A Portfolio of Study, Practice and Research

Volume one

including

Expressed Emotion, attributions and knowledge in carers of people with dementia
(large scale research project)

by

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Submitted for the Doctorate of Psychology
(PsychD) in Clinical Psychology
Surrey University

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Table of contents

<table>
<thead>
<tr>
<th>Acknowledgements</th>
<th>1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction to the Portfolio</td>
<td>2</td>
</tr>
<tr>
<td><strong>Academic Section:</strong></td>
<td>3</td>
</tr>
<tr>
<td>Summary of the Academic Section</td>
<td>4</td>
</tr>
<tr>
<td><strong>Essay one:</strong> Discuss the role of the psychologist</td>
<td>5</td>
</tr>
<tr>
<td>in a rehabilitation/ continuing care multi-disciplinary team and which aspects of a person's care they would be involved in</td>
<td></td>
</tr>
<tr>
<td><strong>Essay two:</strong> Concern has been raised regarding a relationship between two clients of the same sex but of differing levels of ability living in a staffed home. What are the areas that need to be considered when reflecting on this relationship, with specific reference to consent and policy issues?</td>
<td>17</td>
</tr>
<tr>
<td>Introduction</td>
<td>18</td>
</tr>
<tr>
<td>Policy guidelines on sexuality, and the influence of Normalisation/Social Role Valorisation</td>
<td>18</td>
</tr>
<tr>
<td>The concept of choice in sexuality for people with learning disabilities</td>
<td>19</td>
</tr>
<tr>
<td>The influence of law on issues of consent</td>
<td>21</td>
</tr>
<tr>
<td>Gap between level of learning disability of two clients and it's influence on consent to sexual activity</td>
<td>22</td>
</tr>
<tr>
<td>Sex education</td>
<td>24</td>
</tr>
<tr>
<td>Exploration of the homosexual identity</td>
<td>25</td>
</tr>
<tr>
<td>Parental attitudes</td>
<td>26</td>
</tr>
<tr>
<td>Staff attitudes</td>
<td>26</td>
</tr>
<tr>
<td>Summary</td>
<td>27</td>
</tr>
<tr>
<td>References</td>
<td>28</td>
</tr>
<tr>
<td><strong>Essay three:</strong> Consider the utility of the diagnostic classification of Attention Deficit Disorder</td>
<td>30</td>
</tr>
<tr>
<td>Introduction</td>
<td>31</td>
</tr>
<tr>
<td>Shifts in the understanding of the disorder and it's resulting change in nomenclature</td>
<td>31</td>
</tr>
<tr>
<td>Validity of the DSM-IV diagnostic classification and it's sub-classifications</td>
<td>34</td>
</tr>
<tr>
<td>Evidence for a unitary or separate disorder</td>
<td>34</td>
</tr>
<tr>
<td>Associated features of ADHD and co-morbidity with other disorders</td>
<td>36</td>
</tr>
<tr>
<td>The utility of specific properties of the diagnostic criteria</td>
<td>37</td>
</tr>
</tbody>
</table>
Practical value of diagnostic classifications in guiding assessment 38
The usefulness of diagnostic classification for the individual 39
Wider implications of a diagnosis within the medical model 40
Summary 41
References 43
Appendices 49
Appendix 1 Attention Deficit Hyperactivity Disorder - DSM-IV Criteria (American Psychiatric Association 1994) 50
Appendix 2 Hyperkinetic disorder - International Classification of Diseases (World Health Organisation, 1990) 52

Essay four: What psychological models have informed the development of psychotherapeutic work with people with dementia? What are the aims of such work, and how may it be evaluated? 54
Introduction 55
Reality Orientation Therapy 56
Reminiscence Therapy 60
Validation Therapy 62
Conclusions 65
References 66

Essay five: Critically evaluate the effects of transference interpretations upon treatment outcome in brief dynamic psychotherapy 70
Introduction 71
Definitions:
Brief dynamic psychotherapy 72
Transference and transference interpretations 73
Frequency/proportion of transference interpretations in therapy 73
Accuracy of transference interpretations in therapy 76
Patient’s immediate response to transference Interpretations 78
Other factors which may potentially influence the effectiveness of transference interpretations in brief dynamic psychotherapy 80
Clinical Section:
Summary of the clinical section

Placement one (Adult Mental Health Core): Basic details
Adult Mental Health Core Placement Summary
Adult Mental Health Case Summary

Placement two (Learning Disabilities Core): Basic details
Learning Disabilities Core Placement Summary
Learning Disabilities Case Summary

Placement three (Child and Family Core): Basic details
Child and Family Core Placement Summary
Child and Family Case Summary

Placement four (Older Adults Core): Basic details
Older Adults Core Placement Summary
Older Adults Case Summary

Placement five (Specialist I): Basic details
Specialist Placement I Summary
Specialist Placement I Case Summary

Placement six (Specialist II): Basic details
Specialist placement II Summary

Research Section:
Summary of the Research Section

Childhood sexual abuse: risk factors within the family context: A Literature Review
Sequelae of childhood sexual abuse
Definitions
Prevalence
Child characteristics as risk factors
Gender
Age at onset
<table>
<thead>
<tr>
<th>Social isolation of the victim</th>
<th>110</th>
</tr>
</thead>
<tbody>
<tr>
<td>Area of residence</td>
<td>110</td>
</tr>
<tr>
<td>Lack of close personal relationships</td>
<td>110</td>
</tr>
<tr>
<td>Family characteristics</td>
<td>111</td>
</tr>
<tr>
<td>Social class/income</td>
<td>111</td>
</tr>
<tr>
<td>Abuser characteristics</td>
<td>111</td>
</tr>
<tr>
<td>Gender</td>
<td>111</td>
</tr>
<tr>
<td>Step fathers</td>
<td>112</td>
</tr>
<tr>
<td>Social competence</td>
<td>112</td>
</tr>
<tr>
<td>Childhood history of CSA</td>
<td>113</td>
</tr>
<tr>
<td>Authoritarian behaviour</td>
<td>113</td>
</tr>
<tr>
<td>Parental absence and unavailability</td>
<td>114</td>
</tr>
<tr>
<td>Parental absence</td>
<td>114</td>
</tr>
<tr>
<td>Parental unavailability</td>
<td>115</td>
</tr>
<tr>
<td>Conflict between parents</td>
<td>116</td>
</tr>
<tr>
<td>Family environment characteristics</td>
<td>117</td>
</tr>
<tr>
<td>Differences in family characteristics between intra-familial and extra-familial abuse</td>
<td>118</td>
</tr>
<tr>
<td>Models and theories</td>
<td>119</td>
</tr>
<tr>
<td>Finkelhor's Four Preconditions Model of Sexual Abuse</td>
<td>119</td>
</tr>
<tr>
<td>Radical Feminist Theory</td>
<td>120</td>
</tr>
<tr>
<td>Developmental model</td>
<td>120</td>
</tr>
<tr>
<td>Attachment theory</td>
<td>121</td>
</tr>
<tr>
<td>The Biosocial Theory of Incest Avoidance</td>
<td>121</td>
</tr>
<tr>
<td>Interrelational theory</td>
<td>122</td>
</tr>
<tr>
<td>Systemic theories</td>
<td>122</td>
</tr>
<tr>
<td>Methodological limitations</td>
<td>123</td>
</tr>
<tr>
<td>Samples</td>
<td>123</td>
</tr>
<tr>
<td>Sample size</td>
<td>123</td>
</tr>
<tr>
<td>Sample type</td>
<td>124</td>
</tr>
<tr>
<td>Control groups</td>
<td>124</td>
</tr>
<tr>
<td>Measures</td>
<td>124</td>
</tr>
<tr>
<td>Lack of precision in variables</td>
<td>124</td>
</tr>
<tr>
<td>Lack of reliability and validity</td>
<td>125</td>
</tr>
<tr>
<td>Retrospective versus prospective methodology</td>
<td>125</td>
</tr>
<tr>
<td>Statistical analyses</td>
<td>126</td>
</tr>
<tr>
<td>Conclusions</td>
<td>126</td>
</tr>
<tr>
<td>References</td>
<td>127</td>
</tr>
</tbody>
</table>
Perception of control, self perceptions and global self-worth in children with Primary Nocturnal Enuresis
(Combined small scale and service related research)

Abstract

Objectives
Design
Data collection
Results
Conclusions

Introduction
Definitions of Enuresis
Prevalence
Aetiology
  Genetic factors
  Bladder function
  Maturational delay
  Learned response
  Psychological, emotional and behavioural difficulties
Assessment
Treatment
Perception of control
Self concept and self esteem
Rationale for the study

Objectives
Hypotheses
Method
Participants
Sample sources
Inclusion/Exclusion criteria
Procedures
Measures
  1. Semi-structured interview measuring perception of control over symptoms (bed wetting and stomach or head aches)
  2. Multi-dimensional Measure of Children’s Perceptions of Control (Connell, 1985)
  3. Self Perception Profile for Children (Harter, 1985)
Statistical analyses
  Responses to semi-structured interviews
  Responses to questionnaires

Results
Precautionary note
**Symptomatology: Beliefs about locus of control and symptom improvement**  
1. Beliefs about locus of control over occurrence of symptoms 152  
2. Beliefs about locus of control in relation to symptom improvement 153  
3. Ideas about how children themselves could contribute to symptom improvement 154  
4. Responsibility taking behaviour for the consequences of symptoms 155  

**Beliefs about control related to other domains of life**  
(Multidimensional Measure of Children’s Perception of Control) 156  

**Perceived competence in important domains of life and global self worth**  
(Self Perception Profile for Children; SPPC; Harter, 1985) 159  

**Discussion** 161  

**Summary of potential service implications** 165  

**References** 167  

**Appendices**  

<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 1</td>
<td>Ethical permission from Kingston and Richmond Health Authority</td>
<td>172</td>
</tr>
<tr>
<td>Appendix 2</td>
<td>Ethical permission from Merton, Sutton and Wandsworth Health Authority</td>
<td>173</td>
</tr>
<tr>
<td>Appendix 3</td>
<td>Ethical Permission from South West Surrey LREC</td>
<td>174</td>
</tr>
<tr>
<td>Appendix 4</td>
<td>Letter of invite (Enuresis Group)</td>
<td>175</td>
</tr>
<tr>
<td>Appendix 5</td>
<td>Letter of invite (Paediatric Group)</td>
<td>176</td>
</tr>
<tr>
<td>Appendix 6</td>
<td>Information sheet for parents (Enuresis Group)</td>
<td>177</td>
</tr>
<tr>
<td>Appendix 7</td>
<td>Information sheet for parents (Paediatric Group)</td>
<td>178</td>
</tr>
<tr>
<td>Appendix 8</td>
<td>Parent consent form (Enuresis/Paediatric Group)</td>
<td>179</td>
</tr>
<tr>
<td>Appendix 9</td>
<td>Parent consent form (Sibling Group)</td>
<td>180</td>
</tr>
<tr>
<td>Appendix 10</td>
<td>Child consent form (Paediatric/ Enuresis Groups)</td>
<td>181</td>
</tr>
<tr>
<td>Appendix 11</td>
<td>Child consent form (Sibling Group)</td>
<td>182</td>
</tr>
<tr>
<td>Appendix 12</td>
<td>Rapport gaining questions</td>
<td>183</td>
</tr>
<tr>
<td>Appendix 13</td>
<td>GP letter</td>
<td>184</td>
</tr>
<tr>
<td>Appendix 14</td>
<td>Semi-structured Interview (Enuresis Group)</td>
<td>185</td>
</tr>
<tr>
<td>Appendix 15</td>
<td>Semi-structured Interview (Paediatric Group)</td>
<td>187</td>
</tr>
<tr>
<td>Appendix 16</td>
<td>Multi-dimensional Measure of Children’s Perception of Control – What I think about things</td>
<td>189</td>
</tr>
</tbody>
</table>
Expressed Emotion, attributions and knowledge among carers of people with dementia
(Large Scale Research Project)

Abstract

Background

Aims

Method

Results

Conclusions

Guide to the introduction

Introduction

Expressed Emotion

Expressed Emotion in relatives of people with schizophrenia.

Expressed Emotion in relatives of people with other conditions.

Expressed Emotion and its relationship with behavioural interactions.

Expressed Emotion and reciprocity.

Measurement of Expressed Emotion.

Expressed Emotion and psycho-educational intervention.

Expressed Emotion and its theoretical basis
## Studies of EE in carers of people with dementia

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>216</td>
</tr>
</tbody>
</table>

Summary of findings within studies exploring Expressed Emotion in carers of people with dementia.

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>224</td>
</tr>
</tbody>
</table>

Criticisms of EE studies within the field of dementia.

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>226</td>
</tr>
</tbody>
</table>

## Toward an explanation of Expressed Emotion

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>227</td>
</tr>
</tbody>
</table>

Summary of findings about EE, attributions and knowledge in carers of people with schizophrenia.

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>232</td>
</tr>
</tbody>
</table>

The utility of Hooley’s model in explaining EE in carers of people with dementia

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>235</td>
</tr>
</tbody>
</table>

### Objectives of the current study with carers of people with dementia

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>236</td>
</tr>
</tbody>
</table>

### Hypotheses

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>237</td>
</tr>
</tbody>
</table>

### Method

#### Participants

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>239</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carer inclusion criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer exclusion criteria</td>
</tr>
</tbody>
</table>

#### Procedures

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>240</td>
</tr>
</tbody>
</table>

| Carer demographic information |
| Care-recipient demographic information |

#### Measures

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>244</td>
</tr>
</tbody>
</table>

5. Measurement of carers’ perceptions of their pre-morbid relationship.
7. Measurement of additional data.

### Analyses

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>249</td>
</tr>
</tbody>
</table>

### Results

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>250</td>
</tr>
</tbody>
</table>

### SECTION ONE  Part one:

Carer attributions about cause and perceptions of controllability of care-recipient behaviour and mood disturbance, and their relationships with Expressed Emotion (Hypotheses 1.1-1.5)

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>251</td>
</tr>
</tbody>
</table>

| Carer levels of Expressed Emotion (EE) as measured by the Patient Rejection Scale. |
| Carer perceptions of controllability for behaviour and mood disturbance as measured by the BMD Scale. |
| Relationship between carer levels of EE and carer controllability scores. |

<table>
<thead>
<tr>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>253</td>
</tr>
</tbody>
</table>
Part one: Carer attributions about cause of care-recipients’ behaviour and mood disturbance. Relationship between carer levels of EE and carer attributions about cause of care-recipient behaviour and mood disturbance. Relationship between carers’ perceptions of controllability, and attributions about cause of care-recipients’ behaviour and mood disturbance.

Part two: Relationships between carer knowledge and carer levels of EE, carer attributions of cause and perceptions of controllability, and carer levels of depression and anxiety (Hypotheses 2.1-2.4). Carers’ level of knowledge about dementia. Relationship between carer levels of EE and carer levels of knowledge scores. Relationship between carer levels of knowledge and carer perceptions of controllability, and attributions of cause about care-recipients’ behaviour and mood disturbance. a) Relationship between carer knowledge scores and carer controllability scores. b) Relationship between carer knowledge scores and carer causal attribution scores for care-recipients’ behaviour and mood disturbance.

Part three: Carers’ levels of depression and anxiety as measured by the Hospital Anxiety and Depression Scale (HADS). Relationship between carer levels of knowledge and carer levels of depression and anxiety.

Relationships between carer levels of EE and care-recipients’ level of behaviour and mood disturbance, carer levels of depression and anxiety, and carer perceptions of pre-morbid relationship (Hypotheses 3.1-3.3). Care-recipients’ behaviour and mood disturbance as measured by the BMD scale. Relationship between carer levels of EE and care-recipients’ behaviour and mood disturbance as measured by the BMD scale. Relationship between carer levels of EE and carer levels of depression and anxiety. Carer and care-recipient’s pre-morbid relationship. Relationship between carer levels of EE and carer perceptions of pre-morbid relationship.
A caveat to the interpretation of the results 269
SECTION TWO: 272
Further analyses to corroborate findings with regard to carer perceptions of controllability and causal attributions of behaviour and mood disturbance 272
Carer attributions of controllability for behaviour and mood disturbance on items 3, 16 and 27 only. 272
Relationship between carer levels of EE and carer perceptions of controllability scores. 273
Carer attributions about cause of care-recipients’ behaviour and mood disturbance. 274
Relationship between carer levels of EE and carer attributions about cause of care-recipients’ behaviour and mood disturbance. 274
Relationship between carer levels of knowledge and carer perceptions of control, and attributions of cause about care-recipients’ behaviour and mood disturbance. 275
a) Relationship between carer knowledge and carer controllability. 275
b) Relationship between carer knowledge scores and carer causal attribution scores for care-recipients’ behaviour and mood disturbance. 275
Discussion 277
Assessment of the generalisability of Hooley’s attributional model. 277
Exploration of relationships between carer levels of knowledge and other variables. 279
Assessment of relationships between carer EE and other variables formerly studied in carers of people with dementia. 281
Limitations of the study. 284
Limitations of measures. 285
Other methodological issues. 285
Clinical implications. 288
Suggestions for future research. 289
References 291
Appendices 300
Appendix 1: SW Surrey LREC approval letter 301
Appendix 2: Letter of invitation 303
Appendix 3: Carer information sheet 304
Appendix 4: Carer consent form 306
Appendix 5: Letter to GP 307
Appendix 6: Patient Rejection Scale 308
<table>
<thead>
<tr>
<th>Appendix</th>
<th>Description</th>
<th>Page number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appendix 7</td>
<td>Personal communication from Kriesman re. modifications to PRS</td>
<td>310</td>
</tr>
<tr>
<td>Appendix 8</td>
<td>Dementia Knowledge Questionnaire</td>
<td>311</td>
</tr>
<tr>
<td>Appendix 9</td>
<td>Behaviour and Mood Disturbance Scale with added sections for carers to record perceptions of controllability and causal attributions</td>
<td>312</td>
</tr>
<tr>
<td>Appendix 10</td>
<td>Hospital Anxiety and Depression Scale</td>
<td>315</td>
</tr>
<tr>
<td>Appendix 11</td>
<td>Items measuring carer perceptions of the pre-morbid relationship with their care-recipient</td>
<td>317</td>
</tr>
<tr>
<td>Appendix 12</td>
<td>Demographic data</td>
<td>319</td>
</tr>
<tr>
<td>Appendix 13</td>
<td>Histogram of Total PRS Scores</td>
<td>321</td>
</tr>
<tr>
<td>Appendix 14</td>
<td>Table showing Z scores for skewness and kurtosis</td>
<td>322</td>
</tr>
<tr>
<td>Appendix 15</td>
<td>Table showing percentage of carers not making attributions about cause and control on BMD Scale items</td>
<td>323</td>
</tr>
</tbody>
</table>
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Finally, I am so grateful to Luke, whose love, support and patience throughout my training has been a consistent source of strength for me.
Introduction to the Portfolio

This portfolio contains a representative selection of work completed during a three year Practitioner Doctorate in Clinical Psychology at Surrey University (1996-1999). It covers academic, clinical and research domains. An academic section comprises five essays, covering both core and specialist topics. A clinical section contains details of each placement undertaken, including a summary of the range of experience gained, and a summary of a formal case report. Finally, a research section comprises a literature review completed in year I, a small scale/service related combined piece of research completed in year II, and a larger scale project completed in year III. The work within each section is chronologically ordered to reflect a developmental growth in knowledge and skills over time.

A separate confidential volume (Volume two) comprises a clinical dossier including the five formal clinical case reports in addition to all placement documentation including placement contracts, clinical activity log books and supervisor evaluation forms.
Academic Section
Summary of the Academic Section

This section contains five essays presented in the order in which they were completed. One essay has been chosen from each of the four core client groups (Adult Mental Health, Learning Disabilities, Child and Family, and Older Adults) and one essay on a specialist topic from the third year (Brief Dynamic Psychotherapy – Adult Mental Health). The essays are intended to reflect some of the depth and scope of knowledge gained over the three year course.
Discuss the role of the psychologist in a rehabilitation/continuing care multi-disciplinary team and which aspects of a person's care they would be involved in.

March 1997

Year 1
This essay will be concerned only with rehabilitation and continuing care teams working with the adult mental health population, specifically, people with chronic mental illness (CMI). Other important client groups requiring input from such teams may include older adults with progressive diseases such as dementia or rehabilitating stroke victims, head injured adults, continuing care of people with learning disabilities, and even children with long term mental health problems.

Bachrach (1988) suggested there are three criteria which define CMI; duration (indefinite, with the threat of relapse and lack of return to pre-morbid functioning); diagnosis (made on the basis of psychiatric symptoms such as depressed mood, hallucinations or delusions); and disability (secondary and tertiary disabilities which include adverse personal reactions to the consequences of having a psychiatric illness, and social disabilities as a consequence of the disturbances or pre-existing disadvantages).

Since the de-institutionalisation of people with CMI there has been a move away from, or at least a modification of the curative approach of the Biological model, towards the incorporation of Management models within care. Two major Management models can be identified; The Care Management Model and the Rehabilitation Model (Smith, Schwebel, Dunn & Mclver, 1993). Subtle differences exist between these models, the former emphasising support for the client, and help to link them with resources and to manage their illness over the long term. Lavender and Holloway (1992) link continuing care teams to this model. The latter emphasises the training of skills to help the client make the best of his residual capacities, and differentiates between symptoms of psychiatric illness and tertiary disabilities. Rehabilitation teams would link with this model. Within either model, care of people with CMI in Britain is taken on by multi-disciplinary teams as it is acknowledged that in order to help clients with all aspects of functioning (biological, medical, psychological, housing, work and social needs) a wide range of professionals are required. Clinical psychologists are an important component of these multi-disciplinary teams and have had progressively more to offer with the move towards models of care other than the Biological model (Smith et al., 1993).
This essay will discuss the role of a clinical psychologist in multi-disciplinary teams with reference to their different types and levels of input, and attempt to locate these roles within models of care. The aspects of a client's care they are most involved with will be identified in the process. The discussion will indicate that in addition to the core skills for which psychologists are renowned, they may have some less traditional roles to fulfil. Despite the subtle differences in emphasis of the Rehabilitation and Case Management models, rehabilitation and continuing care teams will be discussed interchangeably and referred to simply as teams. Only if necessary will their difference be highlighted with respect to roles. The assumption will be that clients linked to these teams can exist in rehabilitation hostels, sheltered accommodation, or living with families or alone in the community.

Liddell (1983) argues that clinical psychologists are trained to apply their theoretical knowledge and skills to the practical task of working with people with mental health problems, and identifies their core skills as being routed within assessment, therapy or the treatment of disorders via psychological methods, research and teaching. The application of these skills to long term care can then be examined.

Conning (1991) states that assessment is an important part of the clinical psychologist's role due to their training in scientific method. She also states that the aim of assessment should be to integrate the information acquired into a model which can indicate where intervention should take place. Psychologists can assess at three main levels; assessment of the individual, the environment and the service. Firstly assessment of the individual; standardised tests such as the Wechsler Adult Intelligence Scale- Revised (Wechsler, 1981) do not indicate specific intervention strategies (Corrigan, 1995), yet a survey conducted by Hess, Buican & Corrigan, 1994; cited in Corrigan, 1995) revealed that clinical psychologists working with severely mentally ill adults spend 10% of their working day conducting such tests.

Instead a comprehensive assessment of life skills, symptomatology and it's effects on the client's life, social circumstances and finances is required to achieve a package of care tailored to the individual client (Lavender & Holloway, 1992). A clinical psychologist would primarily be involved with the assessment of symptomatology and
it's effects on psychological and behavioural functioning, as well as assessment for suitability in work placements (social aspect). They can work with other professionals in giving valued opinion on other aspects of assessment, for example with regards to sectioning of clients requiring in-patient care.

Teams working within the Case Management model may wish to assess the needs of the individual to determine the most appropriate resources. Conning (1991) suggests it is important to directly involve the client as much as possible in this process. Behavioural skills and deficits may be assessed within Rehabilitation models. Psychologists can carry out these assessments directly or supervise other professionals in the assessment. They may also wish to assess the level of stress (internal and external) that the individual is exposed to and their resources for coping with it (Vulnerability model) or assess apparent cognitive deficits which may influence distorted beliefs (Cognitive model).

In terms of assessment of the environment, psychologists may be involved in it's possible affect on the psychological and behavioural functioning and some of the psychiatric symptoms of the client. One example would be to explore the family members' level of knowledge about CMI and their attitudes towards the mentally ill family member with a view to helping the family to cope better and hence provide the client with a more supportive environment in which he or she is less likely to relapse (Expressed Emotion Construct: EE, Brown, Birley & Wing, 1972). However this kind of assessment has been criticised for locating blame for the course of mental illness within other family members. The concept of EE can extend to non family members such as staff in hostels (Kuipers, 1995; cited in Hughes & Budd, 1996).

It has also been suggested that psychologists are equipped with skills to stimulate and carry out evaluation of new practices at a service level (House of Commons Social Services Committee 1985; cited in Conning, 1991). This is becoming more necessary due to pressure for professionals to be accountable for the service they provide and it's quality.
In terms of treatment it has been argued that psychological methods of intervention in the field of rehabilitation have made a significant contribution to people being able to live outside hospitals (Clifford & Damon, 1988). This is perhaps because of the move away from the curative approach of the Biological model towards other models incorporating more psychological approaches. Conning (1991) identifies four levels of intervention that a clinical psychologist may contribute within a team: the philosophy of care, the organisation, work with or through other disciplines of staff, and with the individual client.

Psychologists are involved in the development or conceptual clarification of appropriate philosophies or models of rehabilitation and continuing care. They can incorporate such philosophies and models within the planning of future organisations and translate the philosophy into language understandable to influential managers outside the field who can effect service planning.

Clinical psychologists frequently work through other professionals in the team, teaching basic psychological techniques, helping care staff to draw up behavioural programmes or trying to change dysfunctional attitudes amongst staff for the good of the long term client. Lavender (1985; cited in Conning, 1991) discusses the point that clinical psychologists have no clear position in the team's professional hierarchy and therefore no given authority over any other discipline. Therefore there is a clear need to influence others through their knowledge and experience. This is aided by the clinical psychologist proving their skills to others and being prepared to "pull their weight" at all times.

In terms of psychological interventions aimed at the individual, one could include psychotherapy, behavioural therapy, cognitive therapy, reality orientation and so on. Essentially the clinical psychologist is more involved with psychological interventions to help clients cope with their symptoms rather than intervening to affect social, financial or medical aspects. Within the case management model the clinical psychologist would be viewed as the psychological treatment resource. Behavioural therapy can encourage sufferers and carers to monitor symptoms for early signs of relapse and intervene to encourage medication compliance using behaviour
management techniques. The issue of enhancing medication compliance can also be approached using the cognitive model by using self instructional training to help clients with schizophrenia to function more appropriately in social situations (Meichenbaum & Cameron, 1973; Smith et al., 1993).

Clinical psychologists are often involved in intervening with psychosis perhaps by challenging beliefs about voices (Chadwick & Birchwood, 1994). Pilling (1995) warns against the limitations of such cognitive and cognitive behavioural treatments for psychosis and argues for the need to locate it within the individual's rehabilitation plan. Within teams using the rehabilitation model psychologists may be involved in behavioural skills training approaches to increase the client's functioning. With all these possibilities for intervention Conning (1991) points out a need for psychologists to offer more than their core skills in treatment, especially if they are designated as case manager in which case they should be prepared to contribute from their own social background and experience.

