><strong>.476</strong> ** .476** **</td>
<td><strong>.380</strong> ** .380** **</td>
</tr>
<tr>
<td>Pearson Cor. Sig (2 Tailed)</td>
<td><strong>.004</strong></td>
<td><strong>.006</strong></td>
</tr>
<tr>
<td><strong>PST</strong></td>
<td><strong>.425</strong> ** .425** **</td>
<td><strong>.401</strong> ** .401** **</td>
</tr>
<tr>
<td>Pearson Cor. Sig (2 Tailed)</td>
<td><strong>.011</strong></td>
<td><strong>.003</strong></td>
</tr>
<tr>
<td><strong>PSDI</strong></td>
<td><strong>.341</strong> ** .341** **</td>
<td><strong>.212</strong> ** .212** **</td>
</tr>
<tr>
<td>Pearson Cor. Sig (2 Tailed)</td>
<td><strong>.045</strong></td>
<td><strong>.132</strong></td>
</tr>
</tbody>
</table>

* Correlation is significant at \(p < 0.05\)  ** Correlation is significant at \(p < 0.001\)
### Table 2 cont.: Significant Correlations between Maternal and Perceived Child Adjustment

<table>
<thead>
<tr>
<th>Maternal Adjustment (BSI)</th>
<th>Perceived Child Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MFQ Total (n=55)</td>
</tr>
<tr>
<td>Somatisation</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.289</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.093</td>
</tr>
<tr>
<td>Obsessive Compulsive</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.331</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.052</td>
</tr>
<tr>
<td>Interpersonal sensitivity</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.220</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.204</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.509**</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.002</td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.399*</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.018</td>
</tr>
<tr>
<td>Hostility</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.395*</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.019</td>
</tr>
<tr>
<td>Paranoia</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.322</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.059</td>
</tr>
<tr>
<td>Psychoticism</td>
<td></td>
</tr>
<tr>
<td>Pearson Cor.</td>
<td>.487**</td>
</tr>
<tr>
<td>Sig (2 Tailed)</td>
<td>.003</td>
</tr>
</tbody>
</table>

* Correlation is significant at p < 0.05  ** Correlation is significant at p < 0.001

### Additional Findings (Table 2)

A number of the maternal adjustment categories were related to maternal perceptions of the child’s strengths and difficulties. Maternal interpersonal sensitivity was associated with perceived child peer problems \((r = .326, p = .018)\). That is, the more the child was perceived to have peer problems the more sensitive the mothers rated themselves. Maternal depression was positively associated with perceived child emotional symptoms \((r = .349, p = .011)\), whilst maternal anxiety was positively associated with perceived child hyperactivity \((r = .300, p = .031)\). Maternal hostility was found to be positively associated with both perceived child hyperactivity \((r = .435, p = .001)\) and conduct problems \((r = .420, p = .002)\). Maternal somatization,
obsessive-compulsive symptoms, paranoia and psychotic self-reported symptoms were not found to be associated with any of the strengths and difficulties sub-scales.

3.5. **Hypothesis 5:** Perceptions of illness controllability would be related to better maternal adjustment.

Bivariate correlation analyses using Pearson's Product Moment correlation were calculated to investigate the relationship between maternal adjustment and illness representations (Table 3, pg. 234).

The hypothesis was supported for treatment control. Treatment (external) control was negatively associated with overall maternal adjustment ($r = -0.315, p = 0.023$) and the number of positive symptoms ($r = -0.338, p = 0.014$), respectively. That is, the more the mothers perceived the treatment to control their child’s problem, the lower (better) their overall adjustment score and number of reported symptoms. Personal (internal) control however, was neither correlated with overall adjustment nor any of the adjustment sub-scales. Hypothesis five was supported for treatment control.

3.5.1 **Hypothesis 6:** Illness representations incorporating a strong illness identity, a chronic timeline and increased seriousness would be associated with depression and poorer psychological adjustment.

Illness identity, timeline and consequences were not correlated with maternal adjustment or maternal depression. Hypothesis six was therefore not supported.

*Additional Findings* (*Table 3, pg 234*)

Treatment control was found to be strongly negatively correlated with obsessive-compulsive symptoms ($r = 0.380, p = 0.005$) and paranoia ($r = -0.275, p = 0.048$). Thus, the less the mothers perceived their child’s treatment to be controlled by the treatment the more they reported symptoms of obsessive-compulsiveness and paranoia. Maternal emotional representations were found to be positively associated with the number of positive symptoms reported by the mothers ($r = -0.275, p = 0.048$), obsessive-compulsive symptoms ($r = 0.289, p = 0.038$) and hostility ($r = 0.290, p = 0.037$). That is the more emotional the mother reported herself, the more obsessive-compulsive
symptoms and hostility she felt. Somatization, interpersonal sensitive, depression, anxiety and psychoticism were not found to be associated with any of the illness representations.

Table 3: Significant Correlations Between Adjustment on the BSI and IPQ-R

<table>
<thead>
<tr>
<th>Maternal Adjustment (BSI) (n=52)</th>
<th>Illness Perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Identity</td>
</tr>
<tr>
<td><strong>BSI Total</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.039</td>
</tr>
<tr>
<td>p (2-tailed)</td>
<td>.783</td>
</tr>
<tr>
<td><strong>Positive Symptoms</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.023</td>
</tr>
<tr>
<td>p (2-tailed)</td>
<td>.870</td>
</tr>
<tr>
<td><strong>Positive Symptom Distress Index</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.045</td>
</tr>
<tr>
<td>p (2-tailed)</td>
<td>.753</td>
</tr>
<tr>
<td><strong>Somatisation</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.061</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.665</td>
</tr>
<tr>
<td><strong>Obsessive Compulsive</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.065</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.647</td>
</tr>
<tr>
<td><strong>Interpersonal Sensitivity</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.071</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.617</td>
</tr>
<tr>
<td><strong>Depression</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.109</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.441</td>
</tr>
<tr>
<td><strong>Anxiety</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>.073</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.606</td>
</tr>
<tr>
<td><strong>Hostility</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.012</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.934</td>
</tr>
<tr>
<td><strong>Paranoia</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.029</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.837</td>
</tr>
<tr>
<td><strong>Psychoticism</strong></td>
<td></td>
</tr>
<tr>
<td>Pearson Correlation</td>
<td>-.014</td>
</tr>
<tr>
<td>p (2 Tailed)</td>
<td>.923</td>
</tr>
</tbody>
</table>

* Correlation is significant at p < 0.05  ** Correlation is significant at p < 0.01
3.6. Hypothesis 7: Illness representations and child adjustment will predict a significant proportion of the variance in measures of psychological adjustment, over and above that of illness and demographic parameters.

Hierarchical multiple regression analyses was conducted to address Hypothesis 7. Given the relatively small sample size, these analyses were conducted on an exploratory basis and the results should be treated with caution. The analyses assessed the increment in maternal GSI (global BSI) scores accounted for by perceived child adjustment and illness representations over and above that accounted for by illness and demographic parameters.

Separate regression equations were computed for each BSI maternal adjustment subscale. Demographic and illness parameters were entered in the first block (eg: consistency of the problem, SES, age, gender, discharge status, presence of symptoms and attendance. Regression equations were computed with variables entered in a stepwise fashion in as predictors in the two blocks representing illness representations and child strengths and difficulties. The mood and feelings questionnaire was not entered as the total number of completed questionnaires fell below 50 (n=35).

Measures of psychological adjustment on the BSI represented the dependent variable in each regression equation. The BSI measure of phobic anxiety was excluded because the data could not be transformed.

Results are summarised in Tables 4 and 5. For each block the regression statistic (R), the adjusted $R^2$ and the $F$ test ($F$ change) for the increase in $R^2$ is reported, along with the cumulative $R$ and the significant $\beta$ weights for the final regression. A significant $F$ indicated that the variables added in the block explained additional variance in the dependent variable. For the primary regression equations, demographic and illness parameters were entered first, followed by illness representations and finally child adjustment. None of the illness and demographic parameters accounted for a significant amount of variance in maternal psychological adjustment (3% to 24%). However, SES made a significant contribution ($\beta = .329$, $p=.035$) to the amount of positive symptoms (PSDI) rated by the mother.
With illness representations entered as the second block, perceived treatment control accounted for significant increments in GSI, PST, somatisation, obsessive-compulsive, interpersonal sensitivity, depression, anxiety and paranoia. Furthermore, maternal emotional representations accounted for significant increments in obsessive-compulsiveness and anxiety. The addition of illness representations significantly improved the prediction, increasing the proportion of explained variability in maternal psychological adjustment by between 7% and 30%.

The five child adjustment scales (SDQ) were entered as the third block. $F$ change statistics were significant for GSI, PST, interpersonal sensitivity, depression and hostility. The addition of child adjustment significantly improved the prediction, increasing the proportion of explained variability in maternal psychological adjustment by between 7% and 20%.

Table 4: Multiple Regression Analysis of the influence of Demographic and Illness Parameters and Illness Representations on Maternal Adjustment Subscales.

<table>
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<th>$F$ Change</th>
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* Significant at $p < 0.05$  ** $p < 0.01$
### Table 4 cont.: Multiple Regression Analysis of the influence of Demographic and Illness Parameters and Illness Representations on Maternal Adjustment Subscales.

<table>
<thead>
<tr>
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* Significant at p < 0.05  ** p < 0.01

A second set of regression equations was computed in order to determine the relative influence of illness representations in explaining additional variance in psychological adjustment after the effects of demographic and illness parameters and child adjustment had been controlled for. The results are summarised in Table 5. Demographic and illness were entered in first, with child adjustment entered in the second block and illness representations in the third. None of the illness and demographic parameters accounted for a significant amount of variance in maternal psychological adjustment (3% to 13%). However, the following child adjustment variables made significant contributions; child emotions to maternal depression, peer problems to maternal interpersonal sensitivity, and hyperactivity to maternal hostility.

With illness representations entered as the third block, incremental $F$ values were significant for all measures of psychological adjustment except positive symptom distress index and psychoticism ($df = 1, 43, p = 0.001 - 0.05$). Those illness representations making significant contributions included perceived treatment control, which was negatively related to increases in psychological adjustment, and emotional
representations which were positively related. The addition of illness representations significantly improved the prediction, increasing the proportion of explained variability in psychological adjustment by between 7% and 21%.

In summary, after controlling for illness and demographic parameters both illness representations and child adjustment were found to contribute significantly to the prediction of variance in maternal psychological adjustment. This provides support for Hypothesis 7.

Table 5: Multiple Regression Analysis of the Influence of Demographic and Illness Parameters, Child Adjustment and Illness Representations on Maternal Adjustment.

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<tr>
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<td>10.083**</td>
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* Significant at p < 0.05  ** p < 0.01
Table 5 cont.: Multiple Regression Analysis of the influence of Demographic and Illness Parameters, Child Adjustment and Illness Representations on Maternal Adjustment.

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* Significant at p < 0.05  ** p < 0.01

Mediating Factors

A comparison of the predictive power of illness representations, when entered in the second and third blocks, indicated that some components of illness representations interestingly changed in their ability to predict measures of psychological adjustment. For example, perceived treatment control increased in its predictive power for maternal anxiety from 18% to 20%, but decreased in predictive power for paranoia from 19% to 9%. These findings suggest that the effects of illness representations on maternal psychological adjustment may be mediated by perceived child adjustment. These findings however, should be treated with caution given the small sample size.