A role which seems similar to treatment and which merits some attention is that of prevention. According to Pransky (1991) there is a critical need for psychologists to become more active in the prevention of mental health problems. Three levels of prevention are identified: primary, secondary and tertiary.

Psychologists within teams are likely to be more involved in prevention at the tertiary level (decreasing short and long term severity of symptoms of individuals already affected by CMI). Smith et al. (1993) point out the difference between tertiary prevention and treatment as an aim to prevent or reduce the severity of future occurrences of illness rather than to remedy present occurrences of the illness. An example within the Vulnerability model would be to try to empower clients to cope better with future stress by teaching skills to reduce the impact of future stressors and strengthen them in ways that make them more resilient.

In terms of research there is plenty of scope for clinical psychologists to carry out research beyond service evaluation within teams. As qualifications within training change to doctorate level there is progressively more emphasis on research and
evaluation, often of the link between theory and practice. This opens up opportunities that all psychologists should be equipped to lead. Expressed Emotion research (e.g. Leff, Kuipers, Berkowitz, Eberlein Vries & Sturgeon, 1982) is a familiar area of research which often involves the evaluation of psycho-educational programs and therapy with families. Within management models of care, important research is required into the efficacy of treatment approaches, rehabilitation programs and coordination of provision of care to clients. However, conducting research alongside other professionals in the team would be essential in order to retain the important focus of the multi-faceted context of the client's needs.

The final core skill of a clinical psychologist yet to be discussed is that of teaching. Conning (1991) states that "at some level most rehabilitation psychologists will be involved in teaching". This often involves teaching other members of the team interventions for clients, or discussions about the implications of putting philosophies and methods of care into practice. Within the psycho-educational model a clinical psychologist's involvement in providing family members with information about the nature, aetiology and treatment of their mentally ill family member in order to enhance their understanding, can also be seen as a form of teaching.

So far this essay has been concerned with the clinical psychologist's core skills and their input in teams. However, they may also fulfil less traditional roles. Corrigan (1995) puts forward a strong case for clinical psychologists taking on the role of 'champion' within teams. In other words, to be responsible for the start-up and maintenance of treatment innovations which overcome organisational barriers. This differs slightly from the already mentioned development of philosophies of care as it's emphasis is upon pioneering and suggests a management role.

Corrigan (1995) criticises the traditional education in clinical psychology which he states ignores essential themes and skills necessary to champion program development in treatment programs. One study (Moore, Davis & Mellon, 1985) showed that psychologists rated their levels of training in the treatment of severe mental illness as lowest among mental health disciplines. Johnson (1992) discovered that clinical training provides only a 'cursory introduction' to the care of people with severe mental
illness. Perhaps Gentry's view (1986) of rehabilitation reaching the point of being perceived as a specialism within psychology can counteract criticism about the current "cursory introduction" to severe mental illness within training due to the extremely broad scope of approaches, skills, client groups and specialisms covered within training. Clinical psychologists can only assume leadership or champion roles within any field after considerable experience within in this client group.

Gourlay (1995) considers that psychologists do have a role to play in case management but admits it may be more cost effective for other professionals with "lesser levels of training" to take on such a role. Certainly with regards to the expense of buying psychologists' time, this may be true. Johnstone (1995) takes the rather radical viewpoint that a psychologist's role should be that of "protest and challenge". Perhaps this is a less poetic way of advocating the role of 'champion'. Whichever the view, it seems certain that psychologists will have to put their theory into practice and gain the respect of team members from other professions in order to take on such roles. There is a need to understand and also experience the viewpoint of other professionals in the team by working along side them in order to understand the many dimensions important to long term care.

Pilling (1995) suggests that the majority of rehabilitation should be within community mental health teams (CMHTs). Though a recent survey (Onyett, in press, cited in Hughes and Budd, 1996) showed that clinical psychologists find it hard to define a role for themselves within CMHTs. This may be due to the already mentioned lack of training in the area of long term illness. However given the flexibility of the psychologist's role there is ample scope to set their own agenda provided they have gained credibility in the team.

One of the current issues raised within the Richmond Twickenham and Roehampton NHS Trust (RTR) Mental Health Directorate is controversy over psychologists' involvement in Care Program Approach initiatives (CPA's) and what role they may assume with clients at any of the three levels of need. Certainly part of their role is to be involved in the planning and reviewing of CPA's but there is less certainty about clinical psychologists key working clients placed at the highest level of need. Due to
the fact that different roles carry different weightings in terms of financial gain for the psychology department, recording schemes should be developed in such a way that reflects the real level of input. It would also be necessary to examine carefully the implications of using psychology resources at this level of co-ordination which may divert time away from using specialised skills.

Participation in working within 'duty' rosters is another role attracting discussion at RTR. Some psychologists whose contracts allow a division of time between involvement with continuing care and out-patient work have been approached with reference to potential input into 'duty'. This idea obviously has implications for using more than the core skills mentioned earlier within this essay. An explicit contract would be required in order to protect the psychologist from being placed in a position whereby he/she would be giving advice on finance, housing and so on. A pilot study is currently being planned within RTR NHS Trust involving occupational therapists on the duty roster.

This essay has discussed the four core skills of a clinical psychologist (assessment, treatment or intervention, teaching and research) with relation to working within rehabilitation and continuing care teams. Psychologists use these skills at various levels of input (the organisation, philosophy of the organisation, the environment, the staff and the individual). Roles can be varied with respect to the different models of care the team may be working within. Although the needs of the client with CMI are multi-faceted, a clinical psychologist would be more heavily involved with using psychological approaches to help clients cope with their psychiatric symptoms rather than with social, financial, housing or medical needs. However it is essential that psychologists step aside from their core skills and be prepared to work alongside other professionals in the team at times. Less traditional roles for psychologists have also been discussed, including the role of 'champion', case manager and work within 'duty' rosters. In order to take advantage of the flexibility that psychologists possess in comparison to other professionals it is essential to gain respect and credibility within the team.
References


Concern has been raised regarding a relationship between two clients of the same sex but of differing levels of ability living in a staffed home. What are the areas that need to be considered when reflecting on this relationship, with specific reference to consent and policy issues?

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Year 1
Introduction

The tenets of normalisation which underpin services for people with learning disabilities have been partly successful in guiding service providers in upholding the rights of people with learning disabilities within the community. However the 'difficult' area of sexuality presents a real challenge. Now that stereotypes of people with learning disabilities are more redundant (for example that they are asexual) and mixed gender residential facilities are in existence, service providers are forced to think through their position with respect to their clients' sexual behaviour. When two clients of the same sex but of different abilities have a relationship within a residential facility, a number of areas require careful consideration; policy issues, consent, the influence of the law and the normalisation principle, staff and parental attitudes, sex education and exploration of the homosexual identity. These areas will be discussed in relation to the above scenario. It becomes clear that the issues at play are numerous and complex.

Policy guidelines on sexuality, and the influence of Normalisation/Social Role Valorisation

When reflecting upon the relationships and sexual activity of clients it is necessary to refer to the service provider's policy on sexuality, as a guideline for the management of any given situation. Adherence to policy guidelines should guard against personal bias and judgement. This becomes particularly important when considering a relationship between two clients of the same sex. Despite society's increasing acceptance of homosexuality it is still a contentious issue and may conflict with the staffs' personal belief systems (the issue of staff acceptance will be discussed later).

A policy on sexuality fulfils a number of purposes. Among it's most important is to interpret and supplement the law, and to interpret statements of right and statements of principle. Residential service provision for people with learning disabilities such as 'United Response' has generally been greatly influenced by the concept of normalisation (United Response Policy and Procedure Operational Handbook, 1994). It's original
conceptualisation reflected the view that people with learning disabilities should have made available to them the same living conditions and legal and human rights as those enjoyed by non disabled members of society. However this conceptualisation was modified by Wolfensberger (1972, 1983) who reformulated normalisation as Social Role Valorisation- the adoption of valued social roles to compensate for the devalued status of people with learning disabilities.

However the value of a social role is societally determined, and as society often rejects or merely tolerates homosexuality, this poses a problem for two clients of the same sex within a relationship. It is difficult for such clients to be supported in their relationship if a policy indicates they work towards socially valued roles. Therefore it can be seen that a policy such as that used by United Response requires careful consideration about the implications such a philosophy has for putting their guidelines into practice.

The concept of choice in sexuality for people with learning disabilities

Despite the fact that society may generally prefer people to assume a heterosexual identity, people without learning disabilities generally have a choice in whether or not to adhere to society's preference. It may well be that the two clients in question have only ever lived with others of the same sex, having restricted access to clients of the opposite sex. Therefore it would be extremely difficult to make a choice to develop a relationship with anyone other than with someone of the same sex. This highlights the importance of including the concept of choice within the philosophy of services for people with learning disabilities. Only if clients are given support in gaining access to clients of both sexes throughout their life can they be said to have been given a choice in the selection of their partner's gender. The extent to which a service policy takes on board the provision of choice for its clients will determine the view taken when reflecting on the two clients' relationship. If the clients can be seen to have a real choice in selecting a same sex partner, it should be respected. Respecting their choice however would still theoretically be in conflict with Social Role Valorisation.
O'Brien's reformulation of normalisation (1987) includes five accomplishments for service providers. Among ideas advocating a presence for people with learning disabilities in the community, developing their competence, ensuring their participation in community life and enhancing respect afforded them, he does emphasise that clients should be encouraged to make a choice about their lives. If service providers do incorporate O'Brien's ideas into their policies on sexuality, clients may be supported in their choice to reject society's preference of heterosexuality. If on the other hand the clients' relationship is seen to develop out of lack of choice, it may be necessary to introduce the element of real choice by encouraging opportunities for opposite sex contact and support in developing friendships which may develop into intimacy if later desired.

The element of choice was recognised as crucial by the Tizard Centre at the University of Kent when they were commissioned by a large provider of residential and staff support services for people with learning disabilities to develop a sexuality policy for the service (Cambridge & McCarthy, 1997). Their use of the consultancy model which enhanced objectivity, involved interviewing the service users about their wishes with regard to sexuality, as well as the service providers and parents. A booklet was designed to cover sexual rights in easy to follow language. This method closed the gap between the principles behind the policy, and the practice of the policy. There were illustrations explaining that clients can have sex with a man or a woman and they should not "feel bad" about choosing someone of the same sex. A picture was provided of two men with their arms around each other. This easy to use guideline was very clear in it's message to service providers and users with regards to acceptance of homosexuality. On the other hand, consultation of the sexuality policy supported by 'United Response' is not entirely clear. It uses the words 'choice' and 'right', yet leaves the reader unclear about the exact position one should take (United Response Policy and Procedure Operational Handbook, 1994).
The influence of law on issues of consent

Policies on sexuality for people with learning disabilities also interpret the current law regarding sexual acts and are concerned with balancing the need to uphold their rights, as well as to protect them from abuse. The law as it relates to people with learning disabilities generally concentrates on the issue of consent. With regards to the two clients mentioned, it is necessary to establish the extent to which their relationship is sexual, by gentle questioning and discussion with staff. If it is sexual and the clients are male, the law applies more specifically than it would to females. There is currently no law against sexual acts between women over the age of sixteen years, unless the acts take place in public, or one party is knowingly exploiting the other.

According to section 13 of the Sexual Offences Act 1956 (Gunn, 1987), no offence has been committed if both men are over eighteen and one of them does not have a severe learning disability, and the sexual acts occur in private. Staff observations and recording should reveal whether their sexual acts take place in public. If in public but not transgressing the other aspects of the Act, the clients should be encouraged or prompted to go to their own rooms and not in view of others should they wish to be sexual. If either client is under eighteen, the law as it pertains to age should be explained in language meaningful to the client and possibly friendship encouraged until they come of age.

The final point within Section 13 states that if one party is severely learning disabled, an offence has been committed because that person is unable to consent. However there are no absolute guidelines and standardised criteria by which to judge the category of severe learning disability within the realm of sexual acts and the law (Parker & Abramson, 1995). Using an IQ score to judge level of learning disability is rather a crude assessment and in itself is not sufficient. If a client is suspected to be severely learning disabled, interviews with the client to determine their ability to give informed consent is necessary by concentrating on their knowledge of sexual acts, level of intelligence and the ability to make a voluntary decision (Ames & Samowitz, 1995). However if the client is suspected
to be too disabled to give consent through verbal expression Ames and Samowitz give suggestions as to how to establish informed consent by observing 'responsible interpersonal behaviour'. They concentrate on the following areas:-

1. **Voluntariness** - Are each of the clients able to make a voluntary decision free from coercion? (Look at person's history with regard to making voluntary decisions and behaviour in situations of coercion).

2. **Avoidance of harm** - Are each of the parties reasonably protected from either being harmed or potentially being harmed by any of the presenting circumstances or actions?

3. **Ability to stop an interactive behaviour when desired** - The person must be able to say no when they desire, either verbally or by their body language.

4. **Appropriateness of time and place** - Is the person either able to chose the appropriate time or place, or be prompted to do so with minimum resistance?

In addition, it would be helpful to ascertain (by knowledge of the client's expression of happiness or desire through their behaviour) whether the client obtains pleasure from the sexual acts or actively seeks sexual contact. It may be helpful to use pictures representing sexual activity with the clients to ascertain the expression of positive or negative emotion in response to each presentation.

**Gap between level of learning disability of two clients and it's influence on consent to sexual activity.**

The other issue to reflect upon within consent is the gap between the level of learning disability of the two clients. It would seem important to follow the rule that the greater the gap, the greater the need to carefully consider issues of consent and exploitation. If a client with a very mild learning disability was engaging in sexual activity with a client with a moderate-severe learning disability, the latter may well be unaware of the subtleties of a
coercive relationship in the absence of physical force or harm. Thompson (1996) talked with learning disabled men who have sex with other men (disabled and non disabled), and discovered that one of the partners generally controlled the sexual encounter, seeking to engage in sexual activities which met his sexual desires, with no attention to the sexual pleasures of his partner. Further questioning revealed that when both men had learning disabilities, the inequality in sexual experience could "be explained by the differential power the men held dependant on ability, and, to a lesser extent, physical strength" (Thompson, 1996). Unfortunately this paper drew interpretations from an unspecified number of 'discussions' with men with learning disabilities. Methods of data collection appear arbitrary and retrospective, rather than forming part of a carefully planned piece of research. Additionally, due to the sensitivity of the information gathered, the author openly acknowledges that many of the men's experiences must have remained hidden and so data was effectively 'filtered', and thus incomplete.

In any case, this inequality of ability, and thus power differential, which often exists between two separate parties suggests a basic understanding of the issues surrounding a positive relationship (for example mutuality, choice, respect and happiness) should be encouraged for both clients in the form of sex education. For in order for anybody to make an informed choice they require knowledge to make their decisions. Brown and Turk (1992) state that many men's abilities to agree or disagree to specific sexual acts with men are frequently compromised by 'barriers to consent'. For example when one partner is more able or is threatening consequences including violence, or advocating the exchange of sex for money or cigarettes. It would be imperative to explore whether a less able client is prevented in giving consent by such barriers. Again, a general understanding of the mutuality of relationships would need to be advocated.
Sex education

As already mentioned, sex education for people with learning disabilities is a resource which may be turned to in the scenario of two same sex clients forming a relationship, especially in terms of addressing the components of a positive intimate relationship and mutual consent. However sex education should be proactive rather than reactive to a crisis. It should cover social interaction and relationships in general, not just sexual ones (Craft, 1994). Craft outlines the need to learn about respecting and valuing themselves and others, and about decisions as well as about safe sex and hygiene. Craft also states the need for ongoing sex education. If this view is taken on board it may be more likely that clients are establishing relationships on more well informed grounds rather than being coerced into activities they lack knowledge of.

A vital component within sex education is teaching about the possible consequences of sex without protection. Pertinent to a sexual relationship between two males is the risk of contracting HIV. There is evidence that people with learning disabilities have become infected with HIV (Kastner, Hickman & Bellehumeur, 1989; Kastner, Nathanson & Marchetti, 1992). McCarthy and Thompson (1994) highlight the importance of prioritising education on HIV for men who have sex with other men. They also state the need for a risk assessment for HIV among people with learning disabilities, emphasising investigation into the kind of sexual activity occurring between the two clients, information about the individuals themselves (in terms of possible previous exposure to HIV) and the frequency of sexual contact. If a client is rated at high risk for HIV a decision may need to be made with regards to the possibility of testing for HIV.

Cambridge (1997) comments that clients' lack of knowledge about the potential of contracting HIV in the absence of 'safe sex' constitutes one of the barriers to informed consent, and stresses that good practice demands that clients be well informed in order to be able to consent. This view reinforces Craft's (1994) view that sex education needs to be proactive so that clients are 'well armed' to make their decisions. McCarthy and Thompson (1994) suggest that the strongest message within safer sex education should
be the necessity for using a condom with penetrative sex. They also advocate that it is preferable to err on the side of caution when attempting to educate about the connection between HIV and the potential development of AIDS. They feel it is better to make a clear connection between unprotected sex and AIDS, rather than confusing the matter by introducing the prerequisite of contracting HIV. Staff looking for appropriate resources to use for safe sex education for two men in a relationship may wish to use those provided by the Young Adult Institute (1987) and the FPA of New South Wales (1990). These resources openly acknowledge and show intimate contact in same sex relationships. Unfortunately there is little literature with regards to sex education about HIV for two females in a sexual relationship. In general it is recognised that males are in greater need for education about the risk of controlling HIV.

**Exploration of the homosexual identity**

The issue of homosexuality is likely to raise question within the realm of proactive sex education. According to Clause 28 of the Local Government Act (Gunn, 1987), it is illegal to promote homosexuality as a natural expression. Staff must therefore consider if the two clients already have a homosexual identity. The aspect of choice as mentioned earlier becomes relevant again here. Clients may not have had the opportunities to make a real choice about their sexual orientation and so it may be difficult to establish if they actually see themselves as being homosexual or having same sex activity. Thompson (1996) spoke with a number of men who have sex with men and discovered that overwhelmingly they did not label themselves as gay or homosexual. Thompson explained this as a product of society's negative and rejecting view of homosexuals. If the two clients do identify themselves as 'gay' or 'homosexual' then it may be helpful to support them in identifying with the homosexual sub-culture for support. Perhaps such clients could have access to sex workers who will advocate for them and help them to fulfil their potential within society. For gay people this will mean introducing them to the gay community. However this does raise the issue of vulnerability. Unfortunately the literature tends to concentrate on male homosexuals. With lesbians the same suggestions
would apply. If truly taking the supporting stance with two female clients who accept the lesbian identity, staff may need to be prepared to access sexual aids for them.

**Parental attitudes**

All of this rests uneasily with the standard views and expectations of sexuality for parents and many staff, and again raises the conflict that Social Role Valorisation poses for people with learning disabilities. Most of the literature advocates the importance of discussing the management of sexuality of people with learning disabilities with the respective parents (for example Cambridge & McCarthy, 1997). Many people with learning disabilities have close relationships within their family network even though they may live in residential facilities. Their parents' views are likely to be important to them even if they differ. If the two clients in question are within the legal rights with regard to consent, age and appropriateness of behaviour in particular places, then they are able by law to continue their relationship. However the parents should be consulted about potential areas of conflict or difficulty, and it will be preferable to reach a consensus of opinion.

**Staff attitudes**

Staff should be facilitated in discussing their feelings about homosexuality perhaps by a psychologist external to the staff team. This is crucial in order for the entire staff team to be united in any decision to support the clients' relationship. Staff members' personal value systems with regards to homosexuality should not bare upon final decision making. It is inevitable however that an aversion to homosexuality will influence the way a member of staff interpersonally relates to such a client. Perhaps then staff members who are accepting of this sexual orientation should be delegated more specifically to support and monitor the developing relationship. Foremost in the discussions should be the consideration of rights and desires of the two clients in question, in line with law and service policy.
Summary

The areas in need of consideration when reflecting upon two clients of the same sex but different abilities within a relationship are numerous and complex. If the relationship is sexual, staff must refer to the service's policy on sexuality for guidance. As many such policies are based upon the normalisation principle or Social Role Valorisation, the presence of a same sex relationship may conflict with the idea of socially valued roles. If O'Brien's five accomplishments (1987) are incorporated into the policy and throughout the philosophy of service provision, it is hoped that the clients may be making a real choice about the sex of their partners based on prior contact with both sexes. If such clients identify themselves as gay they may be supported in being part of the gay subculture with the help of a designated sex worker.

It is essential to keep within the boundaries of the law on sexuality for people with learning disabilities, with specific reference to consent in order to prevent abuse. In the case of a severely learning disabled client within a relationship (and in the absence of any standardised criteria for the classification of 'severe' within the realms of law and sexuality), with another client of higher ability, staff must look for consent within 'responsible interpersonal behaviour' as well as looking to identify any 'barriers to consent'. In order for a client to give informed consent he/she must be aware of the consequences of sexual acts and the risk of HIV. Sex education should be particularly targeted at learning disabled men who have sex with men. Finally it is necessary to explore staff and parents' attitudes toward homosexuality as negative attitudes may affect the quality of support given to such clients. Foremost in any decision making should be the consideration of the rights and desires of the two clients in question, in line with the law and service policy.
References


Consider the utility of the diagnostic classification of Attention Deficit Disorder

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Year 2
Introduction

According to Barkley (1991), Attention Deficit Hyperactivity Disorder (ADHD) or Attention Deficit Disorder (ADD) as it has been known in the past, is a diagnostic label which describes a child who experiences significant difficulties in sustained attention, impulse control, and the regulation of activity levels to situational demands. The diagnostic classification of ADHD has changed consistently over time in each of the revisions of the Diagnostic Statistical Manuals (DSM; American Psychiatric Association) used for diagnosing disorders. These changes have reflected shifts in the understanding of the disorder as a result of empirical research. Controversy about the disorder's psychological mechanisms and aetiological underpinnings continue to prevail. In addition there are overlaps between behavioural symptoms within a diagnosis of ADHD and other emotional and behavioural disorders, specifically Conduct Disorder and Oppositional Defiant Disorder.

In order to consider the utility of the diagnostic classification of ADHD this essay will reflect upon the implications of the above difficulties, as well as critically evaluate the following; the usefulness of specific properties of the diagnostic criteria, the practical value of the criteria in guiding assessment and intervention, the usefulness of a diagnosis for the individual, as well as the wider implications of a diagnosis within the medical model. The validity and reliability of the DSM-IV (1994) will be considered as a result. Unless otherwise specified, ADD will be referred to as Attention Deficit Hyperactivity Disorder (ADHD), as this is the current label for the disorder used in DSM-IV.

Shifts in the understanding of the disorder and it's resulting change in nomenclature

The original attempt at understanding children who exhibited symptoms of inattentiveness, impulsivity and/or hyperactivity began as early as 1902 when Frederick Still (a paediatrician) argued for a biological fault in such children. Along with discoveries such that psychostimulants could reduce hyperactivity levels and
behavioural problems (Bradley, 1937) the aetiological cause of such a clinical presentation in children became understood as a form of Minimal Brain Dysfunction. This phrase was applied to children with a wide range of behavioural and learning problems showing no signs of neurological dysfunction. By the 1960's the lack of evidence for such an understanding prompted a "shift in emphasis from aetiology to behavioural expression" (British Psychological Society; BPS, 1996). Hence the various revisions of the classifications within the Diagnostic Statistical Manuals and International Classifications of Diseases (ICD; World Health Organisation) classify the disorder by description of the disorder's symptoms.

Inherent in these descriptions over time were shifts in emphasis on the central components thought to be underlie the clinical presentation. As a result of research which investigated the attentive abilities of hyperactive children, for example Douglas (1972; cited in BPS, 1996), when it was discovered that such children performed badly on standardised tests of attention, the disorder was relabelled as ADD in DSM-III. However this implied that there was "specific dysfunction in the cognitive mechanisms underpinning attentional processes", for example "limited attentional resources or inability to organise and co-ordinate these resources in a selective and adaptive way" (BPS, 1996). An extensive review by Van Der Meere (1996) who evaluated a variety of research into the attentional performance of children described as having ADD concluded there was limited evidence that cognitive deficits in attentional mechanisms (orientation to stimuli, information uptake, attentional focus, and ability to stay on task) accounted for the presentation of ADD.

The lack of evidence to support attentional deficits as central to the disorder lead to reformulations which considered inhibitory deficits as an alternative explanation. However, support for this hypothesis was limited as the tasks used in studies lacked specificity, so processes unrelated to response inhibition may have been involved in poor performance (BPS, 1996). One common factor evolving from research into both psychological mechanisms of attention, and impulse control is that the children's performance could be improved by manipulating motivational factors (Sonuga-Barke, Houlberg & Hall, 1994; Van Der Meere, 1996). This suggests that reference to the
influence of environmental factors should be made within classifications. In this way the clinician would be guided to examine problems in the child's school or home setting. This however has not been explicitly stated in the DSM's or ICD's and thus can be viewed as a criticism.

Current understanding of the disorder is still developing. There seems no one simple deficit to explain the clinical presentation. Plausible explanations are put forward by Van Der Meere (1996) who suggests that the children are not able to allocate mental effort in the required way, and Sonuga-Barke, Williams, Hall and Saxton (1996) who suggest that the children are delay averse, so that their pattern of performance is underpinned by a desire to minimise delay. Neurological explanations are limited. Reviews of evidence in support of neurological dysfunction suggest that fewer than 5% of children diagnosed with ADHD show neurological dysfunction in their aetiology (Barkley, 1991).

Now that the diagnostic classification of ADHD in DSM-IV (see appendix 1) is merely a description of the behavioural manifestations of ADHD (inattention, impulsiveness and overactivity) with no clear implications of which mechanisms underpin the disorder, sub-classifications of predominantly attention or impulsive/hyperactive symptoms are used. Despite accounting for a heterogeneous group of children within the ADHD umbrella term, the resulting sub-classifications do allow for a more accurate description of individual children's presentation. In this way plans for intervention may proceed from a more exact description of symptoms. However it remains a serious fault of the DSM-IV classification that it is unable to specifically reflect theoretical underpinnings of the disorder and its various sub-classifications. This is in fact a generalised fault with DSM-IV, whereby disorders tend to be classified mainly by their behavioural expressions.

The ICD-10 classification (see appendix 2) uses the term Hyperkinetic Disorder, "an enduring disposition to behave in a restless, inattentive, distractible and disorganised fashion" (Taylor, 1994). Although indicating the three main groups of symptomology, it is a more stringent form of the disorder because it requires that both inattentiveness
and hyperactivity are present in two or more settings. Hence fewer children are
diagnosed with the disorder (0.5-1% in the total population versus 3-5% as diagnosed
by DSM IV; Taylor & Hemsley, 1995). That the ICD-10 classification is more
stringent, indirectly implies that some of those diagnosed with ADHD by DSM-IV may
be incorrectly viewed as deviating from 'normal behaviour'. This in turn has
implications for pathologising individuality.

Unfortunately the ICD-10 classification of Hyperkinetic Disorder is no more successful
than DSM-IV in implicating theoretical underpinnings and it's term 'Hyperkinetic
Disorder' in itself is not as reflective of the three core groups of symptomology.