3.7 Causal attributions

In the top three causes rated by parents for the onset of encopresis (Table 6), the most common reasons were believed to be hereditary factors (13%), diet or eating habits (13%), a germ, virus or injury (11%) and stress or worry (10%). Given the large number of cells with frequencies of less than 5, chi-squared analyses was not possible.
Poorly adjusted mothers appeared to rate diet or eating habits (22%) as the most likely cause followed by a germ, virus or injury (15%). Better adjusted mothers ('good') appeared to perceive hereditary factors (14%) as the most likely cause followed equally by diet or eating habits, a germ, virus or injury, and stress or worry (10%). In summary poorly adjusted mothers appeared to be more likely to perceive the child’s attitude, personality and/or emotions and the child’s diet as causes for the onset of the encopresis, and less likely to perceive poor medical care and holding on/pain upon defecation as a possible cause for the encopresis.

Table 6: Summary of the Top 3 Causes identified for Encopresis

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<th>Primary Cause</th>
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<th>Count (percent)</th>
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<td><em>Poor Psychological Adjustment</em></td>
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<td>10 (14)</td>
<td>4 (13)</td>
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<tr>
<td>Diet or eating habits</td>
<td>7 (10)</td>
<td>7 (22)</td>
</tr>
<tr>
<td>Chance or bad luck</td>
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<td>2 (6)</td>
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<td>1 (3)</td>
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4. DISCUSSION

4.1 LEVELS OF MATERNAL AND CHILD PSYCHOLOGICAL ADJUSTMENT

The findings of this study indicated that approximately two-thirds of mothers of children with encopresis met the criteria for good adjustment. This supported hypotheses 1, that poor maternal psychological adjustment would be present. The 27% rate of poor maternal adjustment to encopresis was consistent with previous findings of between an 8% and 31% rate of poor parental adjustment to child chronic health conditions (Chaney et al, 1997; Sawyer et al, 1998; Thompson et al, 1992a; Thompson et al, 1993; Thompson et al, 1993a). Poor adjustment was not exclusive to mothers whose children were still presenting with symptoms (this will be discussed in more detail later). The moderately high frequency of poor adjustment may therefore have been influenced by the mothers’ experiences of having a child with encopresis. It is conceivable that the personality variables of certain mothers may combine with the emotional and practical burdens of encopresis, and place them at greater risk of poor adjustment.

The emotional strains and practical difficulties of having a child with encopresis were clearly expressed by all mothers. They described their emotional experiences as “unbearable at times”, “an emotional roller coaster” and their emotions as “difficult to control”. One mother commented on her exasperation and how her efforts to be positive and encouraging towards her child were “wearing”. Feelings of exasperation were frequently associated with the practical tasks caused by the encopresis, and the length of time it takes for treatment to be effective. For example, “endless washing of bedding, even when she was still in nappies at 8 years old”, the “changing of underwear and wiping bottoms when your child is 5 and 6 years old, sometimes 20 times a day”, and the difficulty of “having to make sure that we had spare clothes, carting around bags full of soiled ones and explaining [to others], which was likened to “a military campaign”.

The findings of this study also indicated that 17% of the children were consistently rated across the two measures of child psychological adjustment, by their mothers, as
meeting the criteria for poor adjustment. Although age limitations on the MFQ restricted the comparison of consistency across the two questionnaires to a smaller sample of 35, there appeared to be a small sub-group of children with significant behaviour problems. This supports hypothesis 2 and previous research evidence for a sub-group of children, between fifteen and twenty percent, with more serious behavioural and social difficulties (Abrahamian and Lloyd-Still, 1984; Friman et al, 1988; Gabel et al 1988; Loening-Baucke et al 1987). Possible relationships between child and maternal adjustment will be discussed later.

4.2 Maternal Psychological Adjustment and Illness and Demographic Variables

In accordance with the Stress and Coping model, maternal adjustment was generally not a function of illness severity or demographic parameters. These findings are consistent with those of Landman et al (1983), Levine and Bakow (1976), Stark et al, (1990) and the series of studies conducted by Thompson et al (1999). However, there was one exception. Mothers, who reported that their child’s encopresis had ‘disappeared’ in the past, were significantly better adjusted than those who did not report a period of remission. It is possible that a period of remission may offer some hope, some respite from the daily stress and an increase in patience. One mother hinted at the circularity of the difficulties experienced by her family when the condition persists; “The longer it goes on, the more difficult it is to remain patient, and the parent’s impatience or anger can only make the child feel more tense and worried, which then makes you desperately worried in turn.” The persistence of the condition may evidently be related to feelings of helplessness and hopelessness. One mother who met the criteria for poor adjustment commented about the “frustration that we can do so little” and the “lack of hope at times when it seems relentless”. Another said a feeling of hopelessness often overwhelms her when she realises that “another year has gone by and he is still not clean or using the loo as he should.” Instilling hopefulness and providing reassurance about treatment efficacy may therefore help to mediate against poor maternal psychological adjustment, during a child’s treatment.

It was interesting to note that there were no significant differences in terms of maternal psychological adjustment even when the child’s soiling and constipation
symptoms had stopped, the child had been discharged from the clinic or the mother perceived a recent improvement in the child’s symptoms. Relatively recent research has suggested that the impact on parents of having a child with chronic health problems can lead to ongoing worries about their child’s health and an ongoing sense of alienation from others (Van Dongen-Melman et al, 1995 cited in Kazak and Barakat, 1997). This impact is believed to precipitate symptoms of post-traumatic stress in parents (eg: Melnyk et al, 1997; Stuber, 1995), and such effects have been found to last up to two years after treatment in survivors of cancer (Kazak and Barakat, 1997). Although encopresis is not considered a ‘life threatening’ condition some of the mothers considered the impact on the child and family as equally debilitating and distressing. Furthermore, mothers described additional distress because they were “not being taken seriously” by health professionals and because they were constantly being judged and blamed by relatives, other parents and teachers.

Similar to mothers whose children still soiled, mothers of children who no longer soiled also appeared to convey a sense of trauma when reflecting back upon their experiences. This could be related to feelings of helplessness, guilt and isolation and the child’s pain. Several mothers of children who had been clean for between two and six months recalled the heartache of seeing their child in pain. One mother, whose child had been clean for between seven and twelve months described her feeling of “a real fear and distress that the mass of unpassed faeces would build and build until it ruptured her insides”, another mother reflected on her management of the condition; “I know I was contradictory in the way I handled it, changing from kind reassuring to losing my patience and getting cross. Lots of guilt, emotion and negativity”. A third mother reflected on her parenting abilities and her inability to assist her child with “one of the most fundamental human needs” which made her feel that she was “in some way letting her down severely”. Even after a child had been clean for longer than 13 months a mother alluded to her sense of isolation, that they were the only family dealing with encopresis. The relative absence of significant improvements in maternal adjustment following the cessation of the encopresis and the anecdotal evidence for continuing distress suggests that maternal adjustment difficulties may continue even after successful treatment of their child. This suggests that mothers
may benefit from ongoing psychological support as part of their child’s treatment for encopresis. In view of an emerging relationship between maternal and child adjustment (Daniels, et al, 1987; Melnyk, 1995; Whelan and Kirkby, 2000), it is also conceivable that continued maternal support may have a beneficial effect on relapse and remission rates, and consequently enhance current treatment efficacy.

Regression analyses indicated that illness and demographic parameters did not account for significant amounts of variance in maternal psychological adjustment. However, contributions of individual illness and demographic parameters to the amount of variance predicted by the overall block indicated that socio-economic status did contribute significantly to maternal positive symptom distress. This suggests that lower socio-economic status may play a role in the amount of distress associated with the symptoms reported by mothers. Empirical evidence has to date, provided mixed evidence for (eg: Lask and Fosson, 1989) and against (Buchanan, 1992; Levine, 1982) a direct association between the prevalence of encopresis and social class. The results of this study however, indicate that the relationship between socio-economic status and encopresis may be more complex than originally hypothesised. It may play a role in mediating maternal adjustment. Considering that there is generally a higher ratio of boys who experience encopresis than girls, future research into the influence of socio-economic status on maternal as well as paternal adjustment would be beneficial in both identifying parents at higher risk of poor adjustment and designing effective interventions.

In summary, both hypothesis 1 and 2 were confirmed. There was evidence for poor maternal adjustment and child adjustment within this sample. The first component of hypothesis 3, that ‘poor’ and ‘good’ maternal psychological adjustment subgroups would not differ significantly in terms of illness or demographic parameters was generally supported. The one exception indicated that mothers were more likely to experience improved adjustment if the encopresis had stopped for a period of time. Finally, regression analyses indicated that socio-economic status might play a role in the amount of distress induced by symptoms of poor adjustment.
4.3 Maternal and Child Psychological Adjustment

The second component of hypothesis 3, suggested that 'poor' and 'good' maternal psychological adjustment subgroups would differ significantly in terms of perceived child adjustment. This was not confirmed. When comparing the two measures of child adjustment, the child’s mood and feelings demonstrated a stronger association with maternal adjustment than perceptions of strengths and difficulties. Significant results may have been precluded by the small sample size and the relatively small proportion of mothers who met the criteria for poor adjustment (14). Nevertheless, bivariate correlational analyses, using maternal adjustment as a continuum, were supportive of a significant relationship between both measures of child adjustment and maternal psychological adjustment. The correlational nature of the analyses meant that the direction of causality could not be inferred. A certain degree of association could also be anticipated because mothers completed reports of both their own and their child’s adjustment. Future research could therefore be utilised to investigate a larger sample size as well as the use of children's self-report measures.

Bivariate correlational analyses also indicated that maternal anxiety and depression were significantly related to both measures of child adjustment, thus confirming hypothesis 4. These findings are consistent with research from the wider field of chronic child health conditions in which child adjustment has been related to maternal psychological adjustment (Lavigne and Faier-Routman, 1993; Thompson et al, 1994b), maternal depression (Daniels, Moos, Billings and Miller, 1987) and maternal anxiety (Thompson et al, 1992b; Thompson et al, 1993b). In addition to a relationship between both global measures of child adjustment, bivariate correlational analyses on the subscales of child and maternal adjustment demonstrated further significant relationships for maternal anxiety and depression. Maternal anxiety was also significantly associated with child hyperactivity. Although directionality could not be inferred, comments by the mothers implied that the influence could be bi-directional. Some mothers mentioned that their anxiety about their child missing out made them try harder to keep their child active and make them feel happy, secure and confident, whilst other mothers mentioned that their child’s concentration problems at school (one symptom used to indicate hyperactivity) made them anxious about their child’s education and future. The bivariate analyses also indicated that maternal depression
was significantly related to perceptions of the child’s emotions. This was clearly
evident in the comments made by the mothers. One mother mentioned that she “gets
upset when he is in pain - I want to cry for him when he has an accident”, and another
commented on her “sadness at the way it makes him feel”.

Furthermore to the findings regarding anxiety and depression, maternal interpersonal
sensitivity was found to be related to perceptions of child peer problems. This may be
because soiling ‘accidents’ can be socially embarrassing and may lead to isolation of
the child and family. Mothers are thus likely to become very sensitive to signs of
criticism or judgement and consequently, sensitive to any sign that their child may
have soiled so that it can be managed discretely. One mother was aware that she had
become very sensitive to her child’s ‘smells’ for his own benefit because of the name-
calling and bullying at school. Finally, hostility was found to be significantly
associated with both perceived child hyperactivity and conduct problems. This
hostility appeared to be represented by beliefs that the encopresis was caused by the
child’s “deliberate disobedience”, annoyance at the child’s attempts to “hide the
evidence”, and having to make excuses to other parents for their child’s “naughty”
behaviour.