**Validity of the DSM-IV diagnostic classification and it's sub-classifications**

Another important requirement of the diagnostic classification within DSM-IV is it's
ability to justify stating that there are two distinct factors of hyperactivity/impulsivity
and inattentiveness. There is evidence to support the distinction between DSM-IV's
predominantly inattentive type and predominantly hyperactive-impulsive type
(McBurnett, Lahey & Pfiiffer, 1993; Lahey et al., 1994), as well as the existence of the
three subtypes (Lahey et al., 1994). However sample selection in the Lahey study was
dependant upon the criteria used for initial referral. As the age group extended to 17
year olds, many of the older children may have been originally diagnosed by an earlier
DSM classification system and this variation in selection may have confounded results.
Therefore caution is required when drawing conclusions from this study. More
research is required in order to substantiate the validity of DSM-IV sub-classifications.

**Evidence for a unitary construct or separate disorder**

Guevremont and Barkley (1992) discuss factor analytic studies which identify a distinct
group of children who display inattention but not hyperactivity, and so respond to a
diagnosis of ADD. They report such children as sluggish, with a higher prevalence of
anxious and depressive features, social withdrawal and learning disabilities (Lahey,
Schaughency, Hynd, Carlson & Nieves 1987; cited in Hooper, Hynd & Mattison,
Guevremont and Barkley (1992) suggest that this group of children may represent a different disorder from those with hyperactivity and thus possibly require different treatment approaches.

August and Garfinkel (1989) suggest that children with attentional problems without related impulsive hyperactivity present a different pattern of risk in educational contexts. However Erhardt and Hinshaw (1994) found that academic underachievement was equivalent amongst ADHD children with or without hyperactivity. It is certainly possible that the umbrella construct of ADHD is an over inclusive category which assumes children diagnosed with only attention problems are also hyperactive and impulsive. When one considers the evidence which suggests that specifically hyperactivity has implications for later problems in adulthood, such as anti-social behaviour and substance abuse (Mannuzza, Klein, Bonaguna, Malloy, Giampino & Addalli, 1991) this assumption is not a helpful one.

It is worth noting that one of the improvements in the most recent DSM-IV, is it's greater emphasis upon symptoms of inattentiveness which may be present without major symptoms of impulsivity/hyperactivity. This appears to be more affective at identifying girls with this form of ADHD (Lahey et al., 1994). As Guffrey (1992; cited in BPS, 1996) notes, girls are more likely than boys to be considered ADHD without hyperactivity.

In summary, the research mentioned above raises some doubt that ADHD is a unitary construct. The inability to be able to draw firm conclusions has been reflected in the decision to include sub-classifications in DSM-IV which allow for classification according to behavioural expressions. Forming the sub-classifications into disorders in their own right may avoid generalised assumptions about children who exhibit one cluster of symptoms (e.g. inattention) but not all. This in turn may guide more focused intervention strategies.
Associated features of ADHD and co-morbidity with other disorders

The associated features of ADHD are widely evidenced in research. Among them are academic underachievement (Fischer, Barkley, Edelbrock & Smallish, 1990; Whalen & Henker, 1992), specific learning problems in spelling, reading and mathematics (Szatmari, Offord & Boyle, 1989), peer relationship problems and social rejection (Johnston, Pelham & Murphy, 1985), enuresis (Biederman, Santangelo, Faraone & Kiely, 1995), and anxiety (Russo & Beidel, 1994) which is particularly related to the inattentive type (Hinshaw, 1994). Such features are generally viewed as 'secondary features' to ADHD (Hinshaw, 1994).

ADHD has been suggested to have high rates of co-morbidity with Conduct Disorder and Oppositional Defiant Disorder (30-50%; Hinshaw, 1994), and impulsivity/hyperactivity particularly is moderately correlated with aggressive or anti-social behaviour (Hinshaw, 1987). The issue of importance here is establishing whether the overlap with Conduct Disorder is a deficiency in the differential power of the diagnostic classification, or whether one disorder simply exists as a risk factor for developing the other disorder. Certainly longitudinal studies (for example Mannuzza et al., 1991) seem to suggest that anti-social behaviour may develop possibly as a consequence of difficulties over time (such as aversive responses from others) faced by children. Cameron and Hill (1996) state that Conduct Disorder is the condition most commonly associated with Hyperkinetic disorder within ICD-10 and view the child's hyperactivity as increasing their vulnerability to Conduct Disorder. Therefore the literature seems to suggest that it is not a lack of differential power of the diagnostic classification that accounts for the apparent co-morbidity of ADHD and Conduct Disorder, but rather that one disorder simply exists as a risk factor for development of the other.

There is evidence to suggest that British clinicians prefer to diagnose Conduct Disorder rather than Hyperkinetic Disorder when both are present (Prendergast et al., 1988). In such cases there is a need to understand how each disorder contributes to the behavioural expression of symptoms in order to formulate intervention plans.
appropriately for the individual. Unfortunately the DSM-IV criteria, with its distinct lack of reference to theoretical underpinnings does not help the clinician in this process.

The utility of specific properties of the diagnostic criteria

In considering the utility of a diagnostic classification it is essential to examine the usefulness of it's behavioural descriptions, operational definitions and other specific properties. There is evidence to suggest that some of the behavioural descriptions used to classify ADHD are inadequate (Sabatino & Booney Vance, 1994). This study investigated the utility of the behavioural descriptions in DSM-IIIR for diagnosing ADHD. They concluded that eight of the fourteen descriptions were not helpful in accurately describing the symptoms presented by the 75 children. Four of the particularly unhelpful descriptions (often loses things, talks too much, blurts out answers and has difficulty waiting turn) still remain in the DSM-IV. Further research may help lend support to Sabatino and Booney Vance's results, and this may prompt a change in the descriptions used in consequent revisions.

A fundamental flaw within the cited study however is that the age range of children was 5-17 years, yet no account was taken of the developmental changes in the number or severity of symptoms experienced by the children. There is evidence that the prevalence of primary symptoms in children is higher in the pre-school years and declines throughout childhood and adolescence (Guevremont & Barkley, 1992). However DSM-IV does not reflect this developmental change. There is a fixed cut-off score of six or more descriptions to be met in each sub-classification for all ages. Guevremont and Barkley recommend age adjusted cut-off scores for three broad age ranges 3-5, 6-11 and 12-18 years. This would seem a logical revision.

Related to these developmental changes is the view by Barkley (1991) that DSM-IV should indicate 12 months duration of symptoms rather than 6 months as the threshold for diagnosing ADHD in younger children, as overactivity and inattention among pre-school children is a common parental concern (Palfrey, Levine, Walker & Sullivan, 1985) and such symptoms often remit within six months (Campbell, 1990). Thus the
criteria of six months may lead to over diagnosis. Similarly it is suggested that less stringent descriptors should be used for evaluating teenagers whose primary symptoms sometimes tend to diminish (Barkley, 1991).

A major criticism of the DSM-IV is its failure to further define the operational definition of the word 'often'. DSM-IV makes no efforts to quantify this term in order to aid the clinician in his/her judgement and this has implications for the reliability of its classification. Inter-diagnostician agreement for DSM-IV is however reported to be reasonable (Hinshaw, 1994) despite the fact that there is no single tool in existence which is used to comprehensively diagnose children for ADHD and thus no standardised approach.

In summary, the usefulness of the behavioural descriptions in the DSM-IV require further evaluation in order to modify the unhelpful ones. Cut-off scores for different age ranges may be a logical revision to make. Duration of symptoms required for diagnosing ADHD could be increased to 12 months, and operational definitions of the word 'often' may require further clarification for the clinician in subsequent revisions of the DSMs, despite current reasonable inter-diagnostic agreement.

**Practical value of diagnostic classifications in guiding assessment**

It is a great failing of both ICD-10 and DSM-IV that there is no attempt to guide the clinician's assessment by suggesting assessment tools and their likely indicators of the disorder. Accuracy of diagnosis reflects the individual clinician's thoroughness and understanding of the advantages and shortcomings of the various assessment tools available.

Behavioural checklists such as the Child Behaviour Checklist for Parents (Achenbach, 1991; Achenbach & Edelbrock, 1983) the Teacher's Report Form (Achenbach & Edelbrock, 1986), as well as the Conners Parent and Teacher Rating Scales (Conners, 1973; Goyettes, Conners & Ulrich, 1978) are widely used. They are useful screening tools for symptoms and attempt to indicate whether the child's behaviour is
developmentally deviant from the norm. However such scales provide only a cross-sectional view of symptomology, whereas their ability to establish the duration of symptom patterns which are essential for diagnosis is limited (Hodges, 1993). Reliability of diagnosis can be jeopardised by clinicians using unstructured interviews whereby interviewer style can influence responses to questions and thus outcome. Clinicians must be alert to potential differences between informants' subjective descriptions of a child's behaviour. Research has found that depressed mothers for example are prone to perceiving their children as exhibiting behavioural problems (Webster-Stratton, 1988). Youngsters being assessed for the disorder on the other hand are prone to underreporting key symptoms when asked directly about their problems related to attention and hyperactivity (Loeber, Green, Lahey & Stouthamer-Loeber, 1991).

It is clearly up to the clinician to be well versed with assessment procedures though the diagnostic manuals should suggest cut-off scores or likely profiles on certain psychometric tests. For example the Wechsler Intelligence Scale for Children-Third Edition (WISC-III; Wechsler, 1992) contains a ‘Freedom from Distractibility’ dimension whose score may provide useful information when compared to the other WISC-III dimensions (Searight, Nahlik & Campbell, 1995). Only if the diagnostic classifications can give guidelines as to the likely indicators of an ADHD diagnosis can reliability be improved.

**The usefulness of diagnostic classification for the individual**

Once a diagnosis of ADHD has been made, it is the clinician's next step to plan intervention. Unfortunately a diagnosis in itself is not that helpful to the individual, despite the sub-classifications of the disorder as detailed in DSM-IV. This is because a diagnosis in itself does not indicate the various factors which contribute to the unique presentation of the individual's symptomology. Neither does it alert the clinician to the extent of secondary features likely to be associated with the disorder (such as academic performance, peer relationships, family relations; Hinshaw, 1994) which also require input. The most informative information will be that which is obtained as a result of
the comprehensiveness of the clinician's assessment. The BPS (1996) suggest the following areas of information should be considered when attempting to understand the clinical presentation of ADHD in a child:-

i) Environmental factors (life events, home/care, school, culture)
ii) Neurological factors
iii) Information from instruments used for assessments
iv) Individual psychological differences
v) Toxins and diet

This information guides the development of a multi-dimensional formulation which becomes more meaningful for the individual than merely a diagnosis of ADHD on the basis of meeting it's criteria. A thorough evaluation of the multiple causation of behavioural difficulties is required so that intervention can be targeted accordingly. For example Maag and Reid (1994) discuss the importance of investigating a variety of possible explanations for the behavioural difficulties rather than making assumptions as to causality. In this way behavioural presentation can be broken down into separate components for intervention.

Wider implications of a diagnosis within the medical model

In the UK it is not essential to have a diagnosis of ADHD or Hyperkinetic Disorder before statementing takes place in order to provide special education. Rather clinicians can "draw upon the fundamental assessment of variables involved in particular cases" (BPS, 1996). This seems far more useful because it has the effect of tailoring packages of input. However in order for medication to be prescribed, a child must meet diagnostic criteria. Although not a cure, psychostimulants have been shown to be associated with improvements in relationships with family members (Schachar, Taylor, Weiselber, Thorley & Rutter, 1987; cited in BPS, 1996). They also temporarily calm children and so enable them to gain more experience from schooling or peer relationships (BPS, 1996). In this respect diagnosis is helpful as a key to accessing medical help.
However there is a negative side to diagnosis which may involve stigmatising children as 'difficult' at school. A diagnosis also implies that the problem lays within the child and this may impede efforts to examine the flexibility of the school or home environment in adapting to individual needs. The BPS (1996) discusses the need for an appraisal of the interaction between environmental factors and individual characteristics that a child brings to a situation in order to help children at home or at school. If parents and teachers take this balanced perspective on board, the blame should rest on no one individual, but rather a problem solving approach is assumed. The diagnostic criteria themselves do not encourage this balanced reflection as the emphasis is on behavioural 'problems' making no reference to unrealistic expectations of others or maladaptive environments.

Summary

There has been a magnitude of attention directed at the ADHD construct in terms of media interest and professional attempts at understanding and refining it over time. Rather than reaching a clear understanding of the theoretical underpinnings of the disorder, there has been a process of elimination whereby explanations have one by one been discovered to provide limited explanatory power. Subsequently, the diagnostic classification is simply a reflection of behavioural expressions and is not able to refine our understanding.

The DSM-IV criteria runs the risk of over-identifying children and therefore of pathologising individuality. However, within it's umbrella term it provides useful sub-classifications to more accurately reflect a child's presentation and therefore may provide a more sound target for intervention than perhaps a diagnosis of 'Hyperkinetic Disorder'. It is also more sensitive to identifying girls with the disorder. It is not clear whether ADHD can truly be regarded as a unitary construct.

ADHD has co-morbid conditions such as Conduct Disorder and Oppositional Disorder. Research suggests that this overlap with behavioural descriptions in other disorders is a
true reflection of one disorder existing as a risk for developing another, rather than a
reflection of poor discriminatory power within the DSM classification system.
However weaknesses within the specific properties of DSM-IV do exist and may need
improving as more research supports these criticisms.

A major criticism of the classification systems is their failure to guide the clinician in
appropriate assessment procedures in an attempt to improve reliability. However inter-
diagnostician agreements for DSM-IV is reported as reasonable. The criteria
themselves do not guide intervention specifically. Instead a multi-dimensional
formulation is required if it is to be meaningful for the individual. Finally a diagnosis of
ADHD is in itself helpful for accessing medication but is not necessary in the UK for
accessing special education. Advantages of a diagnosis should be weighed against the
danger of 'blaming' the child rather than understanding the interaction between
environmental factors and individual characteristics of the child. This is not the
emphasis encouraged by diagnostic classification.

Both the construct of ADHD, and the diagnostic classifications created to categorise it
require ongoing research in an effort to improve both their utility as diagnostic tools,
and their accuracy.
References


Appendices
Appendix 1

Attention Deficit Hyperactivity Disorder - DSM-IV Criteria (American Psychiatric Association 1994)

A. Either (1) or (2)

(1) Six (or more) of the following symptoms of inattention have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Inattention
a) Often fails to give close attention to details or makes careless mistakes in school work, work, or other activities.
b) Often has difficulty sustaining attention in tasks or play activities.
c) Often does not seem to listen when spoken to directly.
d) Often does not follow through on instructions and fails to finish school work, chores, or duties in the workplace (not due to oppositional behaviour or failure to understand instructions).
e) Often has difficulty organising tasks and activities.
f) Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort (such as school work or home work).
g) Often loses things necessary for tasks and activities (e.g. toys, school assignments, pencils, books or tools).
h) Is often easily distracted by extraneous stimuli.
i) Is often forgetful in daily activities.

(2) Six (or more) of the following symptoms of hyperactivity-impulsiveness have persisted for at least six months to a degree that is maladaptive and inconsistent with developmental level:

Hyperactivity
a) Often fidgets with hands or feet, or squirms in seat.
b) Often leaves seat in classroom or in other situations in which remaining seated is expected.
c) Often runs about or climbs excessively in situations in which it is inappropriate. (In adolescent or adulthood may be limited to subjective feelings or restlessness).
d) Often has difficulty in playing or engaging in leisure activities quietly.

e) Is often "on the go" or acts as if "driven by a motor".

f) Often talks excessively.

**Impulsivity**

g) Often blurts out answers before questions have been completed.

h) Often has difficulty awaiting turn.

i) Often interrupts or intrudes on others (butts into conversations or games).

B. Some hyperactive-impulsiveness or inattentive symptoms that caused impairment were present before the age of seven years.

C. Some impairment is present in two or more settings.

D. There must be clinically significant impairment in social, academic, or occupational functioning.

E. The symptoms do not occur exclusively during the course of a pervasive developmental disorder, Schizophrenia or other psychotic disorder, and are not better accounted for by another mental disorder.

Types of attention hyperactivity disorder:

- **Attention deficit/hyperactivity disorder, combined type:** if both criteria A1 and A2 are met for the past six months.

- **Attention deficit/hyperactivity disorder, predominantly inattentive type:** if criterion A1 is met but A2 is not met for the past 6 months.

- **Attention deficit/hyperactivity disorder, predominantly hyperactive-impulsive type:** if criterion A2 is met but criterion A1 is not met for the past 6 months.

Or:

- **Attention deficit/hyperactivity disorder not otherwise specified:** for disorders with prominent symptoms of inattention or hyperactivity-impulsivity that do not meet the criteria for attention deficit/hyperactivity disorder.
Appendix 2

Hyperkinetic disorder - International Classification of Diseases (World Health Organisation, 1990)

A. Demonstrates abnormality of attention and activity at home, for the age and developmental level of the child, as evidenced by at least three of the following attention problems:

a) Short duration to spontaneous activity.
b) Often leaving play activities unfinished.
c) Over-frequent changes between activities.
d) Undue lack of persistence at tasks set by adults.
e) Unduly high distractibility during study.

And by at least two of the following activity problems:

f) Continuous motor restlessness.
g) Markedly excessive fidgeting or wriggling during spontaneous activities.
h) Markedly excessive activity in situations requiring stillness.
i) Difficulty in remaining seated when required.

B. Demonstrates abnormality or attention and activity at school or nursery, for the age and developmental level of the child, as evidenced by at least two of the following attention problems:

a) Undue lack of persistence at tasks.
b) Unduly high distractibility, i.e. often orienting towards extrinsic stimuli.
c) Over-frequent changes between activities when choice is allowed.
d) Excessively short duration of play activities.

And at least two of the following activity problems:

e) Continuous and excessive motor restlessness in school.
f) Markedly excessive fidgeting and wriggling in structured situations.
g) Excessive levels of off-task activity.
h) Unduly often out of seat when required to be sitting.
C. Directly observed abnormalities of attention or activity. This must be excessive for the child's age and developmental level. The evidence may be any of the following:

a) Direct observation of the criteria in A or B above.
b) Observation of abnormal levels of motor activity, or off-task behaviour, or lack of persistence in activities, in a setting outside home or school.
c) Significant impairment of performance on psychometric tests of attention.

D. Does not meet criteria for pervasive development disorder, mania, depressive or anxiety disorder.

E. Onset before the age of 6 years.

F. Duration of at least 6 months.

G. IQ of above 50.
What psychological models have informed the development of psychotherapeutic work with people with dementia? What are the aims of such work, and how may it be evaluated?
Introduction

The word 'dementia' represents a group of symptoms which lead mainly to a slow, global loss of cognitive functions and is one of the largest categories of chronic disease within the older population (Midence & Cunliffe, 1996). It has been estimated that dementia affects approximately 5% of people over the age of 65, and 15% of people over the age of 80 (Terry & Katzman, 1983). Prominent clinical features of dementia include memory loss, intellectual difficulties, impaired language skills, disorientation, impaired visio-spatial abilities and personality changes (Tobiansky, 1994). Depression is one of the most common psychological problems in dementia, occurring in approximately 30-50% of patients with Alzheimer's Disease (Wragg & Jeste, 1989).

There are various types of dementia which have generally been categorised according to (still incomplete) understandings of differences in aetiology. The most common dementia is Alzheimer's Disease, followed by Vascular dementia. Other forms such as Lewy Body-type dementia have also been identified (see Livingstone, 1994 for further information on rarer forms of dementia). Although clinical presentation tends to differ a little within the various forms of dementia, global loss of cognitive function is a common feature.

During the early stages of dementia when the client is able to retain a certain amount of independence with some guidance, clients are often supported within the community by attending day centres. During more advanced stages of the disease process when clients require all their care needs to be met by others, clients are generally nursed within continuing care wards or nursing homes. It is within these two care settings at different stages of dementia that psychotherapeutic work takes place.

Despite the medical model often enjoying a position of dominance within the National Health Service, its emphasis on cure conflicts with the current incurable status of dementia. The primary goal of treatment for dementia requires modification in order to simply reduce the impact of psychological symptoms such as apathy, agitation, low
mood, anxiety and disorientation. With the exception of administering drugs to maintain symptoms at a manageable level for both the person concerned, and the staff caring for him/her, psychological approaches to work with such clients are generally the treatment of choice.

This essay will explore three common approaches to psychological work with people who have dementia; Reality Orientation Therapy, Reminiscence Therapy and Validation Therapy. These three approaches which have been labelled both as ‘psychotherapies’ (Whitehead, 1991) and as forms of ‘psychosocial therapy’ (Droes, 1997; Woods, 1996) were chosen for their wealth of literature and popularity with care-giving staff. There is also much scope for their evaluation by clinical psychologists. The psychological models which have informed such work will be discussed, as will the aims of each approach. Ways of evaluating the approaches will be explored by discussing examples of studies already completed, and giving suggestions as to how they may be improved upon.

**Reality Orientation Therapy**

A review of the literature on ROT does not reveal an explicit opinion about which psychological models informed the development of ROT and it is thus a major criticism that ROT lacks a sound theoretical base. Its origins were however clearly rooted in attempts by Folsom in the late 1950’s (cited in Woods, 1996) to establish a rehabilitation technique for elderly (chronic) psychiatric patients, which aimed to encourage nursing staff to spend more time in personal contact with the patients, and to stimulate the patients into activity (Folsom, 1983). By the 1960’s the emphasis of ROT had shifted to the stimulation of undamaged cognitive functions to counter the disorientation and confusion generally experienced by people with dementia (Droes, 1997). It is a logical deduction therefore that the cognitive model has influenced the development of ROT. According to Backman’s analysis of cognitive deficits in dementia (1992; cited in Woods, 1996), problems are likely to exist for sufferers where performance depends particularly upon episodic memory (memory for events) and semantic memory (memories in generalised knowledge). Therefore to enhance function, external memory aids are valuable in reducing the level of demand on
effortful, self-initiated cognitive processes, and aid the person in cueing and prompting retrieval information (Woods, 1996). External memory aids or ‘environmental props’ (Karuza & Katz, 1991) such as calendars, name tags, white boards and sign posts are a central feature of ROT.

There are two main types of ROT; Twenty-four hour ROT, and Classroom ROT. Both types aim to reorient people at the moderate stage of the dementia process to their current situation. “It is assumed that reinforcing residents’ contact with reality can counteract their confusion, enhance personal responsibility over behaviour, and foster better interpersonal communication”. It also assumes some “plasticity in cognitive functioning” because it aims to help the sufferer use existing cognitive skills more effectively (Karuza & Katz, 1991).

The twenty-four hour approach involves changing the sufferer’s environment by adding clear signposts of location around the ward and home, as well as using notices and other memory aids. Staff offer orienting information within each and every interaction and are therefore responsible for the implementation of the intervention. The classroom approach involves structured sessions with a small number of patients (5-6) and staff, who meet regularly (daily or 4-5 times a week), lasting half an hour or so (Karuza & Katz, 1991; Woods, 1996). Basic information about names of people in the group, the day, date, time and place is shared and re-iterated with group rehearsal of the information, and reinforcement for correct responses. Again there is a heavy reliance upon ‘props’ such as an information whiteboard as a centre of focus.

Criticisms about ROT are numerous. Firstly, the approach would seem less useful in patients beyond the moderate stage of the disease process, when verbal communication abilities are severely reduced (however this has not been fully evaluated). Also, due to its heavy emphasis upon reading environmental props, it is unlikely to be helpful for people who have perceptual or sensory deficits. A major criticism is concern raised over the clinical usefulness of the material taught, and whether it can make any real impact on the patient’s subjective experience of day to day life (Droes, 1997). Buckhaldt and Gubrium (1983) suggest that techniques of ROT demean, devalue and patronise the patient. However as Woods (1992) points
out, it is the attitude of the staff implementing the intervention, rather than the intervention itself which runs the risk of having such effects on patients, and such attitudes require careful examination before embarking on any intervention. Finally, advocates for specialised care units for dementia patients (e.g. Maas, 1988) state that ROT can overstimulate the residents, placing too many demands on them and therefore creating a stressful environment which has negative effects upon them.

So far evaluation studies on ROT have revealed mainly improvements on cognitive measures (Karuza & Katz, 1991) particularly on measures of verbal orientation such as the Mini Mental State Examination (Folstein, Folstein & McHugh, 1975; Droes, 1997; Woods, 1996). Woods (1996) reports fewer studies indicating improvements in behavioural functioning, although he suggests a lack of sensitivity in behavioural rating scales as a potential reason for this. According to Droes (1997), change in patients’ mood has rarely been evaluated. This is a major criticism bearing in mind the often observed distressed state of mind, and empirically evidenced presence of depression in people with dementia. Also very little attention has been paid to evaluating effects upon staff or informal carers. However one study by Greene, Smith and Gardiner (1983) found improvements in relatives’ self-ratings of mood coincided with the commencement of ROT sessions, and a corresponding deterioration at the cessation of the sessions, even though they were unaware of what treatment their dementing relatives were receiving.

Clearly when planning to evaluate ROT it is imperative to decide exactly what is important to measure in relation to change. It could be argued that verbal orientation is not a clinically useful aspect to measure because it could be rote learned, and have little impact upon the patients’ day to day experience of life. It would seem beneficial to evaluate any behavioural changes (particularly agitation or wandering), mood changes (particularly anxiety), as well as positive effects on carers and staff members. Bearing in mind the earlier criticism by Woods (1996) that behavioural measures are not sensitive, it would be helpful to choose a behavioural rating scale such as REHAB (Baker and Hall, 1983) which, although originally designed for assessing change in long stay psychiatric patients, has been used successfully before with older adults (Baker & Hall, 1983; Nichol, 1989; cited in Baker, Dowling, Wareing, Dawson &
Assey, 1997). This scale involves indicating observed change by placing a pencil mark along a line which represents a continuum between dichotomous ratings. This would be more helpful than forced choice responses.

An experimental design incorporating a carefully considered control group will enable assumptions to be made about any observed difference between the groups, being attributed to the difference in treatment. This approach is especially suitable for the Classroom ROT, whereby the sessions could be compared to Reminiscence Therapy, or activity groups. Time of measurement should be at least pre-treatment (including a baseline measurement), mid, post and follow-up. In addition, ratings immediately before and after sessions should be made. In this way, process of change over time, both short and long term, can be examined (as in Baker et al., 1997). For classroom ROT, it would also be important to measure generalisation to other settings, such as the home environment, if the client is attending a day care facility. This could be achieved by using rating scales designed specifically designed for carers to complete (e.g. Greene et al., 1983).

The twenty-four hour ROT is more complex to evaluate, because it is continuous and would be easier to 'contaminate' by other changes in the ward environment (such as staff to client ratio). Suggestions can be taken from direct observation methods evaluating effects of ward environment on behaviours of long-stay elderly patients, such as that by Bowie and Mountain (1993). They used a 'Psion Organiser' which is a hand held computer enabling the researcher to record patient behaviour continuously, and is therefore a form of ‘event sampling’. This is however a labour-intensive method, and it may be that weekly recording by staff, involving retrospective observations are more manageable to implement.

Finally, there is a strong case for using single-case designs in the evaluation of ROT. This follows the argument that it is more clinically relevant to individualise ROT as a result of identifying areas of need within individual care plans. Hanley (1986) carried out three single case studies to evaluate improvements in individual patients. The improvements noted were deemed more clinically useful for the individuals concerned.
In summary, ROT is a popular approach with much scope for further improvement in evaluation, particularly in terms of choice of targets to measure, improved measurement tools, and potentially including more single case design for individualised ROT.