Multiple regression analyses indicated that the components of perceived child
psychological adjustment were significant predictions in the variance of maternal
psychological adjustment. Child and maternal adjustment were generally related in
accordance with the bivariate correlations described previously. After controlling for
the effects of child age, gender, SES, consistency of the problem, discharge status,
presence of symptoms and length of attendance, clearer relationships between child
and maternal psychological adjustment emerged. Child peer problems appeared to
contribute to the variance in maternal interpersonal sensitivity and child emotions to
predict maternal depression. Hyperactivity was found to significantly predict
maternal anxiety and both child hyperactivity and conduct problems were predictive
of maternal hostility. This confirmed one component of hypothesis 7, that child
adjustment would predict a significant proportion of the variance in measures of
psychological adjustment, over and above that of illness and demographic parameters.
Although this could be an artefact of the parent-rated questionnaires, it could equally
indicate that, by the very nature of encopresis, these mothers have become more sensitive to their child.

In summary, when comparing subgroups of ‘poor’ and ‘good’ maternal psychological adjustment no significant relationships with child adjustment emerged. However, when maternal adjustment was considered as a continuum, the data supported correlational relationships between global maternal adjustment, anxiety and depression, and child psychological adjustment. Multiple regression analyses supported the ability of child adjustment to predict significant amounts of variance in maternal adjustment and the relationships determined by the bivariate correlational analyses. The total proportion of variance accounted for by child adjustment on the various subscales of maternal adjustment, ranged from between 10% to 20%. The addition of illness representations into the equation, once child adjustment had been controlled for, increased the proportion of variance from between 7% and 21%.

4.4 Predicting Psychological Adjustment from Illness Representations and Perceived Child Adjustment

The present study aimed to evaluate the independent contributions of illness representations and child adjustment on maternal psychological adjustment, having first controlled for the effects of illness and demographic parameters. It also aimed to explore the possibility that the effects of illness representations on maternal psychological adjustment may be mediated by child adjustment.

After controlling for the effects of illness/demographic parameters and child adjustment, it was found that illness representations accounted for significant proportions of additional variance in maternal psychological adjustment. Those variables contributing significantly to the predictive power of illness representations were perceived treatment control and maternal emotional representations. On the other hand, after controlling for the effects of illness/demographic parameters and illness representations, it was found that child adjustment also accounted for significant proportions of additional variance in maternal psychological adjustment. Those variables significantly contributing to the predictive power of child adjustment were child peer problems, emotions, hyperactivity and conduct problems. Thus, both
illness representations and child adjustment were related in a conceptually meaningful way to maternal adjustment. This was generally in accordance with the bivariate correlations described previously.

A comparison of the predictive power of illness representations and child adjustment thus indicated that each might mediate the influence of the other. Perceived treatment control appeared to be the strongest predictor of variance in global psychological adjustment, positive symptoms and anxiety. Child hyperactivity accounted for the second largest amount of variance. Treatment control appeared to mediate the relative significance of the proportion of variance accounted for by child hyperactivity in all three measures. Furthermore, in the cases of global psychological adjustment and positive symptoms, the relative influence of child hyperactivity was negatively related to perceptions of treatment control. Conversely, child peer problems and emotions emerged as the best predictors of variance in maternal interpersonal sensitivity and depression, respectively. These appeared to mediate whether or not perceived treatment control accounted for significant amounts of variance. Finally, child conduct problems, followed by hyperactivity appeared to be the strongest predictors of maternal hostility. These appeared to mediate whether or not maternal emotional representations accounted for significant amounts of variance. This suggests that maternal emotional representations may only predict a significant amount of variance in hostility when child conduct problems and hyperactivity increase.

In summary, perceived treatment control appeared to be the strongest predictor of variance in global psychological adjustment, positive symptoms and anxiety. Increasing treatment efficacy beliefs could therefore be instrumental in maintaining maternal adjustment. Child peer problems emerged as the best predictor of variance in maternal interpersonal sensitivity, child emotions emerged as the best predictor of variance in maternal depression and child conduct problems appeared to be the strongest predictor of maternal hostility. This suggests that providing psychological support for children with peer, emotional and conduct problems may also be effective in improving maternal psychological adjustment.
4.5 PERCEIVED CAUSES OF ENCOPEESIS

The most common causes reported for encopresis by the mothers in this study included hereditary factors, diet or eating habits, a germ, virus or injury, and stress or worry. These causal groupings were rated as the four most likely causes amongst mothers in both the good and poor adjustment subgroups, with intestinal dysfunction due to hereditary causes, and diet and eating habits equally rated as the most likely causes of encopresis. This is partially consistent with the findings of Benard-Bonnin et al, (1993), who found that 53% of parents believed in hereditary intestinal dysfunctional, with painful defection as the second most common cause cited for encopresis. Only 5% of mothers in the current study considered painful defecation/holding on as a cause. Slight differences were observed between mothers in the good and poor adjustment groups, although the sample size is too small to reach any meaningful conclusions. It was interesting to note that poorly adjusted mothers tended to report the child’s attitude/personality and or emotions more frequently than those in the good adjustment group. However, 9% of mothers across both subgroups still perceived that the child soiled on purpose, despite psychoeducation. This finding is consistent with 10.7% of parents found in another study (Bernard Bonnin et al, 1993). This implies that psychoeducation at the onset of treatment may not be effective for a small percentage of mothers. Psychoeducation may therefore need to be an ongoing process. Further psychological support may also be implicated if the child exhibits a range of behavioural problems that are challenging to the parent.
4.6 LIMITATIONS AND FUTURE RESEARCH DIRECTIONS

Several methodological issues should be considered when evaluating the findings of this study. As previously mentioned, no distinction was made between different types of encopresis, thus running the risk of underestimating the importance of differences in adjustment across the different types. Statistical analyses on the relatively small sample size may also have led to conservative results. Therefore increasing the likelihood of rejecting the hypothesis when it was actually true, in addition to a change in the likelihood of Type II errors for the correlational and regression analyses. It should also be noted that the interpretations of some of the child adjustment scales are in terms of transformed data and that the BSI measure of phobic anxiety was excluded because the data could not be transformed. The mood and feelings questionnaire was also not entered into the hierarchical regression analyses because of the low number of completed questionnaires. Although the sample was argued to be representative of the encopretic clinic population (despite being younger than the wider paediatric population) the extent to which the sample represents the severity of the condition amongst the general population of children with encopresis is unknown.

The study exclusively relied on self-report and a proxy measure of child adjustment, rated by the mothers, because of the relatively young sample. Although this enabled an initial exploration of the relationships in the Stress and Coping model, it is not able to provide independent verifications of the mother or child’s adjustment. It is likely that the fathers or children themselves may perceive very different patterns of relationships. The self-report measures are therefore unable to reflect the more systemic nature of interaction-connections between people, environments and different systems.

Adjustment should be considered as an ongoing process, but the cross-sectional design of this study only enabled the exploration of maternal adjustment at one single point in time. The use of correlational methods enabled the identification of linear relationships, but did not lend itself to making inferences about causality. Multiple regression analyses were used to strengthen the study of the predictive abilities of both illness representations and child adjustment. Nevertheless, these analyses should only be considered as one aspect of the emerging multi-faceted relationships. It should also
be noted that, because of the number of variables entered as potential predictors and the number of regressions performed, a mediating relationship between socio-economic status and maternal psychological adjustment may have been found by chance.

Future research is necessary to further investigate the utility of the stress and coping model in delineating both maternal and child adjustment to encopresis. Specific attention should be given to exploring relationships between the other variables hypothesised within the model, such as family functioning and coping styles. Other possible mediating variables such as environmental processes, maternal personality, cultural beliefs and paternal adjustment should also be considered. In order to investigate the ongoing nature of adjustment, future research could utilise prospective, longitudinal or time-series studies. This would also assist in the development of multivariate relationships and could possibly take into account the child’s progression through different developmental stages. Finally, in order to confirm and validate causality demonstrated between mediational processes and psychological adjustment, it would be useful to experimentally evaluate the efficacy of proposed treatment interventions.
4.7 CONCLUSIONS
This study, in spite of its inherent limitations, makes several contributions to the existing literature. Firstly, a relationship between socio-economic status and the amount of distress induced by the presence of psychological symptoms was identified. An apparent mediating relationship between socio-economic status and maternal psychological adjustment challenges a direct causal relationship previously hypothesised between socio-economic status and the incidence of encopresis. Secondly, the absence of significant improvements in maternal adjustment following cessation of the encopresis suggests that the mothers and/or their children may require ongoing psychological support even after the soiling and constipation has stopped. In view of the emerging relationship between maternal and child adjustment, ongoing psychological support could conceivably contribute to lower relapse and remission rates. Thirdly, the findings support the proposition that cognitive representations (illness representations) play a significant mediating role in global maternal adjustment to encopresis. Finally, the findings also indicate that child adjustment plays a significant mediating role in maternal adjustment, a more active role than previously conceptualised by the Stress and Coping model (e.g., Thompson et al, 1992, 1999). This was evident in the finding that certain perceptions of child adjustment had greater predictive power than, and could mediate the influence of, specific illness representations. Thus, the results of this study suggest that psychological intervention needs to target both specific illness representations and aspects of child adjustment in order to improve maternal adjustment to encopresis.


Appendices

1. Ethical approval
2. GP Letter
3. Initial letter
4. Information Sheet
5. Consent Form
6. Second letter
7. Reminder Letter
8. Questionnaire booklet
9. Brief Symptom Inventory
10. Transformed data
11. Summary Statistics for Illness and Demographic Variables
Dear Mrs

Re: 01-06-4a Psychological Adjustment of Children and their Mothers to a Soiling and Constipation Problem during Treatment

Local application form dated 22.05.01, support letters from supervisors, proposal dated 14.05.01, CV, initial contact letter, follow-up letter, patient information sheet, consent form – mothers, permission form – children and teenagers, Questionnaires – background information form, Missouri children's behaviour checklist, illness perception questionnaire parent version 1 and parent version 2, Birleson Depression Scale Questionnaire (child scale), Children & Teenagers Questionnaire, GP letter

Helping to improve services – questionnaire booklet – final version, initial contact letter dated 23.07.01; GP letter; follow-up letter with patient information and consent form dated 23.07.01; reminder letter dated 23.07.01.

Thank you for final version of the questionnaire booklet and amended letters and the assurance that the child questionnaires have been removed. Please send us revised versions of your protocol and application form signed and dated, reflecting these changes for our records. This meets the committee's concerns and the study has Research Ethics Committee approval.

All information sheets and consent forms in this study need to carry the Ethics Committee reference number and version number/date.

Permission is granted on the understanding that:

i) Any ethical problem arising in the course of the project will be reported to the Committee;

ii) Any change in the protocol or subsequent protocol amendments will be forwarded to the Committee using the enclosed form. The principal investigator should see and approve any such changes and this needs to be indicated in the forwarding letter to the Committee.

iii) All serious adverse events must be reported within 1 week to the Ethics Committee, at the same time indicating that the principal investigator has seen the report and whether or not they feel it poses any new ethical or safety issues.

iv) A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study. Continuing approval is dependent upon this report.

v) Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee. If the study does not start within 3 months of date of this letter, please notify the Committee of the date of commencement for record purposes.
A list of members is enclosed. All members were present at one or more of the meetings at which this study was reviewed. Dr D declared his interest in the study.