**Reminiscence Therapy**

Reminiscence therapy is a psychotherapeutic approach which has traditionally been perceived as being rooted in developmental theory (Karuza & Katz, 1991), more specifically Erikson’s eight stages of psychosocial development (Erikson, 1968). Erikson proposes that each stage across the life span focuses upon one crisis important to that particular time of life. The individual’s task is to resolve the crisis positively, in order to avoid being troubled psychologically, and to enable them to cope effectively with subsequent crises. In old age the central crisis is that of ‘integrity versus despair’, whereby the person enters a period of reflection in order to assess and evaluate their life, and conclude that it has been worthwhile and meaningful, so that they are able to face death with acceptance and dignity. The alternative is to fall into despair at the realisation of their unaccomplished goals, failures and illspent lives (Bernstein, Roy, Srull & Wickens, 1988). It is already evident that this theoretical base presents a challenge for the more than very mildly impaired dementia sufferer who, firstly is unlikely to be able to coherently review their life in such a sophisticated manner due to cognitive impairment, and secondly is not in a position to rectify negative aspects of their past due to their decreasing autonomy.

There is in fact contradiction within the literature about whether reminiscence can truly be seen to include the goal to achieve integrity, or whether this is reflective more of the process of ‘life review therapy’ (Haight & Burnside, 1993). A review of the reminiscence literature suggests that reminiscence therapy in fact reflects wide ranging goals including increased communication and socialisation, often providing pleasure and entertainment. It can also be individual, group-based, structured or unstructured, including more general memories or specific life events, and involve the use of multi-sensory props or memorabilia to stimulate memories and discussion of the past (Woods, 1996). Already it can be seen that this type of reminiscence with it’s
adaptable goals may be more flexible in the benefits it offers a person with dementia, than life review therapy.

Gibson (1995) distinguishes between two types of reminiscence therapy for people with dementia; ‘General Reminiscence’ which is often used in a group situation and involves the type of multi-sensory material described above, and ‘Special Individual Reminiscence’ whereby a key worker obtains a detailed life history (via the patient and their relatives) and creates from this a care plan of special reminiscence type work. The obtained life history is a tool to improve quality of social exchange in the present. This may include planning trips and activities related to the patient’s interests and experiences, and personalising the environment to suit the patient’s own preferences (Gibson, 1995).

An evaluation of special individualised reminiscence work (Gibson, 1995) revealed “troublesome” target patients (as identified by the staff) to have shown increased sociability, decreased aggression and less demanding behaviour. Staff also learned much about the patients, appreciating the individual person underlying each presentation of symptoms. Unfortunately the literature does not identify standardised measures used within these studies. Rather, conclusions were drawn on “written and verbal reports”. This suggests a reliance upon anecdotal reports for which evaluation of much psychotherapeutic work is often criticised. In order to improve upon such evaluation, it would be preferable to combine objective, standardised, but clinically relevant measures of both cognitive, and behavioural functions, with qualitative evaluation of changes specific to individual targets. Additionally, semi-structured interviews would be appropriate tools for collecting data on perceived benefits gained by staff, such as increased knowledge of useful information about patients.

Evaluations of the more general group reminiscence, have often looked at changes within the group sessions themselves, and have indicated at the very least that engagement and contributions made were increased (e.g. Head, Portney & Woods, 1990). Gibson’s (1995) large scale evaluation of 25 reminiscence groups revealed that dementia sufferers showed pleasure and enjoyment and rarely demonstrated behavioural disturbance within the group. Some patients were observed to be less
agitated outside the group. These findings were based on patients who attended
groups with other non-demented members. In groups when members consisted of
patients with dementia only, verbal interaction tended to be between leaders and
members, rather than between members, as in the mixed groups. This has
implications for selection of group members.

Tools for measuring were again, not made explicit within the literature, although data
appeared to have been collected via detailed written reports of group sessions, with
subsequent analysis of attendance, interaction, emotional climate and content. Again,
the described evaluation reflects a lack of stringent, objective measurement and
design, enabling exhaustive data collection, both short and long term. An
improvement would have been to record predefined categories of interaction for group
members, under a form of 'time sampling' (the selection of periods of observation at
specified or random points in time; Wilkinson, 1995). However unstructured verbal
and written evaluations do seem to lend themselves well to constructing a 'picture' of
benefits and shortcomings of therapy, which may be more appropriate for staff
without professional training, who are often likely to be implementing such therapies.

As a final note it is interesting to point out that evaluations of reminiscence work do
not seem to be guided by it's originally recognised theoretical underpinning (the goal
to attain 'integrity'). Rather it is guided by the less sophisticated target of enjoyment
and meaningful interaction. This emphasis is a more realistic one for use with people
with dementia. It would be helpful for literature on reminiscence work to
consistently distinguish between goals of 'life review therapy' and reminiscence
therapy. Currently this distinction is not immediately and consistently clear to the
reader.

Validation Therapy

A review of the literature on validation therapy revealed commonalties with
reminiscence (or more specifically life-review therapy), in that it is also seen to be
informed by Erikson's Life Stage Theory. Particularly, a ninth stage ('resolution
versus vegetation') is added to the former eight stages whereby clients are assisted by
caregivers to resolve their lives and prepare for death (Feil, 1992). A major premise of validation therapy is that many residents in nursing homes are in a state of despair, and that withdrawal, isolation and disorientation is a defence against anxiety associated with unresolved existential conflicts. This state is made worse by intellectual sensory and social depravation (Karuza & Katz, 1991). By relating to the patient within a humanistically based approach which draws upon the principles of Carl Rogers' Client-Centred Therapy (1957; conveying accurate empathy, genuineness and unconditional positive regard), the person's internal emotional state is validated. In this way the relationships between residents and caregivers are humanised (Karuza & Katz, 1991). The therapy emphasises communication with confused patients in whatever reality they are in (Feil, 1992) and so is ideal for use with people with dementia.

The main technique of validation therapy is to recognise the person’s communication of feelings and emotions, and to acknowledge and validate these, verbally and non-verbally. It thus recognises the individuality of the person with dementia, and respect for their value as a person (Woods, 1996). The technique can be carried out within a group setting or on a one to one basis. Topics within a group may include anger, separation and loss, with the aim of allowing members to verbalise unresolved feelings about their past lives. It can already be seen that validation therapy with a severely demented patient may be more practical on a one to one basis.

There are several criticisms about Feil’s validation therapy. Kitwood (1992) suggests that by emphasising unresolved conflicts and difficulties in the past, current sources of distress may be overlooked. It may be that the reason behind anguished verbal expression and disturbed behaviour is in the here and now. Midence and Cunliffe (1996) criticise Feil’s definition of a target group for validation therapy, stating that it is not clear exactly which target group the therapy is designed for. However Feil is said to have clearly identified people with dementia as a focus (Woods, 1996). Another criticism is the same as the one described for reminiscence therapy; that people with moderate-severe dementia are unlikely to be able to resolve past conflicts, even with the help of validation. Feil however argues that this resolution can be at least temporary, and thus have benefits for the patient (1992).
Evaluation studies are few, and include the following; Babins, Dillon & Merovitz, 1988; Morton & Bleathman, 1991; Peoples, 1982; cited in Toseland et al., 1997; Robb, Stegman & Wolanin, 1986; Scanland & Emershaw, 1993; and Toseland et al., 1997. A review by Toseland et al. (1997) revealed two of the studies (Babins et al., 1988; Peoples, 1982) reported increased communication and decreases in problem behaviour and mental deterioration among validation therapy participants.

Toseland et al.’s study (1997) deserves more detailed comment due to its comprehensive design. Participants were randomly assigned to one of three groups; validation therapy groups, social contact groups or usual care. Members of the former two groups met weekly for 52 weeks. Staff leading both groups were equally qualified. Apart from random allocation and the comparison with two control groups, the study’s strengths lie in its number of different data sources including medical records, non-participant observers and nursing staff, all of which were kept blind to the intervention conditions to which the participants were assigned. Results indicated that only the nursing staff reported reduced physically and verbally aggressive behaviours in residents who received validation therapy. One criticism of this study is that it concentrates upon (albeit comprehensive) indices of behaviour outside the group, with no inclusion of transitory enjoyment, insight or member to member interaction during the group itself. Bearing in mind the transitory experience of emotion and insight often demonstrated by people with dementia, and Feil’s acknowledgement of the importance of transitory gain (1992), it has been afforded little importance within Toseland et al.’s study.

Finally, beyond Feil’s anecdotal reports (1992) there is a lack of experimental evaluation of the effects of validation therapy on a one to one basis. With the increasing importance of acknowledging the individual within an institution as a person in their own right, rather than the member of a group of people with dementia, it is time for evaluation to be tailored accordingly. Additionally, people suffering from different subtypes of dementia are a somewhat heterogeneous group. Drawing conclusions from group evaluations where there is much inter-subject variability can
produce weak results in terms of clinical significance (Wilson, 1995). Thus the case for single case studies becomes even stronger.

**Conclusions**

In summary, a review of the literature on reality orientation, reminiscence and validation therapy reveals rather 'patchy' theoretical underpinnings. Although reference is made to psychological models thought to have informed the development of each of the therapies, there is a certain amount of inconsistency in the way these are conveyed to the practitioner. This theoretical inconsistency is often reflected in the stated goals of the theories (for example within reminiscence therapy and life review therapy).

Finally, evaluations of the therapies require improvement. Well designed studies like that by Toseland et al. (1997) are helpful benchmarks for quality. However even this study fails to measure all of the relevant dimensions. Moreover the development of thoughtfully designed single case experiments appears essential if evaluation is to be useful for assessing increasingly popular individualised programs of care.
References


Critically evaluate the effects of transference interpretations upon treatment outcome in brief dynamic psychotherapy

March 1999

Year 3
Introduction

Focus upon transference interpretations has become “the hallmark of psychoanalytically oriented technique in psychotherapy” (Henry, Strupp, Schacht & Gaston, 1994). One significant view posits that the “ultimate instrument” of therapeutic change is the “mutative interpretation” of the fully developed transference neurosis (Strachey, 1934). Leading contributors to the brief dynamic literature argue that even in brief therapy, where a fully developed transference neurosis does not have time to develop, transference interpretations can promote symptom relief, and often lasting characterological change, and therefore have a central role in intervention (Davanloo, 1978; Malan, 1976; Stifneos, 1972; cited in Bauer & Kobos, 1995).

Until recently there has been a longstanding “faith” in these views with little effort to support them empirically. However, now there exists an increasing emphasis on psychotherapy process research which offers some tentative empirically based conclusions. These conclusions present a challenge to some of the accepted assumptions, and require the psychodynamically oriented clinician to begin to consider a more flexible stance in his or her therapeutic work. Research relating to the effectiveness of transference interpretations in brief dynamic psychotherapy has concentrated mainly upon the frequency and accuracy of transference interpretations in therapy, as well as the patient’s immediate and longer term response to them. Therefore findings related to these aspects will be discussed, and attention will be drawn to possible mediating factors in the effectiveness of transference interpretations; mainly the quality of object relations in the patient. Finally a brief discussion of other factors and interventions which may hold importance in brief dynamic therapy will be discussed.
Definitions:

**Brief dynamic psychotherapy**

By definition, brief dynamic psychotherapy is time-limited, and generally takes place on a weekly basis over a period of approximately six months (Levenson, 1995). Traditionally, twenty-five sessions mark the upper limit of brief dynamic therapy (Koss & Shiang, 1994). The approach is founded on major psychoanalytic concepts. These include the importance of childhood experiences and development, the role of conflicts, unconscious determinants of behaviour, transference, the patient’s resistance to therapeutic work, and repetitive behaviour (Levenson, 1995). However, brief dynamic therapists do not emphasise the exploration of “highly inferential” concepts or “elaborate metapsychological models” with “unclear behavioural referents”, and avoid regression and potential dependency. The “here-and-now” relationship between therapist and patient is attended to and interventions are more readily based upon incomplete information (Levenson, 1995).

Bauer and Kobos (1995) state that brief dynamic therapy involves, 1) rapid establishment of a patient-therapist collaboration, 2) intense, focused work on a carefully delineated problem area, 3) careful interpretative attention to the playing out of the problem theme in the patient – therapist relationship, and 4) a productive and manageable termination. Budman and Gurman (1983, cited in Levenson, 1995) propose that in terms of outcome, the short term therapist, unlike the long term therapist, does not seek to “cure”. Although there are various schools of brief dynamic psychotherapy which emphasise certain theoretical stances and techniques above others, the general goals of therapy are: increased self-understanding, improvements in self esteem as a result of increased mastery, resolution of the crisis that was influential in bringing the patient to therapy, more flexible coping strategies and moderate resolution of focal problems (Bauer & Kobos, 1995). Generally the short term therapist accepts that many changes will occur after therapy (Levenson, 1995).
Transference and transference interpretations

Two major views about transference and its interpretation have developed over time (Cooper, 1987). The “historical” view, rooted in Freud, states that transference is a re-enactment of earlier relationships, where the aim of the transference interpretation is to help the patient to gain insight into the ways that early infantile relationships are distorting or disturbing the relationship with the therapist. This relationship becomes a model for the patient’s life relationships. The “modernist” view regards the transference as a new experience rather than the enactment of an old one. The aim of the transference interpretation is to bring into the conscious all aspects of this new relationship including its colourings from the past. Essentially the historical view posits that the therapist is an observer and interpreter, and the modernist view that he or she is an active participant (Cooper, 1987), and that transference phenomena partially reflect the actual participation of the therapist in the relationship.

There is much disagreement about the limits of transference in the patient-therapist relationship, with some authors including all phenomena which constitute the patient’s relationship with the therapist (Makari & Michels, 1993). Disagreement about definitions have hindered attempts to replicate and cross validate findings in process research (Piper, Joyce, McCallum, & Azim, 1993). At an operational level, interpretations are actual statements made by the therapist to the patient to enhance the patient’s understanding of his or her experiences (Piper et al., 1993). Transference interpretations focus upon the patient’s reactions to the therapist and may be (though not necessarily) linked to other important people in their past or current relationships (such as parents or significant others).

Frequency/proportion of transference interpretations in therapy

Key contributors to brief dynamic psychotherapy advocate early and frequent interpretation of transference (Bauer & Kobos, 1995). This ‘active’ stance is congruent with the productive and intense ethos of time-limited therapy. Originally, support for this ‘more is better’ position came from Malan (1976). In a naturalistic study, he found a significant correlation between the frequency of parental linking
transference interpretations (therapist pointing out the patient’s relationship to the therapist and linking it to the patient’s relationship with a parent) and favourable outcome. However, the value of this finding was limited by methodological problems. Therapist notes were dictated from memory rather than using mechanical recordings or verbatim transcripts, and the evaluators were not blind to the treatment outcomes. Additionally, even the strongest correlation was only marginally significant (Piper, Debbane, Bienvenu, de Carufel & Grant, 1986). Marziali (1984) completed a study which rectified Malan’s methodological problems. Although she claimed to support Malan’s findings, significant correlations involved therapist/parent links and only two out of five sub scores on a ‘dynamic change’ outcome variable. Links involving the therapist and significant others other than parents, were just as strongly correlated.

Since these two studies which claim to support the use of more frequent transference interpretations in therapy, more recent and more methodologically sound research has challenged the findings. Piper et al. (1986) concentrated on proportions of transference interpretations among other interventions used in the therapy, because they criticised reliance on using frequency as a measure, suggesting it may reflect greater therapist activity or interest. In a sample of twenty one patients, the proportion of transference interpretations was not related to outcome (outcome measures concentrated on interpersonal functioning, traditional psychiatric symptomology and personal target objectives).

Piper, Azim, Joyce & McCallum (1991) expanded their research with a larger sample, also exploring the therapeutic alliance and quality of patients’ object relations (QOR). Therapeutic alliance was defined as the nature of the working relationship between patient and therapist, and was rated separately by the therapist by means of six seven-point likert-type items. QOR was defined as a “person’s internal enduring tendency to establish certain kinds of relationships with others” and was rated by an independent rater following an unstructured interview with patients. High –QOR indicated a tendency to have mature relationships with others, and low –QOR indicated a tendency to have more primitive relationships with others.
Significant inverse relationships were found between the proportion of transference interpretations, and measures of therapeutic alliance and therapy outcome. These inverse relationships were most pronounced when concentrations of transference interpretations were high and were among patients with a history of high-QOR. They suggested two causal explanations. The first being that excessive use of transference interpretations may have produced negative effects, or secondly that negative treatment effects may have elicited a high proportion of transference interpretations in an effort to resolve an impasse in the working relationship. Closer examination of the temporal patterns of therapist intervention and patient silences within sessions provided more evidence consistent with the former explanation (transference interpretations sometimes appeared to cause the patient to “shut-down”, reflected in silences). The authors also suggested that high-QOR patients may have been more prone to regard transference interpretations as negative criticism compared with low-QOR patients, for whom the overall active presence of the therapist may have been important. These findings indicate that the needs and thresholds of high and low-QOR patients may be different, and that QOR may be an important determinant in choice of therapeutic technique.

Finally, a paper reviewing data from both a quasi-experimental, and a naturalistic study reported the findings of long term outcome (two to five years follow up) on a measure of overall dynamic change (interpersonal relations, self esteem, new self understanding and problem solving capacity) (Hoglend, 1996). There existed a negative long term effect of a high frequency of transference interpretations given to patients. Therefore even in the longer term, poorer outcomes appear to be correlated with a high frequency of transference interpretations.

Although these studies require replication to further support their findings, some tentative conclusions can be drawn. Contrary to the assumption that “more is better”, it seems that a high frequency and proportion of transference interpretations in brief dynamic psychotherapy may in fact be associated with a poorer therapeutic alliance and outcome (post treatment and at follow up). The patient characteristic of QOR may be an important mediating factor in the effects of interpretation on outcome.
Accuracy of transference interpretations in therapy

So far this essay has addressed the question of whether the therapeutic technique of transference interpretation in various quantities helps or hinders treatment. We now consider the issue of how useful or pertinent particular interpretations are to patients. In other words, how the accuracy of transference interpretations affects outcome in therapy. Due to the time limits of brief therapy, therapists construct focused formulations to guide their interpretations. However, it should not be assumed that all interpretations are uniformly accurate in adhering to the patient’s problem focus (the “Uniformity Myth”; Kiesler, 1966; cited in Silberschatz, Fretter & Curtis, 1986) and that all interpretations will have the same effect. Only a few studies have explored the effects of accuracy of interpretations on the outcome of brief dynamic psychotherapy.

The first study concentrated on the extent to which interpretations were plan-compatible (“the extent to which they addressed the patient’s unconscious and conscious goals and the obstacles or pathogenic beliefs that have prevented the patient from pursuing these goals”) and their association with outcome and immediate progress in sessions (Silberschatz et al, 1986). Immediate progress referred to patient insight and involvement, lack of resistance and productive free-association. Outcome was categorised as excellent, moderately good or poor, as a result of conclusions drawn from scores on “standard psychotherapy outcome measures” including ratings from the patient, the therapist and an independent rater.

Interpretations judged as plan-compatible by four-six experienced clinicians tended to be followed by better immediate progress whereas plan-incompatible interpretations tended to be followed by less immediate progress. Additionally, higher percentages of plan-compatible transference interpretations (versus plan-incompatible) were associated with better outcome, whereas lower percentages were associated with poorer outcome. Interpretations which did not include the patient’s feelings toward the therapist (non-transference interpretations) were no less powerful in producing immediate progress than transference interpretations. This study suggests that the accuracy of interpretations may be a better indication of a patient’s immediate progress and outcome than the category of interpretation used. Unfortunately the
sample included only three patients, and so the results cannot stand alone as substantial evidence for this argument.

Crits-Cristoph, Cooper and Luborsky (1988) expanded on this research using a larger sample of forty-three patients. They defined the accuracy of interpretations as the degree of congruence with the content of the patient’s Core-Confictual Relationship Theme (CCRT). The CCRT is a representation of the patient’s central relationship patterns. They found a direct relationship between accuracy of interpretations and outcome. This association existed regardless of poorer therapeutic alliance and the therapist’s more general technical skills. Unfortunately outcome measures were not adequately described in the study so it is not possible to examine how certain types of outcome were associated with accuracy. Additionally, the average number of therapy sessions was well above the cut-off sessions defining the upper limit of brief dynamic therapy. Finally the study did not explore the patient characteristics which might mediate the effects of varying accuracy of interpretations.

The mediating influence of patient characteristics was investigated with regards to accuracy of interpretations by Piper et al. (1993) who looked again at QOR. Using psychodynamic formulations with assigned accuracy scores, they found that the relationship between accuracy, and outcome and therapeutic alliance ratings were different for high and low QOR patients. For low QOR patients there were inverse relationships between accuracy and both alliance and follow up outcome with regards to individualised objectives. However for high QOR patients a significant relationship with favourable outcome regarding general symptoms and dysfunction was found at follow up. They suggested that for low QOR patients, emphasising similarities between past abusive relationships and the current transference relationship could weaken the alliance and make them feel criticised, contributing to a poorer outcome. Low QOR patients may require the new experience of a non-abusive relationship (as they perceive it). It may be more beneficial for high QOR patients to use therapy to appreciate their role in creating unsatisfactory relationships, because they can tolerate this.
In summary, the results of this small number of studies tentatively contradict the 'uniformity Myth' that all interpretations (transference and non-transference) are equally accurate, and that they have the same effect regardless of patient type. Findings suggest that more accurate interpretations are associated with greater immediate progress and better outcome, regardless of the strength of therapeutic alliance or the therapist's more general technical skills. Also, transference interpretations may be no more powerful than non-transference interpretations in these associations, thus challenging the view that transference interpretations are the most useful interpretations to make (Strachey, 1934). Finally, making highly accurate interpretations may be beneficial for high-QOR patients but may be damaging, or be experienced as abusive by low-QOR patients.

**Patient's immediate response to transference interpretations**

The final cluster of empirical studies concentrates upon the patient’s immediate response to interpretations. This focus developed from a recognition that psychotherapy process research had generally neglected to study therapist or patient variables in a context-sensitive manner, and that 'outcomes' may also be seen as the immediate effects of an intervention (Henry et al, 1994). This research focus is particularly useful in exploring the widely accepted view that transference interpretations are unique in triggering the strongest affective responses in patients (Strachey, 1934) and that these are in turn related to a better outcome in brief dynamic psychotherapy.

Two studies have found that transference interpretations followed by patients' affective or positive response is correlated with improved outcome at termination (Luborsky, Bachrach, Graff, Pulver & Cristoph, 1979; Malan, 1976). However Malan’s methodology has already been criticised, and the former study included only three patients. A larger study included sixteen patients and aimed to investigate the relationship to outcome of three therapist interventions (patient-therapist, patient-significant other interpretations, and clarifications) paired with two types of patient responding: affective (verbally expressed feeling words or non-verbal behaviour suggestive of expression of affect) and defensive (responses which avoid or resist...
facing difficult issues) (McCullough, Winston, Farber, Porter, Pollack, Laikin, Vingiano & Trujillo, 1991). Clarification involved paraphrasing or restating patients’ remarks without providing significant new information. Defensive responses to therapist intervention were all correlated negatively to outcome, although the only significant correlation was for all three categories of intervention collapsed into one category. Affective responses were all correlated positively to outcome, although only two of the correlations were statistically significant to outcome (patient-therapist interpretations and all three categories collapsed into one). The authors concluded that patient affect following patient-therapist interpretation is associated with good outcome, and defensiveness after any therapist interpretation is associated with poor outcome.

Henry et al. (1994) comment that non transference interpretations followed by affect probably failed to be significantly correlated to positive outcome only because of the small sample size, and that patient-therapist interpretations were slightly more likely to be followed by defensive responses than were interpretations involving significant others. Therefore evidence for the “unique positive benefits of transference interpretations is weak at best”. From a methodological point of view these results must again be viewed with caution. Sample selection was restricted to personality disordered patients, who may respond habitually in different ways than patients with less severe presentations and so results may not be generalisable. Also, the modal length of treatment was well above the twenty-five session cut-off point for brief dynamic psychotherapy.

There is a need to explore the interaction of therapist intervention and patient response further by establishing which type of clients readily respond to interventions in certain ways. This may allow the therapist to maximise the occurrence of affective behaviour, and indicate which steps to take when a patient does not readily respond with affect (Winston, McCullough & Laikin, 1993). The authors mentioned have attempted to illustrate ways in which therapist techniques can alter affective level in a series of case studies. These suggest that for low-QOR patients, when transference interpretations are met with defensiveness, taking a more supportive and ego-building approach can create a positive relationship whereby the client becomes more open and
improves substantially by termination. The exploration of patient characteristics as a mediating factor requires systematic study.

In summary, this cluster of studies investigating the interaction between intervention, patient response and outcome, probably offers the most tentative set of conclusions yet. There are suggestions that patients’ affective responses to interventions are positively correlated with outcome, whereas defensive responding is negatively correlated. However, support for transference interpretations being particularly beneficial in therapy is challenged by the finding that transference interpretations were slightly more likely to be followed by defensive responses than were non transference interpretations (Henry et al., 1994). Again, it is possible that with low-QOR patients, therapists may need to employ a more flexible approach to their therapy.

**Other factors which may potentially influence the effectiveness of transference interpretations in brief dynamic psychotherapy.**

Research has thus far failed to address the impact of other important therapist and patient factors on the effectiveness of transference interpretations on outcome. These might include the strength of therapeutic alliance or underlying interpersonal processes between therapist and patient, a history of abuse within the patient, or therapist experience and style. For example Wachtel (1993) stresses the importance of considering the therapist’s wording of interpretations as they can frequently contain an implicit rebuke, even if they are accurate. The patient may then justifiably react with defensiveness. He reviews case studies and therapist notes where defensive reactions of patients have been attributed to ‘resistance’, or all about transference to the therapist, when at an objective level, the interpretation sounded harsh and critical in its wording. Thus the way in which an interpretation is delivered may affect immediate response and outcome.

**Methodological problems**

There are a number of methodological difficulties which impair the strength of the various conclusions drawn so far in psychodynamic process research. Generally, data
was analysed using correlational statistics which merely imply association rather than establishing direction of causality. Outcome measures differ in all studies, making comparison difficult. Also, outcome tends to be measured at termination of therapy, despite the fact that much improvement occurs beyond termination (Levenson, 1995). Finally, bearing in mind that a major indicator of improvement in brief dynamic psychotherapy is a change in the problem focus that brought the patient to psychotherapy, this aspect of outcome in research is largely ignored. Overall, the studies require replication to strengthen or disconfirm the findings.

**Conclusion**

Despite the shortcomings of process research reviewed within this essay, some fairly consistent findings offer some tentative conclusions which challenge widely accepted associations with regards to the effectiveness of transference interpretations in brief dynamic psychotherapy.

Although brief dynamic psychotherapists generally advocate the frequent use of transference interpretations, evidence suggests higher frequencies may be related to poorer therapeutic alliance and outcome, and this suggests therapists should use them more sparingly. It is important that transference interpretations are accurate in order to produce beneficial effects, and so a formulation is an essential basis from which to form interpretations. Also the use of non transference interpretations may be equally as beneficial and so should be regarded as important interventions. Transference interpretations in particular may elicit defensive responses in patients, therefore therapists need to be prepared to alter their technical approach to reduce the possibility of a poorer outcome as a result. Finally, it appears that a patient’s quality of object relations may mediate the effects of both frequency and accuracy of interpretations, thus therapists need to take this factor into consideration in their choice of technique.

The optimum conditions for effective transference interpretations appear to be accurate interpretations, delivered with relatively low frequency, to more highly functioning patients (Henry et al. 1994).
References


Clinical Section
Summary of the Clinical Section

This section comprises details on each of six placements undertaken (four core and two specialist). Basic details and a summary of clinical experience are given for each placement, and a summary of a formal case report is given for each of the core placements and first specialist placement. The placement details are presented in the order in which they were undertaken, and reflect the variety of client problems encountered. A number of different models have been used within assessment, formulation and intervention. A separate confidential volume (Volume two) comprises a clinical dossier of five formal case reports in full, in addition to placement documentation including placement contracts, clinical activity log books and supervisor evaluation forms.

All client names and identifiers have been modified in order to retain client confidentiality.
PLACEMENT ONE

Placement: Adult Mental Health

Type: Core placement

Clinical Supervisor: Ewa Rula

Trust: Richmond, Twickenham and Roehampton NHS Trust

Base: Rookery Resource Centre (CMHT)
Queen Mary’s University Hospital
Roehampton Lane
London

Placement dates: October 1996 – February 1997
Adult Mental Health Core Placement Summary

Experience was gained working with clients showing a range of problems, including depression, anxiety, fixed delusional beliefs, eating disorder, effects of childhood sexual abuse and information processing difficulties. Skills in the assessment, formulation and treatment of clients within cognitive behavioural and psychodynamic models were learned, in addition to report writing skills. Clinical work was conducted within a community mental health team (CMHT), rehabilitation unit and day hospital. CMHT and departmental meetings were attended, and organisational issues within the Trust were explored. Observations and visits encompassed a wide range of professionals in different work environments including a drop-in centre, sexual dysfunction clinic and in-patient ward. Issues arising from the role of a clinical psychologist in a CMHT were pertinent within this placement (e.g. prioritisation of referrals).
Adult Mental Health Case Summary

M.C. (a twenty-two year old woman) was referred by her GP because she was suffering from her third episode of depression since the age of sixteen, which she attributed to her experience of sexual abuse as a child. Assessment interviews and responses to Beck Anxiety (BAI) and Depression Inventories (BDI) revealed that M.C. also experienced panic attacks, self-dislike and self-criticism.

M.C.’s difficulties were understood both within a cognitive behavioural model, and psychodynamic model (hostility turned inwards). Maladaptive dynamics often associated with childhood sexual abuse which affected cognitions and emotions were also considered. Core beliefs incorporating M.C.’s high parental expectations were hypothesised to underlie some of her depressive and anxious symptoms. M.C.’s feelings of shame and guilt were understood to result from the stigma of abuse, exacerbated by pressure from her abuser to keep the abuse a secret.

Case management included review and reinterpretation of M.C.’s abuse from an adult perspective, discussion of the cognitive model of panic, exploration of other aspects of her childhood influencing development, and discussion of goals in making positive life changes (e.g. eliciting more support from friends and family).

M.C.’s BDI and BAI scores reduced from 36 to 6.5, and 31 to 6 respectively at pre and post intervention points. A departmental evaluation form indicated increased self confidence and ability to cope with life, as well as increased understanding of factors influencing her development as a person. M.C. appeared to have reattributed blame for the abuse from herself, to her abuser.
PLACEMENT TWO

Placement: Learning Disabilities

Type: Core placement

Clinical Supervisor: Annabel Poate-Joyner

Trust: Chichester Priority Care Services NHS Trust

Base: Psychology Department
Graylingwell Hospital
Chichester

Placement dates: March 1997 – October 1997
Learning Disabilities Core Placement Summary

Experience was gained working with clients presenting with a range of problems, including mainly cognitive difficulties, interpersonal difficulties, challenging behaviours and an attachment difficulty between mother and son. Skills in the assessment, formulation and treatment of clients within behavioural, systemic and cognitive models were developed. Assessment skills in particular were utilised, both directly using a variety of standardised psychometric assessments, and indirectly by gaining information from formal and informal carers. A group was initiated to develop clients' social skills in order to build friendships. This process involved a literature search, development of carer and client questionnaires, recruitment of group members and consideration of evaluation techniques. A training event focusing on the facilitation of change and loss for people with learning disabilities was attended, in addition to a multi-agency workshop to consider service provision for people with moderate learning disabilities. Skills required to work alongside professionals from other disciplines and agencies were developed within this placement.
The Lacey family (Laura and Gerry - a married couple, and their three year old son Gary) were referred because it was thought likely that Gary would develop learning disabilities in the future. Laura had mild learning disabilities associated with epilepsy, and her husband Gerry was a socially anxious man with high average intelligence. Assessment revealed that Gary’s name had been placed on the Protection Register under risk for physical harm soon after he was born, and Social Services had stipulated Laura could never be left alone in the house with Gary. Concern arose when hospital staff observed her overly protective behaviour toward Gary and angry outbursts, and because she experienced regular epileptic fits. Observations of family interactions revealed an insecure-avoidant attachment pattern between Laura and Gary, Laura’s distress about Gary’s rejection of her, and Gary’s general developmental delay.

A bonding-attachment process model was used to understand Laura and Gary’s attachment. Use of the model highlighted the following factors as influential in the formation of the attachment pattern; Laura’s unmet needs for love; Laura’s learning disability and resultant difficulties in parenting and maternal attunement to Gary; Laura’s unresolved identity crises; and her perception of help received from others as critical and intrusive.

Intervention focused upon improving Laura’s parenting and maternal attunement to Gary within a behavioural approach, exploring and modifying Laura’s perceptions of motives behind help received, liaison with Social Services to re-evaluate current risk posed to Gary, and encouraging the wider family system to give Laura more opportunities to fulfil her caring role with Gary. When intervention ceased, Gary’s behaviour toward Laura had become less avoidant, Laura’s confidence in her mother role had increased, Social Services had relaxed their restrictions on contact between Laura and Gary, and the wider family had allowed Laura to take more responsibility for Gary’s needs. Individual counselling for Laura and continued monitoring of Gary’s development within child services were recommended.
PLACEMENT THREE

Placement: Child and Family

Type: Core placement

Clinical Supervisor: Hilary Morgan

Trust: Kingston and District Community Health NHS Trust

Base: Child and Adolescent Psychology Service
Elm House
84 Ewell Road
Surbiton
Surrey

Placement dates: October 1997 – April 1998
Child and Family Core Placement Summary

Experience was gained working with clients presenting with a variety of difficulties including sleep disturbance, enuresis, temper tantrums, phobias, school refusal, autism and aggressive behaviour. Skills were developed in assessment, formulation and treatment within systemic, behavioural and cognitive behavioural models. Skills in the administration and interpretation of psychometric testing to aid in the assessment of developmental delay were also learned. Observations of clinical work with children were made in a variety of settings including a feeding clinic, soiling clinic and ADHD clinic. Teaching and presentations were undertaken on child development and on the management of childhood obsessive compulsive disorder. A research project investigating children’s perceptions of control, self concept and self esteem was initiated with children with enuresis, and with children experiencing recurrent stomach and head aches. Training events attended included techniques in family therapy, and the management of obsessive compulsive disorder in children. Working with families both individually and within a family therapy team highlighted the importance of considering family factors in clinical work with children.
Child and Family Case Summary

H.N. (a five year old girl) was referred by her GP because she exhibited a disturbed sleep pattern. Assessment involved an interview with H.N. and her parents, and completion of a sleep diary, ABC chart, functional analysis and motivation assessment questionnaires, which also revealed H.N. to exhibit demanding behaviour generally.

H.N.'s sleep pattern and demanding behaviours were understood within a behavioural model (operant conditioning), in addition to a systemic model (structural). H.N.'s maladaptive sleep behaviours and demanding behaviour were frequently reinforced, thus her difficulties were strengthened, and she appeared to hold a position of power in the family. The relationship between Mr and Mrs N seemed slightly disengaged, giving way to an enmeshed mother-child subsystem which impeded effective parental management of her behaviour.

Case management included, facilitating Mr and Mrs N in gaining insight into how their behaviour influenced H.N.'s difficulties, developing an appropriate bedtime routine, use of shaping techniques to help H.N. to fall asleep alone, and exploration with Mr and Mrs N into other factors which might be influencing the problem. Mr N was encouraged to support Mrs N in disciplining H.N. in order to strengthen the husband-wife dyad.

Mr and Mrs N gained insight into how to alter their responses to H.N.'s sleep behaviour and demanding behaviour. A sleep diary and verbal feedback revealed significant improvements in H.N.'s sleep pattern. At a two and three month follow-up Mr and Mrs N had maintained an appropriate bedtime routine, and were being woken at night less often.
PLACEMENT FOUR

Placement: Older Adults

Type: Core placement

Clinical Supervisor: Ajay Kapoor

Trust: Surrey Hampshire Borders NHS Trust

Base: Guildford Community Mental Health Team for the Elderly
     Park Barn Centre
     Park Barn Drive
     Guildford
     Surrey

Older Adults Core Placement Summary

Experience was gained working with clients presenting with a variety of difficulties including anxiety, interpersonal difficulties, health problems, marital conflict, challenging behaviour, cognitive decline, depression and dementia. Skills in assessment, formulation and treatment within behavioural and cognitive behavioural models were developed, and skills in the administration and interpretation of a variety of neuropsychological tests were learned. A weekly reminiscence group for six clients with dementia was co-facilitated with a day centre carer. The planning, structure and content of the group was recorded for use as a template on which to base further reminiscence groups within the centre. Clinical experience was gained within clients’ homes, residential facilities, an Alzheimer’s Disease Society day centre and in-patient ward. A presentation to CMHT members on the rationale behind tests used in neuropsychological assessment was given. Financial issues pertinent to service provision were explored and a research project investigating Expressed Emotion among carers of people with dementia was initiated. Pertinent skills and understanding acquired in this placement related to the assessment of cognitive decline in older adults. In addition, an appreciation of issues often experienced among older adults was gained. (e.g. loss of physical and cognitive decline).
Older Adult Case Summary

Mr R (a 79 year old man) was referred by Dr Z (consultant psychiatrist) for neuropsychological assessment. Mr R had reported suffering memory loss, poverty of concentration and role reversal in his marital relationship. Dr Z thought Mr R’s subjective descriptions might indicate mild to moderate cognitive impairment and give the diagnostic impression of early dementia. Assessment took place over four visits within Mr R’s home, and involved obtaining a detailed description from both Mr R and his wife about his cognitive, emotional and behavioural changes. Mrs R in particular described his deterioration in behavioural and cognitive domains (e.g. less dependable, losing things and decline in personal presentation). Mr R had noticed mainly a decline in his memory (over three years) for people’s names, or for meals he had eaten. He commented that he was feeling a little low about his current relationship with his wife due to her criticism of his behaviour, although he denied feeling depressed.

Neuropsychological assessment included the use of a variety of measures and aimed to assess Mr R’s current levels of general intellectual functioning, and particular deficits, and to compare current performance with estimated pre-morbid levels of ability. Results suggested Mr R was functioning within the average range of intellectual ability. His intellectual ability was hypothesised to have declined from an estimated pre-morbid high average intellectual level. Particular weaknesses related to immediate and delayed recall of contextual verbal information, poor memory for faces and lower ability on visio-spatial tasks in general.

It was concluded that Mr R’s clinical presentation might be indicative of either unilateral organic pathology, or early signs of dementia of the Alzheimer’s type. However, repeat testing within twelve months time was required to assess the clinical significance of cognitive decline. It was also recommended that Mr R be helped to recall contextual verbal information by conveying it to him slowly and asking him to confirm the information by repeating it back. Counselling for Mr and Mrs R as a couple was recommended in order to facilitate Mrs R in understanding the impact of her criticisms on Mr R, and to help them both to adjust to his cognitive changes.
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Specialist Placement I Summary

Experience was gained working with clients presenting with a variety of difficulties including anxiety, depression, obsessive compulsive disorder, substance misuse, interpersonal difficulties, schizophrenia, sexual dysfunction and abusive relationships. Skills in assessment, formulation and treatment within brief dynamic psychotherapy, cognitive behaviour therapy and family therapy were developed. Separate supervision for clinical work within each therapeutic model was provided, and audio-tapes of client sessions were used regularly for supervision on work with a client within a brief dynamic model. Further experience was gained both as co-therapist and as a member of the family therapy team during clinical work within systemic models (mainly structural and strategic). A one day conference on time limited dynamic therapy was attended, in addition to presentations on various topics given by mental health professionals. A one day visit as participant observer within a therapeutic community was experienced at the Henderson Hospital. Pertinent understanding and skills developed within this placement included the use of the therapeutic relationship within brief dynamic psychotherapy, the need for a collaborative working relationship between client and therapist in cognitive behaviour therapy, and the focus upon relationships between family members within systemic work.
Specialist Case Summary

Mrs F (a fifty five year old married teacher) was referred by her GP for psychotherapy because she complained of intermittent anxiety and depression over a number of years. She had married twice, and both husbands regularly consumed too much alcohol and had had a number of extra-marital affairs. A standard assessment interview was conducted with an additional focus upon Mrs F’s interpersonal world, revealing that Mrs F’s sometimes confrontative manner had culminated in a number of serious verbal confrontations with others (including her local vicar and employer).

A time limited dynamic psychotherapy model was used to formulate Mrs F’s difficulties, which were understood as symptoms of dysfunctional interactional patterns that were learned in the past and maintained in the present. Mrs F’s characteristic pattern of attending to other people’s needs above her own, and choice of partners who were unlikely to be able to focus on her needs reinforced the belief that others could not attend to her. Consequently, she continued to deny her own emotional needs, and displaced her anger onto other factors which did not necessarily underpin her emotional distress.

Therapy aimed to provide Mrs F with a more functional experience within a more adaptive interactional pattern through interactions with the therapist, offering Mrs F a different sense of herself. Additionally, it aimed to facilitate her in identifying her dysfunctional pattern and in comprehending the role she played in maintaining it. This was accomplished through the use of interpretations, clarification statements and mild confrontative techniques.

Mrs F gained insight into her own contribution to the maintenance of her interactional pattern, experienced increased self esteem and developed more flexible coping strategies. A departmental outcome form revealed substantial reductions in scores, indicating improved levels of well-being and general functioning.
PLACEMENT SIX

Placement: Adult Mental Health: Systemic Social Constructionist Consultation

Type: Specialist placement II

Clinical Supervisor: Karen Partridge

Trust: Kingston and District Community Health NHS Trust

Base: Adult Community Mental Health Team
The Maddison Centre
Church Road
Hampton
London

Placement dates: April 1999 - September 1999
Specialist Placement II Summary

Experience was gained with clients presenting with a variety of difficulties including a history of childhood sexual abuse, depression, suicidal ideation, anxiety, alcohol misuse, marital difficulties, attachment difficulties, interpersonal difficulties and schizophrenia. Skills in assessment, formulation and treatment within Systemic Social Constructionist Consultation and Narrative Therapy were developed. Regular experience was gained as principal therapist, and as a member of a reflecting team and systemic team, with individuals, couples and families. Additional skills as co-facilitator for a group using narrative principles for people who hear voices were also developed. A presentation on the group was given to a variety of health care professionals within a one day work shop for the ‘Hearing Voices’ network. A two day conference on Narrative Therapy by Michael White was attended in addition to a half day training event on systemic therapy within the Trust’s Learning Disability specialty. Pertinent skills and understanding acquired within this placement included the non-expert (consultative) stance of the therapist in relation to the client, the concepts of neutrality and circularity with regards to the therapist’s position within, and understanding of, the presenting problem, and the techniques of positively connoting and ‘thickening up’ therapeutic material with the aim of modifying the clients’ problem-saturated construction of their reality.
Research Section
Summary of the Research Section

This section comprises three research components completed over three years. The first component, comprising a literature review completed in the first year, discusses studies exploring risk factors for childhood sexual abuse within the family context. The second component comprises a small scale research project investigating perception of control, self perceptions and self esteem among children with Primary Nocturnal Enuresis. This piece of research was conducted within the context of a core placement and thus combines also as the service related research component. It considers theoretical issues as well as service implications. The final component comprises a larger scale research project exploring Expressed Emotion, attributions and knowledge among carers of people with dementia. The research section as a whole reflects my broad range of interests and scope of research skills gained over three years.
Childhood sexual abuse: risk factors within the family context

A literature review

September 1997

Year 1
Sequelae of childhood sexual abuse

Empirical research now supports the widespread recognition by clinical and social welfare professionals that victims of childhood sexual abuse (CSA) often suffer from negative effects. Such children have been reported to suffer from general psychological, emotional and behavioural symptoms such as Post Traumatic Stress Disorder, enuresis, encopresis, self injurious behaviour, sleep disturbance, fear and withdrawn behaviour (Kendall-Tackett, Meyer Williams & Finkelhor, 1993). Sexualised behaviour is a psychological phenomena associated more specifically with CSA. This can include excessive or public masturbation, seductive behaviour, requests for sexual stimulation from others, age-inappropriate sexual knowledge and sexualised play with dolls (Beitchman, Zucker, Hood, DaCosta & Ackman, 1991).

A review of the long term effects of CSA on adults (Beitchman, Zucker, Hood, DaCosta, Ackman and Cassavia, 1992) concluded that women showed greater evidence of sexual disturbance or dysfunction, homosexual experiences in adolescence or adulthood, depression, anxiety, fear, and suicidal ideas and behaviour. They concluded that abuse involving a father or step father was associated with greater long term harm possibly because it involves greater betrayal and loss of trust. Other factors likely to influence outcome were the duration, frequency, physical invasiveness and amount of force used in the act. Watkins and Bentovim (1992) suggest that boys are prone to externalise their effects and develop behavioural problems whereas girls tend to internalise their responses and suffer from anxiety and depression.

In view of the serious effects of CSA it is especially concerning that much sexual abuse goes unreported because the victim may feel ashamed, threatened or fear family dissolution (Bergner, Delgado & Graybill, 1994). Therefore mental health, social welfare and legal professionals need to be alert to factors associated empirically with the occurrence of abuse. This may serve to increase their awareness of the possibility of the occurrence of abuse when working in a clinical setting. Research findings may also contribute to preventative programs. Finkelhor and Baron (1986) in their review of studies looking at risk factors for CSA concluded that the most consistent factors
involve the family. For this reason this review will consider empirical evidence of risk factors within the family context, for intra-familial abuse (abuse by family members) and extra-familial abuse.

Definitions

A review of CSA literature necessitates a discussion of the definition of CSA. Some definitions specify a particular age differential between the child and abuser and others do not. For example Finkelhor (1984) suggested an age gap of five years for children under thirteen within his definition. However Kercher and McShane (1984) simply noted that the abuser should be 'significantly older' than the victim or in a position of power or control over the child. Glaser and Frosh (1988) discuss the importance of including three points when defining sexual abuse.

First, in order to establish which activities can be regarded as 'sexual' or not it is helpful to refer to the activities as intending to provide 'sexual gratification' for the adult. In this way the child does not necessarily have to be sexually aware or to regard the acts as sexual. Secondly, with regard to the age and developmental level of the child in comparison to the abuser, it is useful to refer to the use of coercion in an implicit or explicit way as a central point, rather than an age gap which may not be applicable to every individual case. The final point is that all forms of abuse have at their core the exploitation of a power differential. A child is dependant upon adults and therefore any manipulation of that power within sexual scenarios involving a child and an adult would constitute sexual abuse (Glaser & Frosh, 1988). This final point is more complex in the case of sibling sexual abuse, but if one focuses upon all three of the points outlined and consider that power differentials are not defined merely by age, then the abusiveness of the sexual act between two siblings can be established.

The three core criteria outlined by Glaser and Frosh (sexual gratification for the adult, use of coercion, and exploitation of a power differential) are incorporated into the 'child sexual abuse working definition' provided by the Standing Committee on Sexually Abused Children (SCOSAC, 1984; cited in Glaser & Frosh).
Prevalence

Finkelhor's review (1994) of twenty one epidemiological studies of CSA found rates ranging from 7% to 36% for women and from 3% to 29% for men. Prevalence rates vary widely due to a number of factors. These include variations in operational definitions used in studies (for example Finkelhor 1984, and Kercher & McShane, 1984), the difficulty for many victims in disclosing the abuse, differences in samples between clinical and community populations, and methodology (for example questionnaire versus interview studies).

Child characteristics as risk factors

Gender

In Finkelhor's aforementioned review of studies (1994), the reported abuse rates for girls was generally one and a half to three times the rate for boys. It is possible that the abuse of boys is underreported (Holmes, Offen & Waller, 1997) and it has been speculated that boys are reluctant to admit victimisation because it clashes with the expectation of masculinity. The homosexual character of most abuse of boys may inhibit disclosure (Finkelhor, 1986). Holmes et al. reviewed the literature relating to male victims and concluded that boys who are sexually abused may subsequently develop characteristics such as aggression or conduct disorder that lead them into the criminal justice system rather than the helping professions. They also concluded that clinicians are less likely to enquire about CSA in adult male clients.

Age at onset

Many studies report statistics showing that children are more vulnerable to sexual abuse starting in the preadolescence period between the ages of eight and twelve (e.g. Finkelhor, 1984; Russell, 1983; Wyatt, 1985). Finkelhor and Baron (1986) analysed studies to examine relative vulnerability at different ages. Children increased in
vulnerability at ages 6-7, dramatically increased at age 10, and ages 10-12 were years of particularly acute risk. This is possibly because from the age of ten, children's bodies are beginning to develop as adults yet their understanding of sexual norms and boundaries are as yet undeveloped. This combination of factors could make them attractive yet unthreatening to a potential abuser, and thus extremely vulnerable.

Social isolation of the victim

Area of residence

Results of studies exploring the risk of abuse in different areas of residence are conflicting. Some studies indicate a possibility of higher risk in rural areas (Finkelhor, 1984; Russell, 1983) and others, a lower risk (e.g. Wyatt, 1985).

Lack of close personal relationships

Finkelhor (1984) found that women with two or fewer friends at age 12 were more likely to have been sexually abused. Peters (1984; cited in Finkelhor, 1986) also found higher rates associated with women who reported either lack of closeness with peers or with siblings. In contrast, Bergner et al.'s study of 411 female students (1994) using Finkelhor's Risk Factor Questionnaire (1979) to elicit a retrospective look at their childhood, did not support the notion that the victims were socially isolated.

In relation to social isolation it is of course difficult to disentangle cause and effect. It is possible that social isolation may be a consequence of abuse rather than a risk for abuse. Children who are feeling shame and stigma as a result of being a victim may isolate themselves.

Jehu (1988) in his clinical sample noted that 49% of the victims' father figures and 60% of mother figures were isolated and/or alienated in their interpersonal relationships, but a high proportion (64%) were victims of incest. He proposed that such families often
attempted to meet their social needs within the family circle and viewed the outside world as hostile.

**Family characteristics**

**Social class/income**

Finkelhor and Baron's review (1986) concluded that community studies (which are most likely to be representative of the general population) did not find any relationships between sexual abuse and social class of the family of origin (e.g. Peters, 1984; cited in Finkelhor, 1986; Russell, 1986). However two student based studies show some variation by social class. Finkelhor (1984) found higher rates among female students from families with incomes under $10,000, with blue-collar fathers, and with poorly educated mothers. Bergner et al (1994) in their cross-validation study of Finkelhor's Risk Factor Checklist found that a family income of under $10,000 was the only significant risk factor for CSA. Finkelhor and Baron (1986) noted a strong overrepresentation of the poor among reported cases, but discounted the relationship due to a bias in the welfare system in identifying abuse in the lower social strata. There seems therefore to be no consistent empirical evidence for social class as a risk factor for CSA, with the possibility that the disadvantaged are more likely to be over-represented in referrals to public services.

**Abuser characteristics**

Studies investigating abuser characteristics often concentrate on incestuous fathers or incarcerated sex offenders, thus conclusions drawn from such studies may not necessarily be generalisable to extra-familial abusers.

**Gender**

Offenders are overwhelmingly men (e.g. Crew Solomon, 1992; Finkelhor, Hotaling, Lewis & Smith, 1990; Jehu, 1988). Finkelhor et al's telephone survey of 2,626 men
and women (1990) revealed that 98% of the offences against women were by males and 83% of the offences against males were by males. Abuse by females does occur but to a far lesser degree, it appears. For example Crew Solomon (1992) looked at 3864 cases where intra-familial abuse was indicated or substantiated. Females were the perpetrator in only 13% of the cases and 82% of those cases were mothers. Over half of the female perpetrators were co-perpetrators with a man.

**Step fathers**

Several studies support the finding that having a step father increases the risk for experiencing CSA (Finkelhor, 1980; Gordon, 1989; Gordon & Creighton, 1988; Gruber & Jones, 1983; Parker & Parker, 1986; Russell, 1983). However other studies do not find a higher risk for abuse in stepfather families (e.g. Bergner et al., 1994; Peters, 1984; cited in Finkelhor, 1986). The latter study's subjects' average age was 19.3 years. It is possible that such recent cohorts will reveal different results as stepfather families are now more common and may provide different environments than those provided in previous decades. Faust, Runyan and Kenny (1995) suggest step families are under more stress in many realms of life and have certain tasks to accomplish. However this explanation does not explain how stress may lead to sexually exploitative behaviour. Their other suggestion is that step fathers may be subject to weaker normative taboos against incest and so may exploit more.

**Social competence**

Williams and Finkelhor (1990) reviewed a number of studies and concluded that incestuous fathers were less assertive and more socially isolated than non abusive fathers (biological and non biological). 74.6% of Jehu's victims (1988) reported their father figures to be limited in social skills though this was a subjective retrospective view. Vander Mey and Neff (1984) found social isolation increased the potential for being an abuser. Marshall and Mazzucco's study of incarcerated non familial child abusers (1995) revealed they had lower self esteem than non abusers. However it may be that self-esteem decreases partly as a result of being incarcerated.
Childhood history of CSA

In their review of studies Hanson, Lipovsky and Saunders (1994) found that the majority of abusers did not report victimisation in their own childhood. In their study of incarcerated offenders only a quarter had been victims of childhood incest. Williams and New (1996) review studies which indicate that only between 20% and 30% of adolescents who sexually abuse report a prior history of sexual abuse. However of Marshall and Mazzucco's (1995) sample, 41.7% of non familial abusers had a history of CSA compared to 8.7% of the non abusers. However the sample was small, numbering twenty four abused. Williams and Finkelhor (1995) in their study of 116 incestuous fathers compared abusers with a closely matched control group and concluded that men who had been sexually abused in childhood were at a 2-3 times higher risk for incestuous abuse of a daughter. Physical abuse was also a very important risk factor.

Authoritarian behaviour

Perhaps the most consistent finding concerning male incestuous abusers is they are often considered very conservative and traditional (Dadds, Smith & Webber, 1991) or patriarchal and authoritarian in their role behaviour within the family (Herman & Hirschman, 1981; Kempe & Kempe, 1984; Vander Mey & Neff, 1984). Within Jehu's (1988) study, 58.8% described their family as exhibiting 'male supremacy', although Jehu did not give explanations of how this feature manifested.