Yours sincerely,

Dr J R Quiney BSc MB BS FRCPath
Chairman - Research Ethics Committee
11 September 2001

Ethical Approval

Mrs Gemma Dold
Trainee Clinical Psychologist
Department of Psychology
University of Surrey

Dear Mrs Dold

Psychological adjustment of children and their mothers' to soiling and constipation problems during treatment (ACE/2001/63/Psych) – FAST TRACK

I am writing to inform you that the Advisory Committee on Ethics has considered the above protocol, and the subsequent information supplied, under its ‘Fast Track’ procedure and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed. For your information, and future reference, these Guidelines can be downloaded from the Committee’s website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (ACE/2001/63/Psych) – Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons.

Date of approval by the Advisory Committee on Ethics: 11 September 2001
Date of expiry of approval by the Advisory Committee on Ethics: 10 September 2006

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Advisory Committee on Ethics

cc: Professor LJ King, Chairman, ACE
Dr J Murray, Supervisor, Dept of Psychology
Dr.
Address

Date

Dear Dr.

RE: PSYCHOLOGICAL ADJUSTMENT OF CHILDREN AND THEIR MOTHERS TO
PAEDIATRIC CONDITIONS.

I will shortly be conducting a short research study in conjunction with the Paediatric
Clinic in the Paediatric Department of .......... Hospital. The aims of the study are to
firstly, investigate the psychological impact of paediatric conditions on mother and
child, secondly, to determine how the psychological impact changes during treatment
in the Paediatric Clinic and thirdly, to determine the relationship between illness
representations and maternal emotional states. The study is cross-sectional and will
be comparing families who are on the waiting list, in the clinic and who have been
discharged from the Paediatric clinic.

All families with a child who is aged four and above and connected with the
Paediatric Clinic, will initially be contacted by letter to participate in the study.
Families will only be approached by post and will have the opportunity to turn down
the invitation to participate. Mothers who wish to participate will be sent a
questionnaire booklet, which includes a consent form. I have enclosed a copy of the
information form and the questionnaire booklet for your interest.

The questionnaires to be completed by the mother only include a short background
information form, the Brief Symptom Inventory (Derogatis, 1975) and the Illness
Perception Questionnaire - Revised (Weinman, Petrie, Sharpe and Walker, 2000).
They will also be asked to complete the following about their child, the Strengths and
Difficulties Questionnaire (Goodman, 1997) and the Short Mood and Feelings
Questionnaire (Angold and Costello, 1987).

The postal questionnaires will be the only form of contact with the family and these
will be sent at one point in time. The use of the background information form means
that patient records will not be directly accessed.

This research project has been approved by the Chichester Research Ethics Committee
(ref. no: 01/06/4a) and the Chichester Research and Development Committee. If you
have any questions please contact either myself or Professor ...............

Yours sincerely,

............... , Trainee Clinical Psychologist

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a

VERSION NUMBER/DATE: 2/21.01.02
Mr and Mrs
Address
Address
Address

Dear ..........,

As you are probably aware, the Paediatric Clinic is designed to assess and treat paediatric conditions in children and adolescents. It is a specialist service and we aim to provide the best medical and practical support that we can to both you and your child. In order to continue to improve our services we would like to do a short study to help us to understand more about what it is like to live with paediatric conditions.

We are therefore inviting all families with a child who is aged four and above, and referred to the Paediatric Clinic to take part in our study. We are particularly interested in what you think about the conditions and how it has affected your day-to-day life. An information sheet about the study has been enclosed and we would like you to take your time to read it carefully. Please ask us if there is anything that is not clear or speak to your GP (doctor) if you have any questions.

General research on specialist clinics for paediatric conditions show that specialist services are a better way of meeting the needs of your child. The reason why this study is important is to advance our understanding of what it is like to live with a paediatric condition. Some people who have to live with a paediatric condition may find it difficult or embarrassing to talk about it and this means it is harder to carry out research and to understand exactly what kind of help they need.

We will therefore be sending out questionnaires to all the families who are in contact with the Paediatric Clinic. This includes people who are waiting to join the clinic, those who are in the clinic and those who have been discharged from the clinic. By sending everyone the questionnaires, we will be able to see what people think before, during and after the clinic. We hope that even if your child is not improving as much as you expected that you would try and answer the questions. It is extremely important that we get everybody’s views. As we are expecting a large number of replies, we will only be asking the mothers to complete the questionnaires.

When you receive the questionnaires you will notice that they have an identification number on and not your name. This is to make sure that all the answers you give are anonymous. To guarantee that no one working in the clinic will know who has said what, an independent researcher Mrs .............., Trainee Clinical Psychologist will be co-ordinating the study. The identification numbers will only allow Mrs ........ to link your answers in the booklet to those on the separate questionnaire. The answers you give will not affect your child’s treatment in any way.
This study is of course, voluntary and if you do not wish to be sent the questionnaires please fill and return the slip below in the enclosed FREEPOST envelope to Mrs ...... before ........... (two weeks). The standard of care you receive will not be affected if you choose not to participate. If you have any questions, please contact Mrs ...... on the address at the end of the letter.

Mrs ...... will be sending the questionnaires to you in the next few weeks. We hope that you will fill in as much as you can and we look forward to hearing about your overall thoughts and experiences of living with a paediatric condition. If you have more than one child attending the Paediatric Clinic could you please try and fill in one questionnaire booklet for each child. You will not need to complete the Brief Symptom Inventory twice.

The questionnaires should take about 30 minutes to fill in and we would like to thank you in advance for giving up your time to help improve the services provided by the Paediatric Clinic.

Yours sincerely,

Professor .........., Consultant Paediatric Gastroenterologist
Mrs ............... Trainee Clinical Psychologist

PAEDIATRIC CLINIC - Professor ...... & Team -
Mrs ........ Psychology Department, University of Surrey, Guildford, Surrey. GU2 7XH

What it is like for Children and their Mother’s TO LIVE WITH A PAEDIATRIC CONDITION.

Identification Number:

Thank you very much for asking me to take part in the study, but I do not wish to be sent any questionnaires.

Please return this before the date mentioned if you do not wish to join in with the study.

Please use the enclosed FREEPOST envelope or send to Mrs .......... Psychology Department, University of Surrey, Guildford, Surrey. GU2 7XH.

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a VERSION NUMBER/DATE: 2/21.01.02
Appendix 4

INFORMATION SHEET

(On headed paper)

Study: What it is like for children and their mothers to live witha paediatric condition.

The Paediatric Clinic is inviting you to take part in a study. It is important that you understand why the research is being done and what it will involve. Please take time to read the following information and ask Professor ….. or Mrs……, if there is anything that is not clear or you would like more information. Thank you for reading this.

Purpose of the Study

The aim of this study is to look at how paediatric conditions affect a child’s behaviour and feelings and how this may change during treatment. It also aims to look at what a mother thinks about paediatric conditions, how it affects a mother’s life and feelings and how these may change at the different stages of their child’s treatment. There are no right or wrong answers as this study is all about finding out what it is like to live with paediatric conditions.

Why have I been chosen?

All children aged 4 years and older in the Paediatric clinic will be invited to take part.

Do I have to take part?

It is up to you to decide whether or not you take part. If you do decide to take part you will be given this information sheet to keep and asked to sign and keep a copy of a consent form. If you decide not to take part, fill in and return the slip at the bottom of the letter. The standard of care you receive will not be affected.

How can I take part?

Please complete the questionnaires sent with this information sheet and send them back in the pre-paid envelope. This is all you have to do.

What are the benefits of taking part?

This study has been designed to help the Paediatric clinic to understand more about what it is like for children who have paediatric conditions, and their mother’s to live with them. The information we get from this study will help to treat people better.

Will my taking part in this study be kept confidential?

All information, which is collected during the course of the study, will be kept strictly confidential. The questionnaires will not have your name or address on them so that you can be recognised from them.

Who has reviewed the study?

This study has been reviewed and approved by the Chichester Research Ethics Committee.

Who is organising the research?

The research is jointly being organised by Professor ….. And Mrs……, University of Surrey. If you would like any further information please contact them at:

Professor ……..
Consultant Paediatric Gastroenterologist,
Address

Mrs Gemma Dold
Trainee Clinical Psychologist
Address

Thank You for Taking Part

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a
VERSION NUMBER/DATE: 2/21.01.02
CONSENT FORM

Patient Identification Number:

Title of Project: WHAT IT IS LIKE FOR CHILDREN AND THEIR MOTHERS TO LIVE WITH A PAEDIATRIC CONDITION.

Name of Researcher: Mrs ............

Address: Department of Psychology
University of Surrey
Guildford
Surrey.
GU2 7XH.

Any information provided will be kept strictly anonymous and will not affect your child’s treatment in anyway.

THE STANDARD OF CARE YOU RECEIVE WILL NOT BE AFFECTED IF YOU CHOOSE NOT TO PARTICIPATE

Please Tick

1. I confirm that I have read and understood the information sheet for the above study. ☐

2. I understand that my participation is voluntary and that I am free to change my mind at any time, without giving and reason and without my child’s medical care being affected. ☐

3. I agree to take part in the above study. ☐

Name (in capitals) Signature Date

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a VERSION NUMBER/DATE: 2/21.01.02
SECOND LETTER

Mr and Mrs
Address
Address
Address
Date

Dear Mrs ………,

I am writing to you following your recent letter from Professor ………. As you are aware, the Paediatric Clinic is hoping to find out more about what it is like for children and their mothers’ to live with a paediatric condition. To do this the questionnaires have been enclosed for you to complete.

First of all, could you please read the information sheet provided to remind you about the study and then complete the consent form. This form shows that you understand what the study is about and that you would like your answers to be included. Don’t forget that all your answers will be anonymous and the standard of care you receive will not be affected if you choose not to participate.

There is a questionnaire booklet for you to fill in, which includes a section on background information about your child, their treatment and whether you think anything has changed. The questionnaires include your views on their condition (the illness perception questionnaire), what your child’s behaviour is like at the moment, how they are feeling and how you (the mother) are feeling in the separate general health and symptom questionnaire (the brief symptom inventory).

By using these questionnaires, we hope to be able to see whether the Paediatric Clinic has helped to reduce stress that children and their parents may be feeling because of paediatric conditions.

The questionnaires should take about 30 minutes for you to fill in. If you have any questions or loose any of the questionnaires, please contact me on the address below. Please return the questionnaires and the consent forms to myself in the FREEPOST envelope by ……………. .

Thank you very much for helping the Paediatric Clinic to understand more about your experiences.

Yours sincerely,

Trainee Clinical Psychologist

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a

VERSION NUMBER/DATE: 2/21.01.02
Mr and Mrs
Address
Address

Date

Dear Mrs ................,

I am writing to in relation to the research study on ‘what it is like for children and their mothers to live with a paediatric condition’.

Hopefully you should have received the questionnaire booklet by now. If you have not received one or cannot find it and would like to participate, please contact myself or Professor ........... on the numbers below.