In summary, studies of male abusers within the family, mainly fathers, generally suggest that they are often conservative, authoritarian and patriarchal in their role behaviour. They may abuse alcohol and can be socially isolated and unassertive or lacking in social skills. The view that abusers exhibit psychopathology and aggression is generally not supported (Dadds et al., 1991; Williams & Finkelhor, 1990). Living with a step father may also increase a child's risk of victimisation. However studies using subjective, retrospective reports from adults abused in childhood (such as Jehu, 1988) should be interpreted with caution.
Interestingly, an article by Williams and New (1996) reports that Home Office figures indicate that those under sixteen years of age are responsible for roughly a third of sexual crimes. If this is so, more attention should be focused upon studying characteristics of adolescent abusers to establish if findings are comparable to studies examining adult abusers.

**Parental absence and unavailability**

**Parental absence**

Finkelhor et al.'s telephone survey (1990) found that separation from a natural parent for a major portion of one's childhood was a risk factor. Girls were particularly at risk for all types of abuse when living alone with their fathers, living with two non biological parents, or with one non biological and one biological parent. Boys were primarily at risk when they lived with their mother alone or with two non biological parents. Benedict and Zautra (1993) found that parental absence was the most powerful variable for increasing the odds of CSA. Specifically, having one's mother employed outside of the home and/or not living with one or both parents raised the risk of CSA. Neither study specified whether the parental absence resulted from death or divorce. They propose that parental absence can lead to certain environments that are conducive to CSA. Other studies supporting the above finding are Finkelhor (1984) and Russell (1986).

Two studies do not support the view that parental absence is a risk factor (Bergner et al., 1994; Peters, 1984; cited in Finkelhor, 1986). Furthermore Crew Solomon (1992) in her study of 3864 substantiated and indicated intra-familial abuse cases, found that more girls were victimised by their fathers in two parent homes than in single parent homes. Boys were victimised more in single parent homes by mothers (as in the Finkelhor et al. study, 1990). However Crew Solomon's study did not differentiate between natural and surrogate parents. It seems that parental absence (of unknown cause) is generally a risk factor but for father-daughter incest the presence of a mother figure does not lessen the vulnerability to abuse.
Another variable that might be related to parental absence is the mother's employment outside the home. Finkelhor and Baron (1986) reviewed studies which supported the finding that mother's employment outside of the home increased the risk for CSA (Landis, 1956; Peters, 1984; cited in Finkelhor, 1986; Russell, 1983). Peters found that the relationship only held for white women and Russell found that mother's employment increased risk significantly only in households with stepfathers. Benedict and Zautra (1993) identified the mother's employment outside the home as a powerful risk factor. Finkelhor (1984) did not find any risk for mother's employment. It would be helpful for studies to interview victims on their retrospective perceptions of how they felt parental absence contributed to their vulnerability as victims.

**Parental unavailability**

Parental illness and disability are among the factors that can reduce the emotional availability of a parent(s). For example, studies by Finkelhor (1984) and Benedict and Zautra (1993) showed that adult CSA victims giving retrospective accounts of their family life were more likely to have had a disabled or ill parent. Looking specifically at father-daughter incest Herman and Hirschman (1981) found significantly more mothers were seriously ill (most commonly due to alcoholism, psychosis or depression) or had many children and pregnancies. Jehu (1988) found 53% of the victims' mothers were depressed and 67% of the fathers were 'psychologically' absent from the family. Vander Mey and Neff (1984) in their study of incest reported alcohol dependency in 69.2% of the parents. Berliner and Conte (1990) in their sample of 23 children who were interviewed about the victimisation process reported that their need for attention had been strong due to feeling troubled and/or their parents not being a resource for them. However identification of this variable was based on reports of victims rather than on actual epidemiological studies. A few studies suggest that having a father who abuses alcohol (and thus is perhaps rendered unavailable for adequate and appropriate emotional support) may increase the risk of them incestuously abusing their daughter (e.g. Jehu, 1988; Vander Mey & Neff, 1984).
A poor relationship with parents has been substantiated as a risk factor in a few studies (Finkelhor, 1984; Miller, 1976; cited in Finkelhor, 1986; Peters, 1984). All of these studies used multivariate analysis and identified that the poor relationship made an independent contribution to risk. Finkelhor found the risk was higher among women who said they were not close to their mother or received little affection from their mother or father. Jehu (1988) found that within his sample of women 43.1% of the fathers were physically abusive to their children. 66.7% of the fathers and 39.2% of the mothers were described as psychologically absent from the family.

All of the above factors may reduce the potential capacity of parents to protect or respond to the emotional needs of their children and thus render them more vulnerable to exploitation.

**Conflict between parents**

Sexual abuse victims are also more likely to report a poor marital relationship between their parents. Gruber and Jones (1983) using discriminant function analysis found a poor parental relationship to be the most potent predictor of CSA. However their sample was a specialised one of purely 'delinquent girls' which may not be generalisable to a community sample. Finkelhor (1984) and Peters (1984; cited in Finkelhor, 1986) found higher reports of unhappy marriages and little mutual affection between parents of CSA victims. Edwards and Alexander (1992) in their study of intra-familial and extra-familial abuse used one-way MANOVA and subsequent multivariate analysis and demonstrated that sexually abused women described their families as having significantly more parental conflict than did women who had not been abused. Jehu (1988) whose sample consisted mainly of incest victims recorded marital conflict/disruption reported by 72.5% of victims. 54.9% of the fathers were physically abusive to their spouse. Paveza (1988) in his sample of 102 incest families concluded that marital dissatisfaction and spousal violence were risk factors. One dissenting finding was that by Dadds et al. (1991) in their comparison of incest victims with controls. They found no significant differences between the groups for perceptions of marital satisfaction.
The fact that the studies discussed based their findings on samples of intra-familial and extra-familial abuse either together or separately adds credence to the view that parental marital dissatisfaction is a risk factor for all types of CSA. The studies fail to determine exactly how it contributes as a risk factor. One possibility is that it may be linked to less emotional availability to the child.

**Family environment characteristics**

Retrospective studies which have explored the childhood family environment of adults abused as children have used the Family Environment Scale (FES; Moos & Moos 1981) or the FACES-II (Olsen, Russell & Sprenkle, 1983). These questionnaires examine various family dimensions such as independence, conflict, achievement orientation, cohesion and adaptability. They are reliable measures deemed to differentiate between distressed and non distressed families (Moos & Moos, 1981). However retrospective perception may be contaminated by reactions to the abuse experience. Benedict and Zautra (1993) obtained independent retrospective reports concerning the family environment from siblings of intra-familial and extra-familial sexually abused children. They also included a control group of non abused subjects. The FES as a measure indicated that CSA victims and their siblings were 1.23 times more likely than controls to have been exposed to higher levels of family conflict. Families with a high intellectual-cultural orientation increased the odds of being a CSA victim by 2.32 times for each year in advancing age after the 'youngest' years of a child's life. Children from families rated high on organisation had 1.93 times the likelihood of CSA as other children with low family organisation, particularly when CSA occurred at a younger age.

The finding that victim's families are more highly organised is also a familiar finding in families where intra-familial abuse has occurred. For example Dadds et al. (1991) used the FES with such families who were receiving treatment and discovered they were not lacking in role differentiation and clear boundaries, and were in fact quite structured and role bound. This supports the rigid patriarchal structure discussed
earlier. Alexander and Lupfer (1987) when looking at all types of abuse found traditional family roles were a characteristic of father-daughter abuse only. They also found all types of abuse were associated with significantly less cohesion and adaptability. Dadds et al. (1991) noted that mothers in these families also perceived both significantly less cohesion and expressiveness. Family members were not encouraged to be independent and assertive. Yama, Tovey and Fogas (1993) combined their intra-familial and extra-familial abuse samples. With univariate analysis they discovered such families were higher than controls on levels of conflict, and rules and procedures governing family life and the families were also significantly less cohesive.

One contradictory finding using the FES was that by Long and Jackson (1994) who found that more victims than non-victims described their family as disorganised. However these findings were based on retrospective reports with no independent reports from other members of the family, such as those within Benedict and Zautra's study (1993).

**Differences in family characteristics between intra-familial and extra-familial abuse**

Studies specifically examining differences in familial characteristics between victims of intra-familial and extra-familial abuse using the FES generally indicate that the characteristics are similar (e.g. Ray, Jackson & Townsley, 1991; Yama et al., 1990). However the FES may be not be sensitive to the discrimination between subsets of distressed families. Mian, Marton, Le Baron and Birtwhistle (1994) examined families of 3-5 year old girl victims of intra-familial and extra-familial abuse and found that the intra-familial group showed greater disadvantage and dysfunction than did the extra-familial group. It is possible however that the sexual abuse arising from negative family dynamics might also have produced or exacerbated negative family roles and relationships and so measures were identifying symptoms rather than antecedents.
In general, family environment studies reveal victims' families to be less cohesive, more structured and role bound, and less adaptive. They may also encourage less independence and assertiveness in family members. However none of these studies identify risk factors prospectively and so there is a possibility that perceptions of environment are contaminated by reactions to, or effects of, the sexual abuse.

**Models and theories**

A number of models and theories have been proposed to explain the mechanisms of certain risk factors or the occurrence of sexual abuse. Some of the more commonly cited ones are briefly explored below:

**Finkelhor's Four Preconditions Model of Sexual Abuse (1984)**

Finkelhor's model postulates that four preconditions must exist for sexual abuse to occur.

1. There must be an offender with the motivation to sexually abuse.
2. The offender must overcome internal inhibition against abusing.
3. The offender must overcome external obstacles against abusing.
4. The offender must overcome resistance by the child.

Most of the risk factors reviewed fulfil the third and fourth preconditions however the model states that preconditions three and four make a difference only after preconditions one and two have already been met. Although this model is useful in giving an overall structure to understand the occurrence of sexual abuse it's lack of operational detail is evident and it does not therefore really contribute to a thorough understanding of the risk for CSA.
Radical Feminist Theory

The Radical Feminist Theory as reported by Crew Solomon (1992) states that male dominance and the oppression of women is a sex-based class phenomenon. Men as a class maintain privilege via the subjugation of women. Violence, including sexual violence is one vehicle for attaining this end and therefore certain patterns of sexual victimisation result. However while this model would predict the higher prevalence of male abuse of female daughters under various family compositions, it neither predicts nor explains the existence of an albeit low proportion of female abusers against male children.

Developmental model

Williams and New (1996) proposed a very interesting developmental model to explain the origins of sexually abusive behaviour in adolescent boys. They identified five statistically significant risk factors (violent family environment, experience of physical abuse, discontinuity of parental care, feelings of rejection by the family and a maternal history of CSA), and contextual and situational factors that act as triggers to the development of sexually abusive behaviour. Williams and New propose that experiencing these five factors may contribute to a feeling of grievance and may result in acting out of aggressive fantasies. However, how aggression becomes sexualised remains to be explored. Williams and New go on to state that a history of abuse in adolescent boys remains a risk factor in the development of sexually abusive behaviour. They also discuss how flashbacks and memories, preceded by reminders of past abuse, may lead to sexually abusive behaviour as a start of a pattern of the externalising responses common among boys. Further investigation using this model is vital if their report of a third of sexual offences being committed by adolescents under sixteen years of age is correct.
Attachment theory

The application of attachment theory to the study of CSA is rather hypothetical. Alexander (1992) proposes that a disturbance in attachment relationships in any or all relevant family members is "likely to be associated with diminished capacity to meet one's needs in appropriate ways and to monitor oneself or others and to seek to stop the abuse" and so helps set the stage for sexually abusive behaviour. Haft and Slade (1989) propose that a parent's own insecure attachment in childhood affects their subsequent attachment to their own child and thus the child's insecure attachment. It is suggested that a parent's insecure attachment renders them less likely to protect their child, or possibly more likely to abuse them. In addition, the child's own insecure attachment pattern may render them less able to defend themselves or seek help from others.

Research is necessary to add credence to this theory although there is evidence that parental rejection is more prevalent in abusers compared to non abusers (Marshall & Mazzucco, 1995; Williams & Finkelhor, 1995). In general the theory is fairly consistent with systemic theories and studies using the FES, revealing dysfunctional aspects (Benedict & Zautra, 1993) whereby such dysfunction precedes the onset of sexual abuse.

The Biosocial Theory of Incest Avoidance

Originally put forward by Westermark (1894, cited in Parker and Parker, 1986), the Biosocial Theory of Incest Avoidance receives support from empirical research (Parker & Parker, 1986) and suggests that there exists a noninstinctive mechanism producing an aversion for sexual relations among those who have shared early prolonged and intense interaction during early childhood. These assumptions are based upon 'natural experiments', such as the one by Wolf (1966). Parker and Parker reasoned that father or father-surrogates involved in the early care of their daughters would be less likely to become sexually aroused and abuse them than those who are not as closely involved. Indeed in their albeit small study a greater proportion of the abusing non biological and
biological fathers were not in the home at all or spent less time there than the non
abusers. They were also less involved in care giving activities (such as changing
nappies).

Williams and Finkelhor's (1995) findings also support the theory in so far as they found
that paternal care giving (particularly at age 4-5) may inhibit incest. However their
results suggest that sexual arousal is not inhibited, rather some other mechanism is
involved. One suggestion is that care giving evokes feelings of nurturance and
protectiveness and enhances sensitivity to the impact of the adults' behaviour on the
child. More importantly they concluded that paternal physical violence towards
daughters was also more likely to be inhibited.

**Interrelational theory**

Paveza (1988) explored an Interrelational theory to examine the contribution of marital
satisfaction as a parental risk factor for CSA. He discussed the idea that the major
contributors to sexual abuse are factors that aid in the breakdown of inhibitors or help
the abuser overcome the resistance of the victim. He viewed the potential or
threatened loss of a strong marital relationship as a strong inhibitor for a potential
abuser (father). In contrast, if the marital relationship is already weak, the possibility of
it's loss may fail to serve as an inhibitor. This theory is consistent with empirical
evidence that sexual abuse victims are more likely to report a poor marital relationship
between their parents (Finkelhor, 1984; Gruber & Jones, 1983; Jehu, 1988; Paveza,
1988).

**Systemic theories**

Attempts to apply systems theory to the concept of abuse generally addresses incest
rather than extra-familial sexual abuse (e.g. Alexander, 1985; Trepper & Barrett,
1986). Clinicians hypothesise that incestuous families evidence closed systems
exhibiting a lack of information exchange and entropy (Alexander) and having
particular dysfunctional family styles, structures and communication patterns (Trepper
& Barrett). Unfortunately Trepper and Barrett, and Alexander offer no empirical evidence within their papers to support their hypotheses. However the idea of family dysfunction preceding abuse relates strongly to empirical findings mentioned within family functioning studies (for example Benedict & Zautra, 1993; Dadds et al., 1991).

Methodological limitations

The most striking characteristic that arises from the body of literature studied is the lack of theory driven research that has been carried out. While several theoretical models have been explored, they have not generally been systematically employed in research studies. Exceptions to the rule include Parker and Parker (1986) and Crew Solomon's (1992) test of the Biosocial Theory of Incest Avoidance and the Radical Feminist Theory (respectively). Both of these theories gave rise to testable hypotheses which were empirically supported to some extent. However these theories were applied to families of victims of intra-familial abuse only. There is a distinct lack of theory applied to risk for extra-familial abuse.

The identification of risk factors for CSA is however a complex undertaking, and the above review reveals conflicting findings. There are a number of reasons for this:

Samples

Sample size

The smaller sample size of some studies using clinical populations (e.g. Jehu, 1988; n=51) may be more biased than larger sample sizes (e.g. Finkelhor et al., 1990, n=2626). However such a large sample as Finkelhor's may disguise an important participant variable or specific effect which needs teasing out (Coolican, 1994). The replication of studies using small samples may serve to determine the strength of significant findings.
Sample type

Community samples (e.g. Finkelhor, 1990) offer the possibility of being more representative than clinically referred samples which may be biased by virtue of who comes to the attention of professionals. Those victims who do not evidence disturbed behaviour are not generally included in referred samples. The use of female college student samples (e.g. Benedict & Zautra, 1993; Bergner et al., 1994) may give misleading results because they may have adapted better or come from families of different intellectual-achievement orientation.

Of course the lack of inclusion of male victims due to the likely underreporting of male CSA (Holmes et al., 1997) is a very clear limitation of the literature reviewed.

Control groups

Some studies (e.g. Vander Mey & Neff, 1984) do not include control groups and so one cannot be so sure that their findings relate specifically to abuse victims. Studies which attempt to closely match subjects with those within a control group on important variables such as age, gender, family variables and social class, are more sophisticated in their design (e.g. Williams & Finkelhor, 1995).

Measures

Lack of precision in variables

Studies using measures such as Finkelhor's Risk Factor Questionnaire give rise to empirically identified variables which may increase risk for abuse (e.g. parental absence). However we are then left to hypothesise how this variable may specifically raise the risk for abuse. For example 'Parental absence may be a powerful risk factor because it leads to certain environments that are conducive to CSA' (Benedict & Zautra, 1993). One solution to this is suggested by Finkelhor (1986). He indicates the need for making variables more precise. Such as breaking down the variable 'poor
relationship with one's parents into specific categories such as 'did not spend much time with child, 'expressed high levels of criticism to child'.

A method which may give even more understanding would be to use semi-structured interviews to obtain the victim's understanding of how an identified risk factor made him/her vulnerable. There is more room for exploration using interviews. This may both increase the victims' understanding of the abuse process and alleviate beliefs of self-blame that are frequently reported (e.g. Jehu, 1988). The study by Berliner and Conte (1990) which examines the victimisation process from the abuser and the victim's perspective, is very valuable in moving beyond restrictive measures and providing crucial information potentially useful for prevention programs.

Lack of reliability and validity

It is essential that the measures used in studies are both reliable and valid if their findings are to be incorporated in any form of intervention. Findings resulting from studies which employ standardised measures (e.g. FES) may be more credible than those that lack substantiated reliability and validity (e.g. Finkelhor's Risk Factor Questionnaire). However unfortunately the FES is not specific to sexual abuse, rather to distressed families in general, and so may not be tapping into some important distinguishing variables.

Retrospective versus prospective methodology

The retrospective nature of many studies may give rise to contaminated recall of family functioning by the victim which may contribute to over-reporting of dysfunction. One study which attempted to avoid this problem was that by Benedict and Zautra (1993) which asked for independent reports of family functioning from the victim's sibling.

Another fundamental criticism is that the variables identified as highly associated with the occurrence of abuse are then labelled risk factors. Unfortunately because most studies are retrospective using adult survivors (e.g. Herman & Hirschman, 1981), or
initiated soon after reports of CSA (Paveza, 1988) there is no sure way of knowing if the factors identified actually preceded the sexual abuse. Only prospective studies following children from early childhood into adulthood would be able to identify factors present before any occurrence of abuse. This would be a lengthy and expensive process.

Statistical analyses

Some researchers in the field of CSA (e.g. Benedict & Zautra, 1993; Finkelhor, 1986) point out that certain statistical analysis (e.g. univariate analyses) are not regarded as effective as multivariate analysis, which provide information regarding the extent to which an observed risk factor is a unique predictor or dependant upon other factors. Certainly, methods of analysis that allow the investigator to examine interactions between the predictor variables and their effect on the outcome variable under examination, would be desirable. In other words, it is important to take into account interactions between predictor variables as well as the effect of these variables taken singly, and to undertake analyses that allow any shared variance between the predictor variables to be taken into account.

Conclusions

The empirical evidence revealing serious short and long term negative effects among substantial numbers of CSA victim highlights the need to be alert to factors associated with the occurrence of abuse. Definitions of CSA among researchers are often inconsistent and there remains a need to establish a universal, comprehensive definition which includes the major aspects thought to be involved in CSA (e.g. Glaser & Frosh, 1988).

Research to date suggests girls are more at risk than boys for CSA though it is possible that sexual abuse of boys is underreported. Abuser characteristics most consistently empirically supported include male gender, poor social competence, possibility of a history of CSA within their own childhood and authoritarian behaviour. Children
whose parents are absent or unavailable in some way or who are in conflict with each other may be at more risk from CSA. Families which are more structured and role bound, but less adaptive and cohesive seem to provide environments which are associated with CSA. In general, theories attempting to explain the mechanisms of certain risk factors or the occurrence of sexual abuse need more empirical evidence to support them although some (e.g. The Biosocial Theory of Incest and Radical Feminist Theory) provide testable hypotheses which are empirically supported to some extent.

Among the factors affecting the conflicting findings in studies looking at risk factors are differences in sample sizes and types, a lack of precision in variables within measures and lack of reliability and validity, differences in methodology and differences in statistical analyses.

If all of these criticisms are taken into consideration, findings from the studies thus far conducted require cautious interpretation. They do however point to areas of common ground which are useful for more stringent investigation and indicate potential for establishing clear risk factors for childhood sexual abuse.

Future research looking at risk factors for CSA should venture to gain a more precise understanding of exactly how established risk factors make a victim more vulnerable to CSA. This may best be achieved by interviewing CSA victims about their understanding of how risk factors made them vulnerable. This may also aid their potential for coming to terms with their experiences and alleviating self blame.
References


Perception of control, self perceptions and global self-worth in children with Primary Nocturnal Enuresis

(Combined small scale and service related research)

December 1998
Year 2
Abstract

Objectives

The objectives if this study were threefold:-

1. To assess whether children with Primary Nocturnal Enuresis (PNE) perceived themselves to have any control over their symptoms before treatment, and whether they perceived potential improvements in their symptoms to be under their own control compared to children in two control groups.

2. To assess whether children with PNE perceived control of success and failure over other important aspects of their life (social interaction, physical activity, scholastic events and general events) to be due to internal, external or unknown control compared to children in the two control groups.

3. To assess how the PNE Group’s self perception in important aspects of their life (scholastic and athletic competence, social acceptance, physical appearance and behavioural conduct) as well as global self worth compared to the two control groups.

Design

Three groups of children aged 8-13 years of age participated; The target group (Enuresis Group – children with PNE; n=12) and two control groups (Paediatric Group – children with stomach or head aches; n=12; and Sibling Group – siblings of the children in the other two groups; n=12).

Data collection

Data collection included responses to a semi-structured interview and two self report questionnaires.
Results

As a result of categorical and statistical analyses the following findings emerged:-

1. A substantial proportion of children in both the Enuresis and Paediatric Groups perceived their symptoms to be as a result of factors under their own control.
2. The majority of children in both the Paediatric and Enuresis Groups perceived improvements in their symptoms to be under the external control of their doctor or parents.
3. Children in both the Paediatric and Enuresis Groups were able to offer a variety of appropriate suggestions under their own control to help improve their symptoms.
4. Children in the Paediatric took more responsibility for the consequences of their symptoms than children in the Enuresis Group.
5. There were no statistical differences between the three groups for perceptions of control about important aspects of life, or for self perception and self worth.
6. Children in the Enuresis Group produced scores indicating perceptions of themselves to be less socially accepted, less well behaved and to have lower global self worth than children in the control groups (non significant findings).

Conclusions

It was concluded that due to the small sample size only tentative conclusions could be drawn. However it was deemed useful to use some of the above findings to guide clinical practice (e.g. using progressive prompting to elicit children’s own ideas for improving symptoms based on their experience and encouraging children to perceive contingencies between their behaviour and outcome).
Introduction

Definitions of enuresis

DSM-IV defines enuresis as “repeated voiding of urine during the day or night into bed or clothes”, whether involuntary or intentional (The American Psychiatric Association, 1995). An individual must be at least age five years or more, or for a child with developmental delays, have a “mental age” of at least five years. Further, the voiding should occur at least twice a week for at least three months, or cause “clinically significant distress or impairment” in social, academic or other important areas of functioning. The enuresis is categorised as Primary when an individual has never established urinary continence and Secondary when they have previously been continent of urine. Diurnal Enuresis refers to wetting that occurs during waking hours, and Nocturnal Enuresis occurs during sleep. The diagnosis is made in the absence of contributory organic disorders such as a urinary tract infection or diabetes.

Guidelines provided for nurses to assess continence needs in children confirm that generally, the DSM-IV diagnostic criteria are used in clinical assessment (Cook, 1997). However there are no guidelines for diagnosis on the basis of frequency of wetting. Evidently many services treating enuresis accept referrals regardless of the precise frequency, presumably because they assume that a referral is only made if the wetting is viewed as a problem by the child or their family.

Prevalence

The prevalence of Nocturnal Enuresis decreases with increasing age. In general, children are expected to be continent at night by the age of five, where the incidence is between 15-20% (Blackwell, 1989). Estimates of prevalence then range from 15% of girls and 25% of boys at the age of six years, to 4% of girls and 8% of boys at twelve years of age (Gross & Dornbusch, 1983). Prevalence estimates tend to vary because the results of epidemiological studies are often hindered by differences in methodologies and definitions of enuresis used (NHS Centre for Reviews and
Dissemination; CRD, 1997) Approximately 75-80% of Nocturnal Enuresis is Primary in nature (Mark & Frank, 1995) and about twice as many boys as girls have Nocturnal Enuresis (Fielding, Berg & Bell 1988, cited in Cook, 1997), although this difference reduces from thirteen years of age onwards (Cook, 1997).

Aetiology

A variety of hypotheses and explanations are advanced in relation to the aetiology of Nocturnal Enuresis. These include:-

Genetic factors

Chromosomal investigations over two or three generations in eleven families with PNE indicated that a particular gene may be present in enuretics (Eiberg, Berendt & Mohr, 1995). The risk of enuresis can be increased by five times with a maternal history of enuresis, and by seven times with a paternal history (Jarvelin, Vikevanen-Tervonen, Moilanen & Huttunen, 1988).

Bladder function

A study of 15 children (aged 11-17 years) with PNE suggests an abnormal circadian rhythm in urine output and absence of an anti-duretic hormone in bed wetters (Rittig, Knusden, Norgaard, Pedersen & Djurhaus, 1989).

Maturational delay

Weight and mean bone growth have been found to be less developed in enuretic children than in non-enuretic peers (Gross & Dornbusch, 1983). Also males experience a delay in physical development (Warzak & Friman, 1994) and prevalence of Nocturnal Enuresis is higher in males (Fielding et al., 1988)
Learned response

Behavioural interventions are founded upon the idea that the ability to stay dry at night is a learned response. Habit deficiencies, poor learning experiences and a lack of appropriate reinforcement contingencies may account for Nocturnal Enuresis (CRD, 1997). However this argument seems to have been inferred from the success of behavioural interventions rather than from empirical evidence.

Psychological, emotional and behavioural difficulties

The NHS Centre for Reviews and Dissemination (1997) concluded that enuresis is associated with behavioural abnormalities. Another review concluded that children with Nocturnal Enuresis “are likely to have a quantitative difference in the number of behavioural symptoms” compared with non-enuretic children, but that only a minority of enuretic children are “truly maladjusted” (Moffatt, 1989). The direction of causality is unclear.

In general, studies often fail to differentiate samples according to Primary or Secondary Nocturnal Enuresis. More studies which concentrate upon children with PNE only are required, as this category constitutes the largest proportion of enuretics (Mark & Frank, 1995).

Assessment

Assessment of enuresis is carried out by different professionals in a variety of settings, including paediatric out-patient departments, schools (by school nurses), GP surgeries, psychology services, and specialist enuresis clinics. For initial assessment to meet minimum standards of practice it should include a history of the problem; relevant medical history and family and environmental factors; child and family attitudes towards enuresis and its treatment; factors affecting treatment practicality; bladder and bowel control; history of previous investigations and treatment methods; and a two week baseline of frequency of wetting (Enuresis Resource and Information Centre,
There is no suggestion of evaluating beliefs about a child’s perception of control over factors which might influence their wetting, or of beliefs about their potential contribution to symptom improvement within the guidelines.

**Treatment**

Treatment for PNE can generally be categorised into pharmacological or behavioural interventions (Houts, 1991).

A review of 37 randomised controlled trials revealed that two drugs, Desmopressine and Imiprimine rapidly reduce the number of wet nights per week (Primary and Secondary Enuresis was generally not differentiated within samples), although there was no reliable information about their longer term effectiveness (CRD, 1997). Unfortunately, reliance upon the effects of drugs decreases a child’s opportunities to practise continence skills (Friman & Warzak, 1990).

Behavioural interventions include star charts and rewards, enuresis alarms, dry bed training (multi-dimensional behavioural treatment programs), retention control training, and wakening. Behavioural interventions assume that urinary continence at night can be acquired through learning procedures (Warzak & Friman, 1994). Behavioural modification in the treatment of enuresis has a reported success rate ranging from 20% to 100% (Scharf, Pravda, Jennings, Kauffman & Ringel, 1987). Clearly there are some children for whom these techniques appear less effective. The authors suggest the success of treatment is enhanced if the child is “actively involved”, although they do not operationalise this term.

Logically, it would seem that if a child can perceive a causal link between factors under their own control, and subsequent outcome, they are more likely to be motivated to remain actively involved in their treatment, and success may be more likely. As will be discussed, research has neglected to adequately investigate enuretic children’s perception of control, and this is reflected in an absence of recommendations to enquire about this in assessment and treatment guidelines.
Perception of control

Perception of control is concerned with a person’s understanding of the interdependence of events, and thus of an awareness of contingencies between behaviour and reinforcement. A perception of uncontrollability requires the appreciation of the independence of events (Friedlander, 1984). A subtype of the more global term of perception of control is Rotter’s formulation of Locus of Control (Rotter, 1954), which is defined as an expectancy that a reinforcement is under one’s own control (internal) or not under one’s own control (external) (Connell, 1985).

Originally grounded in Social Learning Theory, this concept proposes that “the effect of a reward in determining behaviour depends upon whether or not a person perceives a causal link between his or her behaviour and that reward.” (Connor, 1995). If a child does not perceive a link between their own behaviour and what happens to them subsequently, there will be little motivation to change their existing behaviour to achieve a positive outcome. Therefore, helping a child to perceive contingencies between their own behaviour and outcome is an important therapeutic goal (Elliot, 1996), and an understanding of a child’s Locus of Control (both over their symptoms, and about potentially contributing to the process of symptom improvement) can provide a useful initial focus in clinical assessment.

Measures to assess Locus of Control have been developed for children and adolescents and focus upon academic achievement (Crandall, Katkovsky & Crandall, 1965), general events (Nowicki & Strickland, 1973), social interaction (Dahlquist & Ottinger, 1983), health (Parcel & Mayer, 1978) and multi-domains such as scholastic, sports, social and general events (Connell, 1985). There appear to be no published measures specific to enuresis.

Researchers have been criticised for trying to obtain predictions about specific behaviour (e.g. academic) by using scales designed to measure generalised expectancies for internal and external control, and are advised to use measures which are domain specific for this purpose (Furnham & Steele, 1993). A further criticism is that perception of control might not be uni-dimensional (internal-external) but multi-
dimensional (Furnham & Steele, 1993). It is suggested that children might not know whose attributes control their successes and failures (others or themselves) and so an 'unknown' dimension should be added to children's scales (Connell, 1985).

A literature review revealed no studies assessing perceptions of control over bed wetting in children with PNE specifically. One study involving fifty children aged between 7-16 years with Nocturnal Enuresis used an eight item, seven point Likert scale to investigate children's beliefs about aetiology, and revealed that the most heavily endorsed belief about cause was 'sleeping too heavily', a factor which the children identified as out of their control (Butler, Redfern & Holland, 1994). However this study did not differentiate between children with Primary or Secondary Enuresis, where beliefs about cause may differ, and the forced choice format of the questionnaire did not allow the children to identify a wider range of potential causes. Additionally, it did not investigate the extent to which the children believe they can contribute to the process of symptom improvement in treatment.

It may be that repeated episodes of perceived failure to achieve continence, generalise to produce a widespread sense of lack of control in enuretic children. Only one study (German language) has investigated generalised locus of control in children with “Primary Enuresis” compared with a control group (Vilhelm, 1983; Abstract). Thirty “5-6th grade” males with Primary Enuresis or Minimal Brain Damage (MBD) formed the target group. They were assessed using the Locus of Control Scale for Children (Nowicki & Strickland, 1973) and compared with a “control group” presumably of symptom free children. Children in the target group were found to have significantly higher externality scores. If enuretic children have a generalised sense of lack of control, this would suggest intervention needs to be holistic in its approach in order to be maximally effective and to address the child's wider needs.

However the validity of these findings are questionable. The scale used in this study has been criticised for being uni-dimensional in nature (Furnham & Steele, 1993) and the target group would have been too heterogeneous in its manifestation of symptoms (MBD or Enuresis) to provide a meaningful comparison to a control group. It would also be helpful to include a control group of children with a specific health problem to
establish if there is something about the nature of PNE as a condition, which is
different from other health related symptoms due to its developmental nature (failure
to achieve a developmental milestone in line with other children).

In summary, no study has investigated perceptions of control over bed wetting, and
more generally in children with PNE, despite its potential relevance to clinical
assessment.

**Self Concept and self esteem**

Many children with PNE avoid spending nights away from home because they fear
detection of their enuresis by their peers (Warzak & Friman, 1994). This secrecy
maintains the feeling in children that wetting is not a common problem in childhood,
and this in turn can contribute to the feeling that they are different from others. This is
supported in one study where children with Nocturnal Enuresis rated themselves as
feeling different from other children without Enuresis significantly more (p<0.01)
(Butler, 1994). However very few studies have used standardised measures to
investigate whether children with PNE (and thus children who have failed to reach a
developmental milestone) generally have poorer self concepts or lower self esteem.

It has been suggested that self esteem is an important psychological variable that is
associated with mental health, and that if it persists over years, later psychological and
psychiatric dysfunction would be expected (Hagglof, Andren, Bergstrom, Marklund &
Wendelius, 1996). Although a logical deduction, the authors fail to offer evidence to
support this view.

The constructs of self concept and self esteem have been criticised for being “vaguely
defined at the conceptual level” and therefore not pointing to clear operational
definitions (Harter, 1982). The terms are often used interchangeably. Furthermore,
measures to assess self esteem or global self worth in children (defined by Harter as
the level of global regard that one has for oneself as a person; 1993) include a diverse
content, with items that are heterogeneous in nature. Responses to items are then
summed and a total score interpreted as an index of global self regard (e.g. The Piers-
Harris Self Concept Scale; Piers & Harris, 1969). Harter (1993) instead proposes that from the age of approximately eight years, children develop domain specific evaluations of their competency and adequacy, in addition to a more global concept of their worth as a person. In essence, she suggests that global self worth or self esteem is not merely the sum of responses to heterogeneous items, but a separate construct of items pertaining to oneself as a whole.

Two studies have used the afore criticised Piers-Harris Self Concept Scale with children with “Nocturnal Enuresis”, n=121 (Wagner, Smith & Norris, 1987) and PNE, n= 100 (Wagner & Geffken, 1986). Both studies found the children’s scores were within the average range. However Wagner et al. did not differentiate between Secondary and Primary Enuresis in their sample, and both studies included responses from children aged between 5-14/16 years of age. It is likely that aggregating responses from children across such a large developmental range is less meaningful than grouping children by smaller age ranges, where psychosocial issues are probably more similar.

One other study including 66 children, aged 6-8 years with a variety of enuretic diagnoses (PNE, Primary Diurnal Enuresis, Secondary Enuresis and mixed) found that enuretic children scored significantly lower (p<0.001) on a Swedish self esteem inventory (Ouvinen-Birgerstom, 1985) than a healthy control group (Hagglof et al., 1996). However the scale used, is subject to the same criticisms as the Piers-Harris Scale and the sample was heterogeneous in diagnosis. Children with a combination of Diurnal and Nocturnal Enuresis have been found to have a lower self esteem than those with Nocturnal Enuresis (Wagner et al., 1987) and so the scores were probably lower than they would have been if children with PNE only were included. Self esteem scores in enuretic children in this study were similar to those of the control group after six months of successful treatment, indicating that the experience of having enuresis may have caused the low self esteem.

In summary, no study has investigated domain specific self perceptions and global self worth in children with PNE only, within a circumscribed developmental age range.
Rationale for the study

It is important to investigate children with PNE in their own right because they constitute the largest diagnostic subtype of enuresis, and represent a relatively large group of children in the community who are failing to reach a developmental milestone alongside their peers. Investigating perceptions of control over wetting is necessary because if children can appreciate a causal link between factors under their own control, and outcome, they may be more likely to feel motivated to change their behaviour or contribute to the process of symptom improvement. Children who perceive control to be external, may be encouraged to perceive contingencies as part of a preparation phase in treatment. Additionally, investigating children’s generalised perceptions of control in relevant areas of life may indicate whether treatment requires a more holistic approach in order to address wider needs. Finally, low levels of perceived competence and adequacy in specific domains, and low global self worth, may predispose children to develop psychological difficulties later in life. If children with PNE score poorly with regards to these concepts, it would suggest treatment needs to be sought promptly, and perhaps wider issues addressed in order to meet their needs.

This study improved upon earlier studies by investigating children with PNE only, (Enuresis Group) within the developmental stage of middle childhood (8-13 years inclusive). It included two appropriate control groups; children with stomach or head aches (Paediatric Control Group) and healthy siblings of the children in the other two groups (Sibling Control Group). The former group were believed to be a useful comparison because they had not failed to meet a developmental milestone, but had experience of symptoms which were recurrent and had not so far been eradicated. Perception of control over symptoms, and more generalised control were measured. The generalised measure of perception of control was multi-dimensional rather than the afore criticised uni-dimensional measures. Finally, domain specific self perception, and global self worth were measured using a tool which did not aggregate heterogeneous items to indicate an overall level of self esteem.
Objectives

The objectives were to assess:-

a) Whether children with PNE perceived themselves to have any control over their symptoms (wetting behaviour) before treatment and whether they perceived potential improvements in their symptoms to be under their own control compared to children with stomach or head aches.

b) Whether children with PNE perceived control of success and failure over other important aspects of their life (social interaction, physical activity, scholastic events and general events) to be due to internal, external, or unknown control compared to children in the Paediatric Control Group and a healthy Sibling Control Group.

c) How the PNE group’s self perception in important aspects of life (scholastic and athletic competence, social acceptance, physical appearance, and behavioural conduct), as well as global self worth, compared to the two control groups.

Hypotheses

Objective a)

1. Children with PNE and with stomach or head aches would be likely to perceive the occurrence of their wetting/symptoms to be due to factors which were not under their control.

2. Children with PNE and with stomach or head aches would be more likely to perceive potential improvements in their symptoms to be under the control of external factors (such as the doctor and their parents) rather than their own control.

Objective b)

3. Children with PNE would be more likely to perceive social, physical, scholastic and general events in their lives to be under the control of external or unknown
factors compared with children in the Paediatric Control Group and the Sibling Control Group.

Objective c)

4. Children with PNE would perceive themselves as less competent/adequate in important aspects of life (scholastic and athletic competence, social acceptance, physical appearance, and behavioural conduct) compared to children in the control groups. They would also have a lower sense of global self-worth.

Method

Participants

Participants included three groups of children aged between 8-13 years inclusive; Enuresis Group (n=12, mean age=11 years, 0 months, SD=2.1), Paediatric Control Group (n=12, mean age=10 years, 9 months, SD=1.4) and Sibling Control Group (n=12, mean age=10 years, 10 months, SD=2.1). The overall mean age within the sample was 10 years and 9 months (SD=1.9). A total of 17 males (47%) and 19 females (53%) participated in the study.

Within the Enuresis, Paediatric and Sibling Groups there were 8 (67%), 5 (42%) and 4 (33%) males respectively. Children within the Enuresis Group wet the bed a mean number of four nights per week. Of the children in the Paediatric Group, 42% (n=5) had stomach aches and 58% (n=7) had head aches.

The researcher originally aimed to include 25 children in each group. Unfortunately, referral rates were lower than forecasted, and the strict criteria (mainly the lower age limit of eight years) made recruiting the required number impossible, despite extending the time frame allocated to data collection. Of a total of 49 parents approached for consent, 73.5% (n=36) consented.
Sample sources

Children within the Enuresis Group and Paediatric Control Group came from three different NHS Trusts in the south west region. Enuresis referrals came mainly from one tertiary referral, multi-disciplinary Enuresis Clinic. Paediatric referrals were from paediatric waiting lists within three separate hospitals. Ethical permission was gained from each of the three Trusts (see appendices 1-3)

Inclusion/Exclusion criteria

Children were eligible to participate if they were aged 8-13 years inclusive. The questionnaires were not appropriate for use with children less than eight years of age.

**Enuresis Group:** children referred by their GP for PNE were eligible (history taking confirmed if they had ever been dry for a substantial period of time).

**Paediatric Control Group:** children were eligible if they had been referred by their GP to a paediatrician for recurrent stomach or head aches.

**Sibling Control Group:** children were eligible if they were siblings of children in the other two groups and did not suffer from either PNE or stomach or head aches.

Children were excluded from the Enuresis Group if their enuresis was Secondary or Diurnal in nature. Children were excluded from all three groups if they suffered a learning disability for which they had been statemented at school, if they had any additional health problems requiring specialist input, or if they were currently attending a psychology or counselling service, or had done so within the last year.

Procedures

Letters of invite and information sheets were sent to parents of children meeting age and GP diagnosis criteria (see appendices 4-7), and followed up with a telephone call by the researcher. Queries were answered, and a verbal expression of interest, or otherwise was given by the parent. If the parent was interested, the researcher asked a number of screening questions to clarify that the participant met remaining inclusion
and exclusion criteria. If so, enquiries were made about any sibling of the participant who might also be eligible for participation. Arrangements were then made to meet.

Data was collected from participants before their appointment with their respective clinicians for initial assessment of symptoms, to ensure they were all at the same point in the clinical process. Additionally, it was important that sense of control was not modified as a result of any current intervention. Informed and witnessed written consent was obtained from parents (see appendices 8-9). The study was explained to children, in language which was meaningful to them and informed consent was obtained using a child consent form (see appendices 10-11).

Data collection took on average 25-40 minutes for each child. A positive rapport was gained with each child by asking non-threatening questions (see appendix 12). Children in the Enuresis and Paediatric Groups were then given a semi-structured interview eliciting beliefs about their perception of control over symptoms. Children from all three groups completed two questionnaires after verbal instructions. GP’s of children in the Enuresis and Paediatric Groups were informed of their inclusion in the study in writing (see appendix 13).

Measures

1. **Semi-structured interview measuring perception of control over symptoms (bedwetting and stomach or head aches).**

As there were no published measures available for assessing perception of control over enuretic symptoms or stomach/ head aches, a semi-structured interview was specifically designed for children in the Enuresis Group and Paediatric Control Group (see appendices 14-15). The questions differed slightly in wording in order to make sense for the symptoms experienced. However the format remained consistent for both. Interviews included 7-8 questions and were divided into two halves. The first half contained questions concentrating upon when bedwetting or aches occurred, and the second half contained questions concentrating upon when they did not.
Questions elicited information on:-

a) responsibility-taking behaviour for the consequences of the symptoms (Questions 2 and 3 on Paediatric and Enuresis interviews respectively).

b) beliefs about locus of control over occurrence of symptoms (Questions 3 and 4 on Paediatric and Enuresis interviews respectively).

c) beliefs about locus of control in relation to possible symptom improvement (Questions 5 and 6 on Paediatric and Enuresis interviews respectively.)

d) ideas about how children themselves could contribute to symptom improvement (Questions 6 and 7, and 7 and 8 for Paediatric and Enuresis interviews respectively).

When specifically assessing locus of control (b and c) pre-defined categories were provided from a set of cards laid out before the child. The child chose the response which best reflected their opinion. They were then asked to provide examples to illustrate their choice. These categories of responses were formulated to remain consistent with Connell’s Multi-dimensional Measure of Perception of Control (Connell 1985). In other words, responses indicated internal, external (powerful others) or unknown loci of control.

2. Multidimensional Measure of Children’s Perception of Control (Connell, 1985)

This 48 item questionnaire (see appendix 16) has a four point response scale to indicate the extent to which participants agreed with various statements. The questionnaire investigates children’s perception of control in three domains:- physical, scholastic and social. Perception of control is multi-dimensional including internal (under own control), powerful others (under teacher, adult’s control), and unknown (not sure). The scale demonstrates acceptable reliability (Alpha coefficients of 0.43 – 0.75) and acceptable construct and predictive validity (Furnham & Steele (1993).
3. Self Perception Profile for Children (Harter, 1985)

This 36 item, four point scale (see appendix 17) evaluates perceived competence and adequacy in five domains (scholastic competence, social acceptance, athletic competence, physical appearance, behavioural conduct), and also measures global self-worth. Each item consists of two statements. The respondent is asked to decide which statement is most like them. Both statements represent a legitimate choice thereby reducing the effects of social desirability. Reliability using Cronbach’s Alpha obtained scores between 0.74 to 0.83 across the sub scales. The scale has good face validity. Construct validity was addressed through factor analysis. Factor loadings supported the five competence sub scales but firm conclusions about validity could not be drawn as sample size was not reported (Keith & Bracken, 1996).

Statistical analyses

Responses to semi-structured interviews:

Children’s responses to open ended questions were classified as belonging to one of a number of categories. The remaining responses had already been allocated to pre-defined categories by the children themselves. Categorical analysis was undertaken and Fisher’s Exact tests were performed where appropriate.

Responses to questionnaires:

Means and standard deviations were calculated for sub scales of the Connell and Harter questionnaires. Non parametric Kruskal-Wallis tests were performed to detect differences between groups as data from the small sample size were not normally distributed. Differences in standard deviations were calculated to explore size of effects between groups where appropriate.
Results

Precautionary note:

The sample size of each group was very small. The results can only be viewed as preliminary in nature and require cautious interpretation, such that only tentative conclusions can be drawn. The statistical power of the tests was reduced, making it less likely to detect an effect if one was present.

Symptomotology: Beliefs about locus of control and symptom improvement

Inter-rater consistency for categorising responses to the semi-structured interview was calculated using Cohen’s Kappa (k) (Cohen, 1960). A colleague (a psychologist in clinical training) was asked to allocate participant responses to categories already established by the researcher. Contingency tables were then drawn up to tabulate the degree of agreement between the two raters. Cohen’s Kappa was calculated for each individual table of categories (see points 1-4 and their corresponding tables below). The mean was then calculated to give an overall proportion of agreement (see appendix 18). The overall proportion of agreement was high (k=0.9).

1. Beliefs about locus of control over occurrence of symptoms

This was assessed on the basis of children’s responses to a choice of pre-defined categories. Substantial percentages of children in both groups perceived the occurrence of their wetting or symptoms to be a result of factors under their own control (Enuresis: 42%; e.g. the amount of fluid drunk, frequency of visits to the toilet. Paediatric: 33%; e.g. running too much, eating certain foods). Similar percentages of children in both groups were unable to articulate what factors influenced the occurrence of their symptoms.

152
Table 1. Percentages of beliefs about locus of control over occurrence of symptoms

<table>
<thead>
<tr>
<th>Category</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enuresis</td>
</tr>
<tr>
<td>‘Things that I do for myself’</td>
<td>42% (n=5)</td>
</tr>
<tr>
<td>Under own/ internal control)</td>
<td></td>
</tr>
<tr>
<td>‘Things that other people around me say or do’</td>
<td>17% (n=2)</td>
</tr>
<tr>
<td>Under others/ external control)</td>
<td></td>
</tr>
<tr>
<td>‘There are things but I’m not sure what they are’</td>
<td>0% (n=0)</td>
</tr>
<tr>
<td>(Unknown control)</td>
<td></td>
</tr>
<tr>
<td>‘Don’t know’</td>
<td>42% (n=5)</td>
</tr>
<tr>
<td>(Unknown control)</td>
<td></td>
</tr>
</tbody>
</table>

2. Beliefs about locus of control in relation to symptom improvement

This was assessed on the basis of children’s responses to a choice of pre-defined categories. The majority of children in both the Enuresis Group (58%) and Paediatric Group (67%) believed that their doctors or parents would be best at improving their wetting/symptoms (external control). A substantial proportion of children with enuresis (33%) believed that a joint effort between others and themselves would be most successful at improving enuresis. The same percentage of children in the Paediatric Group (33%) either did not know who would be best (unknown control) or believed no one could help. One enuretic child believed they would be the best person to improve their condition and no children in the Paediatric Group believed this. Differences between the groups could not be explored further with Chi-square because expected cell values were less than five and there were too many categories to perform a Fisher’s Exact test.

Table 2. Percentages of beliefs about locus of control in relation to symptom improvement

<table>
<thead>
<tr>
<th>Category</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enuresis</td>
</tr>
<tr>
<td>The self (Internal control)</td>
<td>8% (n=1)</td>
</tr>
<tr>
<td>Doctor/parents (External control)</td>
<td>58% (n=7)</td>
</tr>
<tr>
<td>Joint effort between self and doctor/parents (Joint internal and External control)</td>
<td>33% (n=4)</td>
</tr>
<tr>
<td>Unknown control</td>
<td>0% (n=0)</td>
</tr>
<tr>
<td>No one can</td>
<td>0% (n=0)</td>
</tr>
</tbody>
</table>
3. Ideas about how children themselves could contribute to symptom improvement.

This was assessed on the basis of children’s responses to prompts requesting examples of how they could contribute to symptom improvement if they had already indicated that they could, in addition to responses to further prompts about whether they thought they could contribute if not already indicated, and then how they might be able to. Such prompting revealed that despite the fact that none of the Paediatric children and only a limited percentage of the Enuretic children originally believed they themselves could contribute to symptom improvement, on further direct questioning, many were able to offer appropriate suggestions.

For Enuretic children, ideas fell into four categories with the most popular being to drink less or earlier in the evening (33%). Three children were unable to offer a suggestion.

Table 3. Percentages of ideas under own control which might improve symptoms for Enuretic children (N represents a single idea)

<table>
<thead>
<tr>
<th>Idea</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drink less or earlier in evening</td>
<td>33%</td>
</tr>
<tr>
<td>(n=5)</td>
<td></td>
</tr>
<tr>
<td>Go to toilet more often</td>
<td>27%</td>
</tr>
<tr>
<td>(n=4)</td>
<td></td>
</tr>
<tr>
<td>Use willpower/ self talk</td>
<td>20%</td>
</tr>
<tr>
<td>(n=3)</td>
<td></td>
</tr>
<tr>
<td>Unable to offer a suggestion</td>
<td>20%</td>
</tr>
<tr>
<td>(n=3)</td>
<td></td>
</tr>
</tbody>
</table>

Children with stomach and head aches offered an even wider variety of suggestions. The most frequent suggestions involved changing their activities in some way to avoid onset (watch less T.V. avoid getting too hot, run less; 29%). However four children were unable to offer a suggestion.
Table 4. Percentages of ideas under own control which might improve symptoms for Paediatric children (N represents a single idea)

<table>
<thead>
<tr>
<th>Idea</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Change activity</td>
<td>29% (n=4)</td>
</tr>
<tr>
<td>Follow doctor’s instructions well</td>
<td>14% (n=2)</td>
</tr>
<tr>
<td>Go to toilet more regularly</td>
<td>7% (n=1)</td>
</tr>
<tr>
<td>Exclude certain foods</td>
<td>7% (n=1)</td>
</tr>
<tr>
<td>Pray</td>
<td>7% (n=1)</td>
</tr>
<tr>
<td>Think about symptoms less</td>
<td>7% (n=1)</td>
</tr>
<tr>
<td>Unable to suggest</td>
<td>29% (n=4)</td>
</tr>
</tbody>
</table>

4. Responsibility taking behaviour for the consequences of symptoms

It was also believed valuable to explore whether children with enuresis and children with stomach or head aches differed in their responsibility taking behaviour with regards to the consequences of their symptoms.

Firstly, 33% (n=4) of the enuretic children stated that they did not wake up after wetting, whilst 42% (n=5) awoke only sometimes. Only 25% (n=3) always woke up.

Responsibility taking behaviour was assessed on the basis of children’s responses to open-ended questions. Relatively low percentages of children in both groups took sole responsibility for either wetting, by removing dirty sheets and making a clean bed, or for symptoms, by seeking to alleviate stomach or head pain. Within the Enuresis Group half the children indicated their parents (usually mum) took full responsibility. This was in contrast to the children in the Paediatric Group where 75% (n=9) indicated they took joint responsibility. This usually meant that the child sought to alleviate initial symptoms of pain, and parents intervened if pain persisted.
Table 5. Percentages of responsibility taking behaviour

<table>
<thead>
<tr>
<th>Category</th>
<th>Group</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Enuresis</td>
</tr>
<tr>
<td>Child takes responsibility</td>
<td>20% (n=2)</td>
</tr>
<tr>
<td>Parent takes responsibility</td>
<td>50% (n=5)</td>
</tr>
<tr>
<td>Parent and child take joint responsibility</td>
<td>30% (n=3)</td>
</tr>
</tbody>
</table>

N.B. Percentage calculations for enuresis group were based on responses from ten children because further information was not sought from two children who said they never woke up after wetting.

To establish whether children in the Paediatric Group took significantly more responsibility than children in the Enuresis Group, a Fisher’s Exact Test was performed. The ‘Child takes responsibility’ and ‘Parent and child take joint responsibility’ categories were collapsed into one to represent ‘Child contributes to taking responsibility’. This category was compared with ‘Parent takes responsibility’ (i.e. child takes some/all responsibility versus parent takes full responsibility). The difference narrowly missed significance (p=0.056; 2-tailed).

Beliefs about control related to other domains of life
(Multidimensional Measure of Children’s Perception of Control)

Table 6. shows the means and standard deviations for total scores on each dimension of control (internal, powerful others and unknown) across all of the domains combined together (social, physical, cognitive and general).

Table 6. Means and standard deviations of total scores on each dimension of control

<table>
<thead>
<tr>
<th>Group</th>
<th>Powerful others</th>
<th>Internal</th>
<th>Unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enuresis</td>
<td>Mean 36.42</td>
<td>48.33</td>
<td>35.42</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>(9.23)</td>
<td>(5.76)</td>
<td>(8.21)</td>
</tr>
<tr>
<td>Paediatric</td>
<td>Mean 37.33</td>
<td>48.33</td>
<td>35.83</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>(7.10)</td>
<td>(4.79)</td>
<td>(6.67)</td>
</tr>
<tr>
<td>Sibling</td>
<td>Mean 34.92</td>
<td>46.17</td>
<td>35.75</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>(6.07)</td>
<td>(8.14)</td>
<td>(7.83)</td>
</tr>
</tbody>
</table>
Wilcoxon Signed Rank tests for paired data revealed that internal control scores were significantly higher than powerful others control and unknown control for each group.

Table 7. Z values for differences between internal control, powerful others and unknown control

<table>
<thead>
<tr>
<th>Group</th>
<th>Internal/ Powerful others</th>
<th>Internal/ unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>Enuresis</td>
<td>-2.936**</td>
<td>-2.983**</td>
</tr>
<tr>
<td>Paediatric</td>
<td>-2.936**</td>
<td>-3.062**</td>
</tr>
<tr>
<td>Sibling</td>
<td>-3.061**</td>
<td>-2.449*</td>
</tr>
</tbody>
</table>

**= sig. at p<0.01; *= sig. at p<0.05

Kruskal-Wallis One Way Analysis of Variance tests were performed to detect differences between groups for each dimension of control. No differences were significant at p<0.05.