I would just like to remind you to complete and return the questionnaires as soon as possible and preferably before the ............ Please do not worry if you are only able to return the questionnaires after the closing date, as your views will still be included.

If you have already returned the questionnaires, please ignore this letter.

Thank you very much for helping the Paediatric Clinic to understand more about your experiences.

Yours sincerely,

Trainee Clinical Psychologist

PAEDIATRIC CLINIC - Professor ...........& Team
..........., Psychology Department, University of Surrey, Guildford, Surrey.

ETHICS COMMITTEE REFERENCE NUMBER: 01/06/4a

VERSION NUMBER/DATE: 2/21.01.02
We would welcome any comments you have on what it is like to live with a child with a paediatric problem:

Identification Number:

What it is Like for Children and Their Mothers to Live with a Paediatric Condition

HELPING TO IMPROVE SERVICES - QUESTIONNAIRE BOOKLET

In order to continue to improve the Paediatric Clinic services we are doing a short study to help us to understand more about what it is like to live with a paediatric condition.

We know that paediatric conditions can sometimes be difficult to talk about but we hope you will help us by completing the questionnaire booklet.

All the answers you give will be anonymous.

The answers you give will not affect your child’s treatment and your child’s treatment will not be affected if you choose not to participate.

Thank You in Advance for Helping Us

Thank you very much for helping Us
• Please complete all the answers as best as you can, even if some are a little difficult or seem a little unusual to you.

• Please also complete the Brief Symptom Inventory and the Consent Form, which are on separate sheets.
5. How often does your child experience difficulties related to their condition?
   Once a day  [ ] Twice a day  [ ] More than twice a day  [ ]
   Once a week  [ ] Twice a week  [ ] More than twice a week  [ ]
   Other .............................................................................
   Not at all  [ ] ... how long has this been? .........................

6. Does your child have any other problems? (please describe)
   ..........................................................................................

If your child has soiling or constipation problems please complete the following six questions (6–11).

7. Was your child ever potty-trained?  Yes  [ ] No  [ ]

8. Have there ever been periods when the problem or soiling seemed to disappear?  Yes  [ ] No  [ ]

9. How often does your child soil/have accidents at the moment?
   Once a day  [ ] Twice a day  [ ] More than twice a day  [ ]
   Once a week  [ ] Twice a week  [ ] More than twice a week  [ ]
   Not at all  [ ] ... how long has this been? .........................

10. When do the current accidents happen?
    At Night  [ ] Day time  [ ] Both  [ ] Not at all  [ ]

11. Does your child also experiencing wetting problems? Yes  [ ] No  [ ]

12. What treatment is your child currently receiving?
    Laxatives  [ ] Inpatient Care  [ ] Regular Toileting  [ ]
    Enema  [ ] Mineral Oil  [ ] Suppository  [ ]
    Lactulose  [ ] Movicol  [ ] Senokot  [ ]
    Other .............................................................................

13. Which of the following best describes your ethnic background?
    White – UK  [ ] White Other  [ ] Indian  [ ] Bangladeshi  [ ]
    Black – UK  [ ] Black-Other  [ ] Pakistani  [ ] Chinese  [ ]
    Other .............................................................................

14. What do you do for a living? ................................................ (mother)

15. How many years have you been in education?  ........................................ (mother)

16. Please indicate who currently lives with your child (eg: mother, father, sisters, brothers, step family).
   .....................................................................................
   .....................................................................................

17. Have you noticed any changes in your child’s condition in the past month?
    Yes  [ ] No  [ ]

18. Why do you think there have or have not been any changes?
    (If there have been any changes, please describe them)
    .....................................................................................
    .....................................................................................
<table>
<thead>
<tr>
<th></th>
<th>True</th>
<th>Sometimes Not</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>He/she felt miserable or unhappy?</td>
<td></td>
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<tr>
<td>2</td>
<td>He/she felt they didn’t enjoy anything?</td>
<td></td>
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<tr>
<td>3</td>
<td>He/she felt less hungry than usual?</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>He/she has eaten more than usual?</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>He/she felt so tired they just sat around and did nothing?</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>He/she has been moving and walking more slowly than usual?</td>
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</tr>
<tr>
<td>7</td>
<td>He/she has been very restless?</td>
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<td>8</td>
<td>He/she felt they were no good any more?</td>
<td></td>
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<td>9</td>
<td>He/she sometimes blamed themselves for things that weren't really his/her fault?</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>He/she found it hard to make up their mind?</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>He/she got grumpy and cross easily?</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>He/she felt like talking a lot less than usual?</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>He/she been talking more slowly than usual?</td>
<td></td>
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<tr>
<td>14</td>
<td>He/she cried a lot?</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>He/she thought there was nothing good for them in the future?</td>
<td></td>
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<tr>
<td>16</td>
<td>He/she thought that life was not worth living?</td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>He/she thought about death or dying?</td>
<td></td>
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<tr>
<td>18</td>
<td>He/she thought the family would be better off without them?</td>
<td></td>
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<tr>
<td>19</td>
<td>He/she thought about taking their own life?</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>He/she felt that they didn’t want to see friends?</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>He/she found it hard to think properly/concentrate?</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>He/she thought bad things would happen to them?</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>He/she hated him/herself?</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>He/she thought they were a bad person?</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>He/she thought they looked ugly?</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>He/she worried about aches and pains?</td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>He/she felt lonely?</td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>He/she thought that nobody really loved them?</td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>He/she not had any fun at school?</td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>He/she thought they could never be as good as other kids?</td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>He/she thought they were doing everything wrong?</td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>He/she slept worse than usual?</td>
<td></td>
</tr>
<tr>
<td>33</td>
<td>He/she slept worse than usual?</td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>He/she has not been as happy as usual even when you praised or rewarded them?</td>
<td></td>
</tr>
<tr>
<td>Number</td>
<td>Description</td>
<td>Not Somewhat</td>
</tr>
<tr>
<td>--------</td>
<td>-----------------------------------------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td>1</td>
<td>Considerate of other people’s feelings</td>
<td>☐</td>
</tr>
<tr>
<td>2</td>
<td>Restless, overactive, cannot stay still for long</td>
<td>☐</td>
</tr>
<tr>
<td>3</td>
<td>Often complains of headaches, stomach-aches or sickness</td>
<td>☐</td>
</tr>
<tr>
<td>4</td>
<td>Shares readily with other children (treats, toys)</td>
<td>☐</td>
</tr>
<tr>
<td>5</td>
<td>Often has temper tantrums or hot tempers</td>
<td>☐</td>
</tr>
<tr>
<td>6</td>
<td>Rather solitary, tends to play alone</td>
<td>☐</td>
</tr>
<tr>
<td>7</td>
<td>Generally obedient, usually does what adults ask</td>
<td>☐</td>
</tr>
<tr>
<td>8</td>
<td>Many worries, often seems worried</td>
<td>☐</td>
</tr>
<tr>
<td>9</td>
<td>Helpful if someone is hurt, upset or feeling ill</td>
<td>☐</td>
</tr>
<tr>
<td>10</td>
<td>Constantly fidgeting or squirming</td>
<td>☐</td>
</tr>
<tr>
<td>11</td>
<td>Has at least one good friend</td>
<td>☐</td>
</tr>
<tr>
<td>12</td>
<td>Often fights with other children or bullies them</td>
<td>☐</td>
</tr>
<tr>
<td>13</td>
<td>Often unhappy, down-hearted or tearful</td>
<td>☐</td>
</tr>
<tr>
<td>14</td>
<td>Generally liked by other children</td>
<td>☐</td>
</tr>
<tr>
<td>15</td>
<td>Easily distracted, concentration wanders</td>
<td>☐</td>
</tr>
<tr>
<td>16</td>
<td>Nervous or clingy in new situations, easily loses confidence</td>
<td>☐</td>
</tr>
<tr>
<td>17</td>
<td>Kind to younger children</td>
<td>☐</td>
</tr>
<tr>
<td>18</td>
<td>Often lies or cheats</td>
<td>☐</td>
</tr>
<tr>
<td>19</td>
<td>Picked on or bullied by other children</td>
<td>☐</td>
</tr>
<tr>
<td>20</td>
<td>Often volunteers to help others (parents, teachers, other children)</td>
<td>☐</td>
</tr>
<tr>
<td>21</td>
<td>Thinks things out before acting</td>
<td>☐</td>
</tr>
<tr>
<td>22</td>
<td>Steals from home, school or elsewhere</td>
<td>☐</td>
</tr>
<tr>
<td>23</td>
<td>Gets on better with adults than other children</td>
<td>☐</td>
</tr>
<tr>
<td>24</td>
<td>Many fears, easily scared</td>
<td>☐</td>
</tr>
<tr>
<td>25</td>
<td>Sees tasks through to the end, good attention span</td>
<td>☐</td>
</tr>
</tbody>
</table>
Listed below are a number of symptoms that your child may or may not have experienced with their condition. Please indicate by circling Yes or No whether you believe that these symptoms are related to your child's paediatric condition.

<table>
<thead>
<tr>
<th>My child has experienced this symptom since their condition developed</th>
<th>This symptom is caused by my child's paediatric condition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain</td>
<td>Yes</td>
</tr>
<tr>
<td>Sore Throat</td>
<td>Yes</td>
</tr>
<tr>
<td>Nausea</td>
<td>Yes</td>
</tr>
<tr>
<td>Breathlessness</td>
<td>Yes</td>
</tr>
<tr>
<td>Weight Loss</td>
<td>Yes</td>
</tr>
<tr>
<td>Fatigue (tiredness)</td>
<td>Yes</td>
</tr>
<tr>
<td>Stiff Joints</td>
<td>Yes</td>
</tr>
<tr>
<td>Sore Eyes</td>
<td>Yes</td>
</tr>
<tr>
<td>Wheeziness</td>
<td>Yes</td>
</tr>
<tr>
<td>Headaches</td>
<td>Yes</td>
</tr>
<tr>
<td>Upset Stomach</td>
<td>Yes</td>
</tr>
<tr>
<td>Sleep Difficulties</td>
<td>Yes</td>
</tr>
<tr>
<td>Dizziness</td>
<td>Yes</td>
</tr>
<tr>
<td>Loss of Strength</td>
<td>Yes</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>Yes</td>
</tr>
<tr>
<td>Poor Appetite</td>
<td>Yes</td>
</tr>
<tr>
<td>Bed Wetting</td>
<td>Yes</td>
</tr>
</tbody>
</table>
We are interested in your own personal views of how you see your child's current paediatric problems. Please indicate (tick) how much you agree or disagree with the following statements about your child's problem by ticking the appropriate box below.

<table>
<thead>
<tr>
<th>VIEWS ABOUT YOUR CHILD'S CONDITION</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree Nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. My child's condition will last a short time</td>
<td></td>
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<tr>
<td>2. My child's condition is likely to be permanent rather than temporary</td>
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<tr>
<td>3. My child's condition will last a long time</td>
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<tr>
<td>4. The condition will pass quickly</td>
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<tr>
<td>5. I expect my child to have the condition for the rest of his/her life</td>
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<tr>
<td>6. My child's problem is a serious condition</td>
<td></td>
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<tr>
<td>7. My child's condition has major consequences on his/her life</td>
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<tr>
<td>8. My child's condition does not have much effect on his/her life</td>
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<tr>
<td>9. My child's condition strongly affects the way I see him/her</td>
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<tr>
<td>10. My child's condition has serious financial consequences</td>
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<tr>
<td>11. My child's condition causes difficulties for those who are close to him/her</td>
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<tr>
<td>12. There is a lot which my child can do to control his/her condition</td>
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<tr>
<td>13. What my child does can determine whether his/her condition gets better or worse</td>
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</tbody>
</table>

### Views About Your Child's Condition

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neither Agree Nor Disagree</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>14. The course of my child's condition depends on him/her</td>
<td></td>
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<td></td>
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<tr>
<td>15*. Nothing my child does will affect their condition</td>
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<tr>
<td>16. My child has the power to influence his/her condition</td>
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<tr>
<td>17*. My child's actions will have no affect on the outcome of his/her condition</td>
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<tr>
<td>18. My child's problem will improve in time</td>
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<tr>
<td>19*. There is very little that can be done to improve my child's condition</td>
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<tr>
<td>20. My child's treatment will be effective in curing his/her condition</td>
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<tr>
<td>21. The negative effects of my child's condition can be prevented (avoided) by their treatment</td>
<td></td>
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<tr>
<td>22. My child's treatment can control his/her condition</td>
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<td></td>
<td></td>
<td></td>
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<tr>
<td>23*. There is nothing which can help my child's condition</td>
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<tr>
<td>24. The symptoms of my child's condition are puzzling to him/her</td>
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<tr>
<td>25. My child's condition is a mystery to him/her</td>
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<tr>
<td>26. My child doesn't understand his/her condition</td>
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<tr>
<td>27. My child's condition doesn't make any sense to them</td>
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<tr>
<td>28. My child has a clear picture or understanding of his/her condition</td>
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<tr>
<td>29*. The symptoms of my child's condition change a great deal from day to day</td>
<td></td>
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</tr>
<tr>
<td>Views About Your Child's Condition</td>
<td>Strongly Disagree</td>
<td>Disagree</td>
<td>Neither Agree Nor Disagree</td>
<td>Agree</td>
<td>Strongly Agree</td>
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<tr>
<td>30. My child's symptoms come and go in cycles</td>
<td></td>
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<tr>
<td>31. My child's condition is very unpredictable</td>
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<tr>
<td>32. My child goes through cycles in which his/her condition gets better and worse</td>
<td></td>
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<tr>
<td>33. My child gets depressed when he/she thinks about his/her condition</td>
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<td></td>
</tr>
<tr>
<td>34. When my child thinks about his/her condition he/she gets upset</td>
<td></td>
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<tr>
<td>35. My child's condition makes him/her feel angry</td>
<td></td>
<td></td>
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<tr>
<td>36*. My child's condition does not worry him/her</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>37. Having this condition makes him/her feel anxious</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>38. My child's condition makes him/her feel afraid</td>
<td></td>
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</tr>
</tbody>
</table>

**POSSIBLE CAUSES**

- C1. Stress or worry
- C2. Hereditary - it runs in my family
- C3. A Germ or virus (eg: illness)
- C4. Diet or eating habits
- C5. Chance or bad luck
- C6. Poor medical care in his/her past
- C7. Pollution in the environment
- C8. His/her own behaviour (eg: disobedience/laziness)
- C9. His/her mental attitude (eg: thinking about life negatively)
- C10. Family problems or worries
- C11. His/her emotional state (e.g. feeling down, lonely, anxious, empty)
- C12. Age - the age he/she is
- C13. Accident or injury
- C14. His/her personality (eg: worrier)
- C15. Altered immune system

In the space below please list in order the three most important factors that you believe caused **YOUR CHILD'S condition**. You may use any of the items mentioned above, or you may have your own additional ideas. The most important causes of my child's condition for me are:

1. 
2. 
3. 

---

**CAUSES OF YOUR CHILD’S CONDITION**

We are interested in what you consider may have been the cause of your child's paediatric problem. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your child’s condition rather than what others including doctors or family may have suggested to you. On the next page is a list of possible causes for your child’s condition.

Please indicate how much you agree or disagree that the following were causes for your child’s condition by ticking the boxes on the next page.
MATERIAL REDACTED AT REQUEST OF UNIVERSITY
### Transformed Data

#### Data Prior to Transformation

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If, $z$ is equal to or greater than +/-3.29 = transform (Tabachnik and Fidell, 2000)

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- Log
- Log
- Log
- Log

Log

-0.569
-1.054
-0.586
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## Appendix 11

### Summary Statistics for Illness and Demographic Variables

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<td>2-6 times</td>
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<td>7-11 times</td>
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### TIME SINCE LAST SYMPTOMS

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### Appendix 11

#### COMORBID PROBLEMS

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#### TIME OF SOILING ACCIDENTS

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#### WETTING

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#### SES

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APPENDIX

QUALITATIVE RESEARCH

"Exploring the Personal Accounts of Men’s Transitions to Fatherhood using Interpretative Phenomenological Analysis"

April 2001

Year 2

PARTICIPANTS NAMES HAVE BEEN CHANGED TO PRESERVE ANONYMITY
INTRODUCTION
The transition to parenthood is a multidimensional process (Hyssala et al, 1993) and can symbolize important changes for a man’s, as well as a woman’s sense of identity (Smith, 1999; Strauss and Goldberg, 1999). This transition however, has largely been researched using quantitative methods (Smith, 1999; Strauss and Goldberg, 1999), has traditionally focused on pathology in women (Smith, 1999) and has yet to clearly identify the mechanisms of change which accompany the transition to parenthood (Strauss and Goldberg, 1999).

In order to provide insight into the mechanisms of the transition to fatherhood, Strauss and Goldberg’s (1999) quantitative study draws on the social psychological concept of “possible selves” and integrates it with constructs of adult development. Cowan, (1991 cited in Strauss and Goldberg, 1999) describes developmental transitions in adulthood as a qualitative re-organization of both inner psychological self-concepts and external roles and relationships. The results from Strauss and Goldberg’s (1999) study supported both internal changes in a man’s self-identity and external changes, as men increased the emphasis on their role as a father and decreased their emphasis on spousal and social roles. Findings from a qualitative study into the transition to motherhood (Smith, 1999) also supported an identity change to that of a ‘mother’ and a shifting focus from social roles to immediate family roles.

Given the lack of qualitative research into the transition to fatherhood, the purpose of this study was to provide a more comprehensive account of men’s experiences of becoming a father for the first time. An idiographic, phenomenological and qualitative approach was adopted (Smith, 1995a cited in Smith, 1999), to capture a more detailed verbal account of the transition from the fathers’ subjective reality.
As theories of transition to parenthood and particularly fatherhood are limited, this study was informed by, but did not test, theories of developmental transitions in adulthood and adjustment to change.

The qualitative experience of the transition to parenthood will undoubtedly be significantly different for men and women. This research thus, only focuses on men and aims to conduct parallel qualitative research to that initiated with women. The experience of the transition to fatherhood is conceivably the most poignant for the first-born child and it was therefore decided that this would be the focus of the research. The phenomenological and exploratory nature of this study into personal accounts of the transition to fatherhood, aims to facilitate the fathers’ recollections of their experiences with as little influence from the researcher as possible. However, the researchers presence during the interview is undeniable. It is therefore important to note the researchers interpretative frameworks, which may have been brought to this study. All of the researchers had completed a clinical placement within child and adolescent services, most knew someone who recently had a baby, and one researcher was male and had a child.

**Methodology**

**Participants**
Fathers were recruited by approaching people that were either known to the researchers or the Psychology department. Father’s of children under the age of five were included to reduce problems with retrospective recall. It was believed that fathers’ of older children would have had more experience of fatherhood and therefore find it harder to recall their initial experiences and expectations. The participants were interviewed about their experiences of fatherhood in relation to the birth of their first child.

**Design and Measures**
A semi-structured interview schedule (Appendix 1) was devised by discussing the experiences of fatherhood with the male researcher within the group and by considering a similar interview schedule designed for mothers (previous year’s project).
Six fathers were approached to participate in the thirty-minute, face-to-face interview schedule about their experiences of becoming a father for the first time. The interview schedule commenced with the completion of a demographics form (Appendix 2) and included questions on changes they experienced as a father and their expectations of fatherhood both before and after the birth. The semi-structured interview was designed with open-ended questions and prompts in order to provide a rich source of data (Smith, 1995) to guide the researchers and to encourage the participants to make connections. An information sheet, introductory statement and the prompts were included to establish consistency across the researchers. The interviews were audiotaped and transcribed (Appendix 3).

**PROCEDURE**

Interpretative phenomenological analysis (IPA) (Smith 1996 cited in Smith, 1999; Smith, Jarman and Osborne, 1999) was used to analyse the data. IPA enables a systematic analysis of the data and aims to explore the participants’ experiences, cognitions and way they make sense of the world (Smith, Jarman and Osborne, 1999). The interpretative analysis, conducted by the researcher, is recognised as a construction of the participants’ personal account and the researchers’ interpretative frameworks (Coyle and Rafalin, 2000). The combination of the participants’ subjective account and the researchers’ analysis makes the process phenomenological, and interpretative. IPA is also idiographic and assumes that the interpretations are meaningful because the analysis is grounded in the fathers’ accounts (Smith, Flowers and Osborn 1997 cited in Coyle and Rafalin, 2000).

Participants were informed about the study verbally and written information provided on an information sheet (Appendix 4). Informed consent to participate and audiotape the interview was obtained from the participant and confidentiality assured in writing by the researcher (Appendix 5). A demographic sheet was completed before the interview was conducted.
The following idiographic analytic process was conducted:

1. One transcript was randomly selected and jointly analysed by the researchers. The script was read several times. Initially, interesting comments, connections and preliminary interpretations were noted and later emerging theme titles were developed.

2. The emerging themes were listed on a separate page and connections that fitted the data were made.

3. An initial themes list from the first transcript was made.

4. The researchers then individually analysed their own transcripts by using and adding on to the initial theme list.

5. After all the transcripts had been analysed, the researchers collectively clustered together subordinate concepts, looked for connections between the themes and combined themes in ways that made sense.

6. A final list of themes was agreed upon, and which themes to focus on in the discussion. Examples of the themes were pulled from the transcripts.

The process of analysis was collaborative amongst the researchers and the themes were generated from the participants’ accounts. The use of illustrative quotations from the data in IPA provided evidence for the themes and the validity of the analysis. In these illustrative quotations, points (...) indicate a pause in the participant’s speech, empty square brackets indicate that material has been omitted and information provided within square brackets is for clarification. Further validity of the analysis is supported by the repeated analysis of the data and the consensus of the six researchers.
**ANALYSIS AND RESULTS**

Six fathers participated in this study (Table 1). All participants were of white ethnic origin, were employed and living with the mother of their child. The mean age was thirty-four years (SD = 6.3, range 26-42 years). Four participants had one child, and two had more than one child. The age of the first-born child ranged from three and a half months to five years (mean of 21 months, SD = 1.85 years) (Table 2). All of the children were mainly cared for by their mothers, half had another form of childcare and none had special needs.

**Table 1: Demographics Concerning Father**

<table>
<thead>
<tr>
<th>Participant</th>
<th>Age</th>
<th>Ethnic Origin</th>
<th>Occupation</th>
<th>Marital Status</th>
<th>Number of Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>G</td>
<td>35</td>
<td>White UK</td>
<td>Plumbing / Heating Engineer</td>
<td>Married</td>
<td>Two</td>
</tr>
<tr>
<td>D</td>
<td>34</td>
<td>White UK</td>
<td>Tax Consultant</td>
<td>Married</td>
<td>One</td>
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<tr>
<td>H</td>
<td>42</td>
<td>White Other</td>
<td>Psychology Professor</td>
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<td>One</td>
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<tr>
<td>M</td>
<td>26</td>
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<td>Manager</td>
<td>Living together</td>
<td>One</td>
</tr>
<tr>
<td>C</td>
<td>28</td>
<td>White UK</td>
<td>Technician</td>
<td>Living together</td>
<td>One</td>
</tr>
<tr>
<td>S</td>
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<td>Technician</td>
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</table>

**Table 2: Demographics Concerning First Born Child**

<table>
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<tr>
<th>Participant</th>
<th>Age of Child</th>
<th>Main Carer</th>
<th>Other Care Arrangements</th>
<th>Special Needs</th>
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<tbody>
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<td>3 years</td>
<td>Mother</td>
<td>Nursery</td>
<td>None</td>
</tr>
<tr>
<td>D</td>
<td>3 ½ months</td>
<td>Mother</td>
<td>None</td>
<td>None</td>
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<tr>
<td>H</td>
<td>5 months</td>
<td>Mother</td>
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<td>None</td>
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<td>M</td>
<td>1 year</td>
<td>Mother</td>
<td>Family</td>
<td>None</td>
</tr>
<tr>
<td>C</td>
<td>1 year</td>
<td>Mother</td>
<td>Family</td>
<td>None</td>
</tr>
<tr>
<td>S</td>
<td>5 years</td>
<td>Mother</td>
<td>None</td>
<td>None</td>
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</table>
The key themes derived from the analysis of the transcripts are listed below (Table 3), with illustrative examples. All participants felt that something changed internally about themselves or externally in their relationships when they became a father for the first time. The theme pertaining to relationship changes generated a large amount of data and subsumed relationship changes relating to their partners/wives, work colleagues, parents and friends. It was decided to choose this theme for further discussion due to its breadth and relevance to previous work.

Table 3: Fathers' Themes

<table>
<thead>
<tr>
<th>THEMES</th>
<th>EXAMPLE</th>
</tr>
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<tbody>
<tr>
<td>Denial</td>
<td>“May be I was denying I was going to be a dad” (Mr C).</td>
</tr>
<tr>
<td>Change of priorities/Responsibilities</td>
<td>“I think because you have the responsibility of a child, your whole life changes really” (Mr G).</td>
</tr>
<tr>
<td>Change of self perception</td>
<td>“I am sort of surprised by my capacity to care. I am certainly surprised by my determination to find time and prioritise for him [child]” (Mr H).</td>
</tr>
<tr>
<td>Shared experiences with other parents</td>
<td>“Yes, you are suddenly in a club as well, there’s a whole group out there you suddenly relate to” (Mr M).</td>
</tr>
<tr>
<td>Feelings of protectiveness</td>
<td>“I’d kill for my child, there’s no two-ways about it” (Mr M).</td>
</tr>
<tr>
<td>Change in relationships</td>
<td>“... there is a sense of loss for a way of life and a relationship (wife) because this is gone, this is different” (Mr S).</td>
</tr>
<tr>
<td>Worries/concerns</td>
<td>“I had some dreads that he [child] would have been unhealthy or had a disability or that Y [wife] would have had a traumatic birth” (Mr H).</td>
</tr>
<tr>
<td>Lack of knowledge/experience/preparedness</td>
<td>“... you suddenly realise you are about to become an adult to another person and you think hell, I don’t know anything” (Mr S).</td>
</tr>
<tr>
<td>Feeling distant</td>
<td>“N [partner] can say ‘Oh L [child] did this today’ and I feel dreadful that I missed it” (Mr M).</td>
</tr>
<tr>
<td>Change for the better</td>
<td>“You know life is going to change, it’s not going to change for the worse, it’s going to change for the better” (Mr G).</td>
</tr>
<tr>
<td>Making comparisons of child</td>
<td>“Every child is different, parents all have set expectations and when you talk to someone else your child is probably not doing some of the things another child is” (Mr G).</td>
</tr>
<tr>
<td>Emotional intensity</td>
<td>“… but that strength of feeling is something that wasn’t anticipated ... I didn’t expect it to be so unconditional and so powerful” (Mr H).</td>
</tr>
<tr>
<td>Conflicting emotions</td>
<td>“... I felt because of that sense of loss that I was feeling as well, that somehow that was bad. How could I possibly feel that way at a time like this?” (Mr S).</td>
</tr>
<tr>
<td>Difficulty sharing emotions</td>
<td>“... it is also far more emotional and that's not the things that we blokes chat about all that much” (Mr S).</td>
</tr>
</tbody>
</table>
Change in Relationships
The participants described changes in their external roles and relationships with other people after becoming a father. Many of these changes could be associated with the man’s reorganization of his inner psychological self and inclusion of a new aspect of his identity, a ‘father’.

With Wife/Partner
Adjusting to the reality of fatherhood featured as an important issue within the participants’ relationships with their partners/wives. For Mr. M, the strength of his relationship with his partner developed, along with his new identity:

    I think it brought us closer in a different kind of way as I started to realise what we had made together and what we were about to do together.

Mr H also felt that a stronger relationship had developed with his wife:

    [ ] there’s a still deeper bond by virtue of ... connected to [child] ... which we didn’t have.

For Mr D, the development of his wife’s new identity as a mother was an important aspect in the way their relationship advanced:

    ... perhaps just seeing her as a mother and how she is coping has added a new dimension to the love and respect ... but the core is still the same.

Although the transition to fatherhood was seen to evoke positive changes for most fathers in their relationships with their partners, some fathers identified a conflict between what they had gained and what they had lost:

    ... there is a sense of loss for a way of life and a relationship because that is gone, this is different. [ ] The feeling is almost like, I do say almost like, a bereavement because you are losing something. And that isn’t something that people are encouraged to talk about. (Mr S)
Mr C also indicated the presence of a conflict, in relation to the way his role as a father was detracting from his role as a spouse:

Well, we don't really see that much of each other [ ] we are both a lot more tired and kind of pre-occupied with our own things, we don't do things we used to do together.

With Friends

In the same way that some fathers felt their new role as a father had detracted from their role of a spouse, they also felt that it detracted from their wider social relationships. Mr D, a father of five months, explained how his ‘whole new priority’ as a father had not only changed his expectations of others, but also effected the time he had for them:

... I expect people to take account of the fact that my circumstances have changed and so to some extent I think that makes me a bit more pressed in dealing with people for the time than I would have been.

Although the ability to continue with social relationships appeared to ‘all come down to time’ (Mr G) for all of the fathers, identification with the role of a father and ‘family life’ also appeared to have a wider impact on the development of old and new relationships. Mr G described how friendships physically changed:

... we lost touch with some friends who haven’t got children, are not interested in children .... and closer with friends who have got families and children.

For Mr G the change in his relationships were related to his change in identity and priorities as a family man:

If you have friends who are single and want to do single things, you can’t do that as a parent. [ ] He [a friend] is leading a life of a single man [ ], whilst I am a living a family life and it’s hard to ... it’s not that we don’t have common interests ... it all comes down to time.
With Work Colleagues

Mr D described how his identify and being perceived as a father also influenced the nature of existing relationships, particularly those with his work colleagues:

... I have a management role where I work and it's quite interesting, people see me as much more human now than they would have seen me before.

For Mr M the change in relationships at work, came from changes in his own perceptions about himself:

My feelings about work have changed because of it. [...] Before I did not always take work and things seriously at times and yet now I feel more settled, I have been given a promotion am loads more reliable. I think they know that I will not always be the one to joke around, as I am keen to do well.

With Parents

For some of the fathers, the nature of their relationships with their parents also appeared to change on a more qualitative level. Mr M explained what some of the changes were:

 [...] they have certainly taken me under their wing more as they are always giving us lots of advice and there is always support, which is nice. [...] I also feel as if they consider me finally to be a mature adult with real responsibilities.

Mr D summed why he felt his relationship with his parents had changed when he become a father:

"I suppose appreciating what they've gone through makes me see them [parents] in a different light and in a more understanding, more appreciative ..."

The changes in relationships described by the fathers are connected to a number of other themes that emerged in the transcripts, such as; change in self-perception, shared experiences with other parents and change in priorities/ responsibilities. These other themes could be seen to underlie and therefore contribute to the actual changes in the quality, nature and basis of relationships.
**DISCUSSION AND OVERVIEW**

**THEORETICAL IMPLICATIONS**

This study draws attention to the importance of the reorganisation of a man's identity and the inclusion of a 'parental' identity during the transition to fatherhood. The fathers in this study appeared to describe the impact of this transition as both an internal change and an external, behavioural change. According to Cowan, (1991) the transition to fatherhood is a developmental process, which includes a qualitative reorganisation of the way a father understands and feels about himself and the world. This was reflected in the way the fathers identified themselves as being more responsible, mature, part of a 'parent club' and very protective of their child. Cowen (1991) also included changes in the father's outer roles and relationships with other people as part of the transition. This was evident in the way the fathers described changes in their relationships with their partners, work colleagues, friends and parents and identified conflicts between their new role and losses in their old roles. Strauss and Goldberg's (1999) quantitative study supports evidence for the reorganisation of a man's identity to include the creation of a new facet, the 'parent', at the expense of spousal and wider social roles. Similarly, Smith's (1999) qualitative study of the transition to motherhood describes the move from a wider social role to the family role as a 'shift in focus' and transformation of identity.

**IMPLICATIONS FOR PRACTICE**

As an exploratory study into the transition into fatherhood, several important issues were identified that could form the foundations for further qualitative research. Although some of the fathers' experiences reflected similarities to a woman's transition to motherhood (Smith, 1999) the fathers also discussed different issues; such as being perceived differently at work, feeling more responsible as the provider for the family and difficulties discussing feelings of ambivalence during the pregnancy. The most important issue highlighted by one of the fathers was his feelings of bereavement towards losing a way of life he had become accustomed to with his partner and his feeling that it would be socially unacceptable to discuss this. The discussion of such feelings of ambivalence may have important clinical implications.
for parenting skills groups. Therapeutic interventions should not assume that experiences are equivalent for both parents and should take account of gender differences and the different social pressures on them.

**LIMITATIONS**

The study provides a valuable insight as an exploratory piece of work. However, the sample size of six, although acceptable within qualitative research, does not claim to represent the experiences of all men. The sample is fairly homogenous in that it consists of white, middle class men, in stable relationships and in employment and future research with men from different cultures and circumstances should be considered. The sample does however, include a range of ages, both planned and unplanned pregnancies and fathers with more than one child. It should be acknowledged that the inclusion of fathers with older and more than one child may have led to slightly different views on becoming a father, however their views did not appear to be too dissimilar to the other fathers. Finally, the gender of the researchers may have influenced the content of the interviews. Five of the six were female and it is possible that the men may have been influenced by what they considered appropriate to discuss in front of the women. However, since all encounters between people involve expectations, interviews with a male researcher could equally have been influenced in this manner. The phenomenological nature of this study also reduces the researchers influence because it is grounded in the participants’ accounts and constructs, not the researchers.
REFERENCES


APPENDIX

1. Interview Schedule

2. Demographics Form

3. Interview Transcript

4. Research Information Sheet

5. Research Consent Form
APPENDIX 1

SEMI-STRUCTURED INTERVIEW

Introduce the research by providing and reading through the information form. Draw attention to confidentiality procedures outlined on the consent form and obtain written consent to interview and audio-tape the interviewee. Counter-sign the consent form.

Provide the demographic information form and ask the interviewee to complete it.

As mentioned earlier, this research is looking at whether men experience any major changes, not just practical ones, when they became fathers.

1. Do you think that anything has changed about you or your relationships with other people since you became a father?

2. What do you think has changed since becoming a father? [Can you give me an example? Can you tell me a little more?]

Prompts:

Self, Leisure

Relationship with partner, family, friends, work colleagues

Personal circumstances (finance, housing)
3. What were your expectations of fatherhood before the birth of your (first) child?
[Can you give me an example? Can you tell me a little more?].

Prompts:
Self (responsibility, feelings, self-image, skills)
Child (behaviour, temperament, health)
Relationships with others (partner, family, friends, work colleagues)

4. Have your expectations of fatherhood been met since the birth of your (first) child?
[Can you give me an example? Can you tell me a little more?].

Prompts:
Self (responsibility, feelings, self-image, skills)
Child (behaviour, temperament, health)
Relationships with others (partner, family, friends, work colleagues)

5. Do you have any other comments?

THANK YOU VERY MUCH
To start, I would like to get some background information about you and your first child. The information will help me understand you and your child better within the context of this research.

The research is entirely confidential and neither you or your child will be identified in any way. If you feel that there are questions you do not want to answer, please feel free to do so. Again, I would like to thank you for your time.

1. How old are you? _________________________________

2. Which (if any) of the following best describes your ethnic background (tick the most appropriate answer)
   - White-UK
   - White Other
   - Black-African
   - Black-Caribbean
   - Black Other
   - Indian
   - Pakistani
   - Bangladeshi
   - Chinese
   - Other

3. What is your current (or last) occupation? _________________________________

4. What is your marital status? (tick most appropriate answer)
   - Married
   - Single
   - Living Together
   - Divorced
   - Separated
   - Widowed

5. How many children do you have?
   - One
   - Two
   - Three
   - Four
   - Five
6. How old are they?

Prompt: Ask interviewee of their first child’s name

7. Who is (the child's name) main carer? (tick most appropriate answer)

- Father
- Mother
- Family
- Friends
- Childminder
- Other (please specify)

8. Does (the child's name) have any other child care arrangements not previously mentioned? (tick most appropriate answer)

- Day Care
- Nursery
- Family
- Friends
- Nanny
- Other (please specify)

9. Does (the child's name) have any special requirements (for example, learning disability, health problem, developmental delay)

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
**INTERVIEW TRANSCRIPT**

Do you think that anything has changed about you or your relationships with other people since you became a father?

Yes.

What do you think has changed since becoming a father?

Perspective of life has changed, priorities have changed, financial situation has changed, outlook on life has changed - you know lots of changes.

What was your change in priorities?

Your children become your priority, and other social commitments take second place to the children. ... I think because you have the responsibility of a child, your whole life changes really.

You mentioned your outlook on life changed?

You are providing for a child. You are trying to give them the best, if you can, guide them through life as they grow up to be a good person, help them as much as you can. You know, think about them and you take it off yourself. Your outlook on life is more for them then yourself probably. Probably only until ... until, they get to an age when they are not relying on you and they get more independent ... then ... probably get more freedom of life back then your outlook on life would probably change back then. You can do more things that I want to do ... we want to do, I suppose now we are basing it around the children.

So, how have things changed in your social life?

Well, not as much as I thought. Just a re-structure of things, get more organised. You have them to think about as much as yourself. You have to re-arrange your social diary, carry on with and not completely cancel it. You can’t do as much as you would have done, like before you had children ... Again, I think it’s only until the age when they are dependent on us, then ... once they are old enough to be left on their own you can do more. In my situation doing scouting, you know, like if I have a weekend away, you can take one of them with you, it’s unfair to leave the wife on her own with two, so we share the work load. Luckily, I do an interest she [my daughter] can come along to, I suppose if I played an individual sport, like squash, it would be more awkward you wouldn’t leave her in the corner of the squash court.
Do you think that has changed things with your wife as well?

I suppose we [my wife] haven’t been able to do as much together, when one is out the other one is in. We split up the week. I go out certain nights, she goes out other nights. When she goes out I look after the children and when I’m out, she looks after the children. I have had to give up certain things, not many, but especially with my job. You have to balance your job, your life and your family. Now she is three, we have found the procedure easier to manage now, than when she was under one and when she was completely relying on us. Now she is getting a little more independent, it is making things easier.

What were your expectations of fatherhood before the birth of [child’s name]?

What my perspective of a child was?

What your expectations of fatherhood were.

I think before she was born and got used to having an extra person in the house ... it was quite daunting and frightening. A lot of things we spoke about in the last question really... umm ... financial things and responsibility of having a child ... I think looking forward to it... again, because you are not thinking of yourself all the time, you have got a young person to share and do things with, play with, you know, play with children, go to places with you wouldn’t go with an adult to, enjoy yourself I think I have never been bored since I have had children, there is always something happening. You never get time to consider things and sit down and think ‘I’m bored’.

Were you expecting that before she was born?

Yes, I was expecting that because I knew you would get a major disruption in what you would normally be doing. Life would centre around them for quite a few years. You know, like holidays, everything is based on them, not yourself ... till they grow older. I think that’s something that’s going to happen and you know that before you are going to have children. You know that life is going to change, it’s not going to change for the worse, its going to change for the better. You just sort of have to give and take. I suppose you don’t have to ... you don’t have to put life on hold, you have to keep going. I suppose everyone ... you don’t really know what it’s going to be like until it arrives. You just get used to it really. When you first take them home from the hospital, you just sort of think, what do I with this thing? You sort of learn as you go.

Before she was born, were you expecting your outlook on life to change?

Probably ... Yes. Umm ... You know, I have got a sister and friends who have children ... you see things. You know they don’t physically change, their outlook on life changed. I think with scouts and being involved with other children I think I knew what I was letting myself in for. You know ... I was thinking that it would change my life ... I had a pretty good idea about what it would all be about. You
think back and you think, it’s much more for one child, I suppose it’s not much
different the second time. You get used to it by then.

Have your expectations of fatherhood been met since the birth of your (first) child?

I probably ... umm... thought she would progress quicker than she did. It seemed a
long time, a year, before she was up and walking. Umm ... things took longer than I
probably thought they would ... when she progressed and her independence would
start to come. Sometimes they go forward and they go backward. You don’t
appreciate that. You think that they are always going to progress and that once they
have learnt something that that’s it and they are off ... but they go backwards for a
few weeks or months and then they go forward again. A lot of the time you don’t
know what to expect ... so you have some expectations, but you don’t really know
what...every child is different, parents all have set expectations and when you talk to
someone else your child is probably not doing some of the things another child is. But
then yours is doing things that the other child isn’t. So they are all individual. Unless
you have personal and individual expectations, it is really just waiting and taking it as
it comes.

I think the expectations of having a child were met. We were lucky to have a healthy
child ... you know, baby. She developed closed to the norm, she’s full of beans and
doing everything a child of her age should. So ... you know, probably an expectation
of being a father is that your child is healthy... A1. If your child wasn’t A1, it
wouldn’t meet your expectations. If she wasn’t then I would think, well ..., you know
I think she met all the expectations. I don’t know if we met all the expectations for
what we should do ... but you learn as you go along ... make mistakes. You learn
from other people.

So did it affect your relationships with other people, in the way you thought it would?

Yes, we lost touch with some friends possibly who haven’t got children, are not
interested in children or are not directly in the company of children and closer with
other friends, who have got families and children. Once you got children ... I was
going to say your friends change ... but you tend to mix, especially [wife], who mixes
more with people who have children rather than haven’t got children. You are going
to clubs and nurseries and meetings. That’s changed your life in some ways. It has
moved your circle of friends ... your life on in one direction, rather than another
direction. Your main nucleus of friends stays that same, but it broadens out in one
direction, but I do think the problem is not that I have lost friends... but not seen
friends since we have had children.

Were you expecting that to happen before [child’s name] was born?

No. I don’t think I was. That was something that happened. Again it’s your outlook
on life that changes. If you have friends who are single and want to do single things,
you can’t do that as a parent, so ... then probably that friendship drifts. I know at least
one friend who I have probably drifted away from as I now have children and he
hasn’t. He is sort of leading the life of a single male and he’s living that sort if life,
whilst I am living a family life and its hard to... you know, it's not that we don't have any common interests ..... it all comes down to time.

*Do you have any other comments?*

I think, once you have a second child you are much more relaxed ... you still have your main expectations, that you want a healthy child and your expectations are based on the first child I suppose. But things are a lot easier because you are more relaxed, you have done it once before. You know what to do and hopefully know what not to do. You have already adapted to having a child already, so a second child coming into the family is only an extension of the first. You are literally spending time with more, with both of them .. you know trying to spend time with both of them. Probably split [my wife] and me up a bit. You are concentrating with one and then you swop over and concentrate on the other. When you are out and about, you individually look after one each. You know, you try not to .. you don’t particularly ... go for one child all the time, you try and swop about.
RESEARCH INFORMATION SHEET

Exploring the transition to fatherhood following the birth of a first child

I am a trainee Clinical Psychologist at the University of Surrey, conducting a research study into how men experience the change from fatherhood following the birth of their first child.

After the birth of their first child men take on a new role as fathers. Although there has been considerable research into the parallel transition in women, there has been little research in the experience of men becoming fathers. I am undertaking this research to help develop a greater understanding of this process.

I am seeking people who have children of pre-school age. Those who volunteer for the research will be interviewed about their experiences for approximately 30 minutes. Interviews will take place in a location convenient to you.

I hope this research will help psychologists, therapists and counsellors working with children and families. I also hope that those who take part in the research find it helpful to talk about their experiences.

Trainee Clinical Psychologist
Psychology Department
University of Surrey
Guildford. GU2 5XH.
Appendix 5

Research Consent Form

Exploring the transition to fatherhood

The aim of this research is to explore the transition of men to fatherhood following the birth of their first child.

You will be asked to take part in an informal interview about your experiences of fatherhood. The interview will be recorded on audio-tape so that, in writing up the research, I can cite people's experiences directly. Naturally, to protect confidentiality, I will not quote any identifying details such as names and locations. In making the transcriptions, therefore, your name will be replaced by a letter and I will not record the names of other people or places that arise in the interview. Once transcribed, the audio-tape recordings will be destroyed.

If you have any questions so far, or feel that you would like further information about this research, please ask the researcher before reading on.

Please read the following paragraph and if you are in agreement, sign where indicated.

I agree that the purposes of this research and what my participation in it would entail have been clearly explained to me in a manner that I understand. I therefore consent to be interviewed about my experience of the transition to fatherhood. I also consent to an audio-tape being made of this discussion and to all parts of this recording being transcribed for the purposes of research.

Signed .......................................................... Date.................................

On behalf of those involved with this research project, I undertake in respect of the audio-tape (s) made with the above participant, professional confidentiality will be ensured and that any use of audio-tapes or transcribed material from audio-tapes will be for the purpose of research only. The anonymity of the above participant will be protected.

Signed .......................................................... Date.................................