Table 8. $\chi^2$ values obtained for each dimension of control

<table>
<thead>
<tr>
<th>Connell Dimensions of Control</th>
<th>$\chi^2$</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Internal Control</td>
<td>.056</td>
<td>.97</td>
</tr>
<tr>
<td>Powerful Others Control</td>
<td>.475</td>
<td>.79</td>
</tr>
<tr>
<td>Unknown Control</td>
<td>.091</td>
<td>.96</td>
</tr>
</tbody>
</table>

Means and standard deviations were calculated for each dimension of control within each of the four domains.
Table 9. Means and standard deviations for each group on each dimension of control within each of the four domains

<table>
<thead>
<tr>
<th>Control Dimension</th>
<th>Enuresis Group</th>
<th>Paediatric Group</th>
<th>Sibling Group</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Internal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>13.92</td>
<td>13.92</td>
<td>12.75</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.08</td>
<td>1.83</td>
<td>2.53</td>
</tr>
<tr>
<td><strong>Cognitive Power, Others</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>7.67</td>
<td>8.67</td>
<td>7.83</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.77</td>
<td>2.10</td>
<td>2.25</td>
</tr>
<tr>
<td><strong>Cognitive Unknown</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.50</td>
<td>8.08</td>
<td>8.33</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.84</td>
<td>2.27</td>
<td>2.15</td>
</tr>
<tr>
<td><strong>General Internal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>11.00</td>
<td>11.50</td>
<td>9.58</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.86</td>
<td>2.43</td>
<td>3.09</td>
</tr>
<tr>
<td><strong>General Power, Others</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>10.50</td>
<td>11.75</td>
<td>10.17</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.94</td>
<td>1.82</td>
<td>2.04</td>
</tr>
<tr>
<td><strong>General Unknown</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>10.08</td>
<td>9.42</td>
<td>10.50</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.88</td>
<td>1.78</td>
<td>2.65</td>
</tr>
<tr>
<td><strong>Physical Internal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>11.42</td>
<td>11.83</td>
<td>11.83</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.57</td>
<td>2.12</td>
<td>3.19</td>
</tr>
<tr>
<td><strong>Physical Power, Others</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>10.17</td>
<td>9.67</td>
<td>9.33</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.79</td>
<td>2.10</td>
<td>3.03</td>
</tr>
<tr>
<td><strong>Physical Unknown</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>7.67</td>
<td>8.08</td>
<td>7.33</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.57</td>
<td>2.64</td>
<td>2.67</td>
</tr>
<tr>
<td><strong>Social Internal</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>12.00</td>
<td>11.08</td>
<td>12.00</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>2.22</td>
<td>1.98</td>
<td>1.86</td>
</tr>
<tr>
<td><strong>Social Power, Others</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>8.08</td>
<td>7.25</td>
<td>7.58</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>3.12</td>
<td>3.08</td>
<td>2.23</td>
</tr>
<tr>
<td><strong>Social Unknown</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>9.17</td>
<td>10.25</td>
<td>9.58</td>
</tr>
<tr>
<td>Std. Dev.</td>
<td>1.99</td>
<td>1.96</td>
<td>2.02</td>
</tr>
</tbody>
</table>
Kruskal-Wallis tests were performed to detect differences between groups for each dimension and domain of control. None were significant at \( p<0.05 \).

**Table 10. \( \chi^2 \) values obtained for each dimension and domain of control**

<table>
<thead>
<tr>
<th>Connell Domains/sources of control</th>
<th>( \chi^2 )</th>
<th>( \text{P} )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cognitive Internal Control</td>
<td>1.047</td>
<td>.593</td>
</tr>
<tr>
<td>Cognitive Powerful Others Control</td>
<td>1.923</td>
<td>.382</td>
</tr>
<tr>
<td>Cognitive Unknown Control</td>
<td>.165</td>
<td>.921</td>
</tr>
<tr>
<td>Physical Internal Control</td>
<td>.364</td>
<td>.834</td>
</tr>
<tr>
<td>Physical Powerful Others Control</td>
<td>1.481</td>
<td>.477</td>
</tr>
<tr>
<td>Physical Unknown Control</td>
<td>.919</td>
<td>.632</td>
</tr>
<tr>
<td>Social Internal Control</td>
<td>1.990</td>
<td>.370</td>
</tr>
<tr>
<td>Social Powerful Others Control</td>
<td>.693</td>
<td>.707</td>
</tr>
<tr>
<td>Social Unknown Control</td>
<td>1.726</td>
<td>.422</td>
</tr>
<tr>
<td>General Internal Control</td>
<td>2.468</td>
<td>.291</td>
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<tr>
<td>General Powerful Others Control</td>
<td>3.667</td>
<td>.160</td>
</tr>
<tr>
<td>General Unknown Control</td>
<td>2.011</td>
<td>.366</td>
</tr>
</tbody>
</table>

**Perceived competence in important domains of life and global self worth (Self Perception Profile for Children; SPPC; Harter, 1985)**

Means and standard deviations for all sub scales of the SPPC were calculated.

**Table 11. Mean and standard deviation scores for the six self perception sub scales.**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>Std. Dev.</td>
<td>Mean</td>
<td>Std. Dev.</td>
<td>Mean</td>
<td>Std. Dev.</td>
</tr>
<tr>
<td>En.</td>
<td>17.25</td>
<td>(5.08)</td>
<td>15.00</td>
<td>(3.74)</td>
<td>16.17</td>
<td>(4.84)</td>
</tr>
<tr>
<td>Paed.</td>
<td>17.58</td>
<td>(3.29)</td>
<td>18.08</td>
<td>(3.45)</td>
<td>16.83</td>
<td>(4.11)</td>
</tr>
<tr>
<td>Sib.</td>
<td>16.17</td>
<td>(5.73)</td>
<td>16.83</td>
<td>(3.71)</td>
<td>15.92</td>
<td>(5.66)</td>
</tr>
</tbody>
</table>

159
Kruskal-Wallis tests were performed for each of the six sub scales to detect differences between groups. No differences were significant at $p<0.05$.

Table 12. $\chi^2$ values obtained for SPPC sub scales

<table>
<thead>
<tr>
<th>Harter Sub Scales</th>
<th>$\chi^2$</th>
<th>$P$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scholastic Competence</td>
<td>.904</td>
<td>.636</td>
</tr>
<tr>
<td>Social Acceptance</td>
<td>.637</td>
<td>.727</td>
</tr>
<tr>
<td>Athletic Competence</td>
<td>.261</td>
<td>.878</td>
</tr>
<tr>
<td>Physical Competence</td>
<td>.147</td>
<td>.929</td>
</tr>
<tr>
<td>Behavioural Conduct</td>
<td>3.409</td>
<td>.182</td>
</tr>
<tr>
<td>Global Self Worth</td>
<td>1.768</td>
<td>.413</td>
</tr>
</tbody>
</table>

Despite the fact that Kruskal-Wallis tests revealed no significant differences between the groups, the means indicated in table 11. did reveal that children in the Enuresis Group scored lower compared with children in the other two groups on Social Acceptance, Behaviour Conduct and Global Self Worth. Figure 1 illustrates this.

**Figure 1. Illustrating mean scores for Social Acceptance, Behaviour Conduct and Global Self Worth sub scales**

N.B. Lower scores = lower self perception of competency and adequacy.
It can also be seen from table 11 that the Behaviour Conduct sub scale was the one scale that differed substantially between the Paediatric and Enuresis Groups. Consequently, calculations were made to establish the size effect of the difference between the mean scores for the groups. When children in the Enuresis Group were compared with children in the Paediatric Group, the difference was approximately 0.82 of a standard deviation, which is a reasonable size effect (Cohen, 1977). Thus children in the Enuresis Group perceived themselves to be less well behaved than the children in the Paediatric Group.

Discussion

The findings of this research will now be discussed in connection with each of the original hypotheses. The potential service implications of the findings will then be considered. Limitations of the research will be highlighted and future research suggested.

Contrary to the prediction of hypothesis one, a substantial proportion of children with enuresis and with stomach or head aches perceived the occurrence of their symptoms to be as a result of factors under their own control, although similar proportions in both groups were unable to articulate which factors influenced the occurrence of their symptoms. This suggests that some children are clearly able to perceive contingencies between their own behaviour and outcome. Health care professionals could usefully explore this understanding during assessment and then utilise it in the hope of fostering active involvement of the child during treatment. This might maximise motivation to participate in the treatment program. Additionally, those children that are unable to perceive any links between factors under internal control and symptom occurrence, could be identified during assessment so that they could be encouraged to do so as treatment progresses.

As predicted by hypothesis two, the majority of children in both groups (Enuresis =58%; Paediatric =67%) perceived potential improvements in their symptoms to be under the external control of their doctor or parents. This raises the suggestion that
although some children might be able to pinpoint factors under internal control which influence their symptom occurrence, they might not necessarily make the link in their own minds that they can then actively contribute to the future process of symptom improvement. Facilitating children to make this link might therefore be an important therapeutic goal. It is encouraging that a substantial proportion of enuretic children believed that a joint effort between themselves and external sources would be the best way forward. This would allow for a collaborative therapeutic relationship and should be encouraged from the beginning of treatment so that the child perceives increased ownership of the process and is encouraged to be “actively involved”.

Despite the finding that children generally did not view themselves as being in the best position to improve their symptoms when asked specifically to choose between internal, external or unknown sources, they were able to offer a variety of appropriate suggestions under their own control with additional prompting (for example drinking less or go to the toilet more often). This is an important point to note in the process of working therapeutically with children. Care is required to question and prompt the child gently in order to encourage them to access their own experience and creativity. In this way they may be facilitated in offering their own ideas which might maximise their chances of success in treatment.

It is interesting to note that the majority of the enuretic children either never, or only sometimes woke up after they wet the bed. This has implications for children taking responsibility for changing the wet bed sheets for clean ones. They are probably less likely to be involved in the process of changing the sheets the next day, especially if it is a school day. Indeed the finding that half of the parents took full responsibility for this process indicates that they may not be encouraging the children to at least share the consequences of their wetting. Being part of the reparation process may be an important part of the “active involvement” of the child that Scharf et al. (1989) advocate in treatment.

Although the findings showed that children with stomach or headaches took more responsibility for the consequences of their symptoms it is possible that responsibility taking behaviour had a different meaning for children in the Paediatric Group. They
were seeking to alleviate pain or discomfort, whereas the enuretic children were involved merely in a reparation process so that they would be comfortable the next night. Logically, they might be less motivated to do this than the children in the Paediatric Group. This explanation may therefore account for the near significant difference between the two groups.

Originally it was hypothesised that children with PNE might have a more generalised sense of lack of control compared with the children in the other two groups. The results indicated that this was not so and therefore contrasted with Vilhelm’s (1983) findings that children with enuresis or Minimal Brain Damage had higher externality scores than a control group. This suggests that repeated episodes of perceived failure to achieve continence may not necessarily generalise to a widespread sense of lack of control. All three groups of children endorsed internal sources of control to a greater extent than external or unknown sources.

Contrary to the predictions of hypothesis four, no significant differences between the groups were found for the sub scales of the Harter Self Perception Profile for Children. However, enuretic children scored lower than the other two groups on the three sub scales of Social Acceptance, Behaviour Conduct and Global Self Worth, with the mean score on the Behaviour Conduct Scale being substantially lower than that of the paediatric children. As previous research into self concept and self esteem did not investigate children with PNE only, or included a broad age range of children, comparisons with the current piece of research were difficult to make. However, scores on the three sub scales mentioned above were in the predicted direction as indicated by some of the previous research, for example more behavioural difficulties (CRD, 1997; Moffatt, 1989) and children feeling different (Butler, 1994) which may lead to a perceived decrease in Social Acceptance.

Enuretic children may be experiencing social difficulties as a result of feeling different, or they may even be perceiving themselves as badly behaved because they are unable to stop wetting as their peers have done. Such beliefs may possibly have been internalised as a result of negative parental attitudes about wetting, and thus
should be addressed accordingly. Additionally, tentative suggestions that enuretic children may have lower Global Self Worth suggests prompt treatment is required, particularly if this concept is correlated with the later development of psychological difficulties. It may be useful to employ the Self Perception Profile for Children as a tool for use in the assessment for treatment of enuresis, in order to pinpoint children with lower scores on relevant sub scales. It would be important to then re-administer the measure post treatment to assess whether or not scores have improved in line with any symptom improvement, and if not, to follow children up at a later date as part of a monitoring process.

There are a number of limitations to this piece of research. Most importantly, the sample size of the three groups was very small and thus the statistical power of the tests used was reduced, making it less likely to locate statistically significant differences between the groups. The necessity of choosing non-parametric tests over their (usually more powerful) parametric equivalents also made it less likely that differences would be found if they existed. Secondly, there may have been a bias in the results due to the recruitment procedures. Despite contacting the parents of all children who met inclusion criteria, some parents did not permit participation and others did not attend their assessment appointment at the clinic and so did not participate. It is impossible to know how results may have been altered if all those contacted had been recruited.

Finally, as with the use of all self report measures, it is possible that participants did not report their thoughts and feelings accurately. Despite encouraging children to ask for help in understanding the questions, some may have completed items without full understanding. This seemed unlikely however as most children seemed comfortable with requesting help when it was required. The Multidimensional Measure of Children’s’ Perception of Control was very long and rather repetitive in its language. It is possible that some children may have become bored when responding to items on this questionnaire. It is hoped that this did not influence them in responding inaccurately.
The major strengths of this piece of research lay within the use of strict inclusion and exclusion criteria, which gave rise to 'purer' within group samples, and in the choice of two control groups for comparison. However one potential criticism of the choice of children with stomach or head aches as controls was that there may have been psychosomatic aspects to the symptoms. The psychological concepts of Locus of Control and self concept may have been influenced as a result, making those children less valid as controls. As medical assessments had not been carried out, it was impossible to identify how many of the children experienced symptoms of non-organic origin.

Summary of potential service implications

Despite the tentativeness with which conclusions can be drawn from this research, there are some interesting findings which may potentially inform clinical practice in services treating Enuresis. The following points may be useful to bear in mind:-

1. In addition to the standard assessment as recommended by ERIC (1996), explore the child’s understanding of contingencies between factors under their own control (e.g. drinking less before bed) and subsequent effect on their wetting behaviour.

2. Use progressive prompting to elicit their own ideas based on their previous experience.

3. Encourage the child to make links between perceived contingencies between their behaviour and outcome, and the child’s potential for actively contributing to symptom improvement.

4. Explore the extent to which the child takes responsibility for the consequences of their wetting at assessment.

5. Administer the Behaviour Conduct, Social Acceptance and Global Self Worth sub scales of the Self Perception Profile for Children as part of assessment, to explore the need for addressing issues beyond Enuresis. Re-administer post treatment and
follow-up at a later date if scores have not improved in line with symptom improvement.

These recommendations may also be relevant to children with other symptoms such as stomach or headaches, or other paediatric conditions.

Despite the potential usefulness of assessing a child’s Locus of Control with regards to wetting behaviour specifically, and then encouraging them to link perceptions of control with perceptions of ability to contribute to symptom improvement, this research did not investigate whether there would actually be any treatment gains as a result. It is instead a hypothetical assumption that a motivation to remain “actively involved” might be maximised and perhaps symptom improvement might be either quicker, or more complete. Future research is required to test these hypotheses within an experimental design.
References


Appendices
Appendix 1
Ethical permission from Kingston and Richmond Health Authority

Kingston & Richmond Health Authority
22 Hollyfield Road, Surbiton, Surrey KT6 4AL. DX 119075 Surbiton 2
Telephone 0181 339 8014 Facsimile 0181 339 8100

0 0181 339 8014

GKK/JCW

1 April 1998

Ms Zena Dowling
32D Copenhagen Gardens
Chiswick
London W4 5NN

Dear Ms Dowling

PERCEPTION OF CONTROL AND SELF ESTEEM IN CHILDREN WITH PRIMARY NOCTURNAL ENURESIS

Thank you for your letter faxed to Mrs White yesterday together with amended appendices. I was pleased to note that you would be discussing the Committee’s concerns with your supervisor and will look forward to feedback on the outcome of the meeting in due course.

I am now happy to confirm approval of the above study.

Yours sincerely

[Signature]

Dr G K Knowles
Chairman
Local Research Ethics Committee
Appendix 2
Ethical permission from Merton, Sutton and Wandsworth Health Authority

MERTON, SUTTON & WANDSWORTH HEALTH AUTHORITY

MERTON & SUTTON LOCAL RESEARCH ETHICS COMMITTEE

Tel: 0181 296 3525 Fax: 0181 644 9324
26 June 1998

Re: LREC No. 44/98
[Please quote above reference in all correspondence]

Ms. Zena Dowling
32D Copenhagen Gardens
Chiswick
London, W4 5NN

Dear Ms. Dowling,

re: Perception of control and self esteem in children with Primary Nocturnal Enuresis

I am pleased to say that this study was approved by the Committee at our meeting on 17 June 1998.

Thank you for your phone call of 24 June. There is no need to write back on this. The Committee simply asked me to say that they would prefer future projects to involve patients in less work.

LREC permission is granted on the understanding that:

i) any change or amendment to the protocol will be reported to the committee.
ii) a brief report will be submitted after completion.
iii) the study is commenced within the next 12 months. Should the start of the study be delayed beyond the period of one year, a re-application to the committee will be required.

Yours sincerely,

[Signature]

Dr Hervey Wilcox
Chairman
Local Research Ethics Committee

All correspondence to:
The Chairman LREC, R&D Unit, The St. Helier NHS Trust, Carshalton, Surrey SM5 1AA

173
Dear Ms. Dowling,

Re: Perception of control and self esteem in children with Primary Nocturnal Enuresis

Thank you for your letter dated 24th June in response to the Committee’s initial concerns regarding the above study. At its meeting held on 14th July 1998 the Committee raised no further ethical issues and the study was approved. I enclose a signed copy of the application form for your records.

Resource implications and insurance arrangements for the study should be discussed with Mr. J. Caffrey, Finance Dept. RSCH. Should the start of the study be delayed by more than one year from the date of approval you should resubmit the protocol to the Committee.

Please inform the Committee of any adverse effects to the subjects which may be related to taking part in the study.

The Committee requests that you provide a final report of your study or a copy of any published paper.

Yours sincerely,

[Signature]

[Name]
Chairman, Ethics Committee
Appendix 4

Letter of invite (Enuresis Group)

Date

Dear Mr and Mrs X

My name is Zena Dowling and I am training to be a clinical psychologist. With the permission of the Enuresis Team at The Enuresis Clinic, Hawkes Road, I am conducting an independent study within the clinic which involves children who wet the bed. My colleagues at the clinic have informed me that your son/daughter has been referred for assessment and have agreed that I may contact you to see if you may be interested to hear about the study.

We are interested in exploring how children think about their bed wetting, and about more general aspects of their life. We hope that taking children's views into account will help us gain a better understanding of their symptoms and also help us to continue to provide a service that meets their needs.

I would like the opportunity to explain the study to you to see if you might be interested in your son/daughter taking part. There is no obligation to take part and certainly if he/she did not wish to participate I would respect his/her wishes.

So that we can learn from the information that children share with us, the general results of the study will be shared with the Enuresis Team, and with all parents who participate if they so wish. However, in order to maintain confidentiality, information gained about your son/daughter during the study would not be passed on to the team unless you gave permission for that to happen. This study is an independent study and will have no influence upon the team's assessment of your son/daughter's bed wetting.

I will contact you by telephone in the near future so that you may ask me any questions you wish. We may then set up a mutually suitable time, only if this is acceptable to you. Your son/daughter would simply need to answer two questionnaires designed specifically for children of his/her age and answer a few questions about his/her bed wetting. However I can explain this in more detail to you at a later date. Meanwhile I have enclosed an information sheet which tells you about why we are doing the study and what it involves.

I look forward to speaking with you in the near future.

Yours sincerely

Zena Dowling
Psychologist in Clinical Training.
Appendix 5  

Letter of invite (Paediatric Group)

Date

Dear Mr and Mrs X

My name is Zena Dowling and I am training to be a clinical psychologist. With the permission of Dr Y and Kingston Hospital, I am conducting an independent study at The Children's Department which involves children with symptoms such as stomach or head aches. My colleagues at the Department have informed me that your son/daughter has been referred for assessment and have agreed that I may contact you to see if you may be interested to hear about the study.

We are interested in exploring how children think about their symptoms and about more general aspects of their life. We hope that taking children's views into account will help us gain a better understanding of their symptoms and also help us to continue to provide a service that meets their needs.

I would like the opportunity to explain the study to you to see if you might be interested in your son/daughter taking part. There is no obligation to take part and certainly if he/she did not wish to participate I would respect his/her wishes.

So that we can learn from the information that children share with us, the general results of the study will be shared with Kingston Hospital, and with all parents who participate if they so wish. However, in order to maintain confidentiality, information gained about your son/daughter during the study would not be passed on to his/her paediatrician unless you gave permission for that to happen. This study is an independent study and will have no influence upon the paediatrician's assessment of your son/daughter's symptoms.

I will contact you by telephone in the near future so that you may ask me any questions you wish. We may then set up a mutually suitable time, if this is acceptable to you. Your son/daughter would simply be asked to answer two questionnaires designed specifically for children of his/her age and answer a few questions about his/her symptoms. However I can explain this in more detail to you at a later date. Meanwhile I have enclosed an information sheet which tells you about why we are doing the study and what it involves.

I look forward to speaking with you in the near future.

Yours sincerely

Zena Dowling
Psychologist in Clinical Training

176
Appendix 6

Information sheet for parents (Enuresis Group)

This study is being carried out at the The Enuresis Clinic, Hawkes Road in Kingston Community NHS Trust. We are interested in exploring how children think about their bed wetting. More specifically, we are interested in exploring the extent to which children believe they themselves are able to take some control in improving their bed wetting. Gathering this valuable information will help us to gain a better understanding of children's bed wetting and help improve our current approaches to treatment with children.

In addition, we wish to explore how much children who wet the bed think success and failure in certain areas of life (such as at school, in physical activities and social relationships) is influenced by their own qualities or actions. Finally we would like to explore how the children feel about themselves in different areas of their life. For example, whether or not they feel they do well at school work, or at various sports activities, and about themselves generally.

If you give your consent, I will explain the study to your son/daughter in language he/she is able to understand and ask if he/she would be interested in being part of the study. I would explain to him/her that I would like to ask a few questions about his/her bed wetting and also give him/her two questionnaires to fill in. I will of course show these questions to you before your son/daughter sees them. In fact, most children find the questionnaires interesting to complete.

All of the responses from the questionnaires will remain confidential and scores included in reports about the study will become anonymous. Taking part in the study does not affect your son/daughter's assessment or treatment by the Enuresis Team in any way.

I hope this information gives you a flavour of our study. I will be able to clarify any details within this information sheet with you at a later date by telephone or face to face.

I look forward to speaking to you soon.

Zena Dowling, Psychologist in Clinical Training.
Appendix 7

Information sheet for parents (Paediatric Group)

This study is being carried out at the Children's Department at Kingston Hospital. We are interested in exploring how children think about their stomach or head aches. More specifically, we are interested in exploring the extent to which children believe they themselves are able to take some control in improving their symptoms. Gathering this valuable information will help us to gain a better understanding of children's symptoms and help improve our current approaches to treatment with children.

In addition, we wish to explore how much children with symptoms think success and failure in certain areas of life (such as at school, in physical activities and social relationships) is influenced by their own qualities or actions. Finally we would like to explore how children with symptoms feel about themselves in different areas of their life. For example, whether or not they feel they do well at school work, or at various sports activities, and about themselves generally.

If you give your consent, I will explain the study to your son/daughter in language he/she is able to understand and ask if he/she would be interested in being part of the study. I would explain to him/her that I would like to ask a few questions about his/her stomach or head aches and also give him/her two questionnaires to fill in. I will of course show these questions to you before your son/daughter sees them. In fact, most children find the questionnaires enjoyable to complete.

All of the responses from the questionnaires will remain confidential and scores included in reports about the study will become anonymous. Taking part in the study does not affect your son/daughter's assessment or treatment by his/her paediatrician in any way.

I hope this information gives you a flavour of our study. I will be able to clarify any details within this information sheet with you at a later date by telephone or face to face.

I look forward to speaking to you soon.

Zena Dowling
Psychologist in Clinical Training.
Appendix 8
KINGSTON AND RICHMOND HEALTH AUTHORITY

CONSENT FORM FOR PARTICIPANT IN RESEARCH PROJECTS AND CLINICAL TRIALS

PARENT FORM

Organisation
Research as part of requirements of Psych D Clin. Course at Surrey University, Guilford

Title of Project
Perception of control, self perception and global self-worth in children with Primary Nocturnal Enuresis

Investigator: Zena Dowling, Psychologist in Clinical Training, Surrey University

Supervisor: Linda Dowdney, Course Director/ Senior Lecturer, Surrey University

Outline Explanation (For Enuresis/ Paediatric Group)

It is hoped the findings of this study will give a fuller understanding of children's beliefs in order to aid the assessment and treatment of bedwetting or health problems.

The study aims to explore children's beliefs about who or what will help improve their problem (bed wetting or other), and about who or what controls success and failure in other aspects of their life. It also aims to explore how children feel about themselves in various areas of their life. The study will involve meeting and talking with your child in order to ask a few questions to begin with. Then I will give him/her two questionnaires to fill out. These have been specifically designed for children of his/her age.

The information your child gives will be strictly confidential and his/her scores will become anonymous when added to others and written up within a report. However if you and your child wish, the information can be passed on to the clinic he/she will be attending as extra information in the assessment of his or her enuresis/health problem.

I (name) 

I (name) of (address)

______________________________

hereby consent that my child ____________ may take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw my child from the investigation at any stage without giving a reason for doing so and that this will in no way affect the care my child will receive as a patient.

SIGNED

(Parent) ___________________________ Date __________________

(Researcher) ______________________ Date __________________

(Witness) _________________________ Date __________________
Appendix 9
KINGSTON AND RICHMOND HEALTH AUTHORITY

CONSENT FORM FOR PARTICIPANT IN RESEARCH PROJECTS AND CLINICAL TRIALS

PARENT FORM

Organisation
Research as part of requirements of Psych.D Clin. Course at Surrey University, Guilford

Title of Project
Perception of control, self perception and global self-worth in children with Primary Nocturnal Enuresis

Investigator: Zena Dowling, Psychologist in Clinical Training, Surrey University
Supervisor: Linda Dowdney, Course Director/ Senior Lecturer, Surrey University

Outline Explanation (Sibling group)

It is hoped the findings of this study will give a fuller understanding of children's beliefs in order to aid the assessment and treatment of bedwetting or health problems.

The study aims to explore children's beliefs about who or what will help improve their problem (bed wetting or other), and about who or what controls success and failure in other aspects of their life. It also aims to explore how children feel about themselves in various areas of their life.

In order to make sense of the information gathered in the study it is necessary to compare the answers gained, to those given by children who do not have a particular problem needing specialist treatment. A useful way to do this is to gather information from siblings. This will involve administering the same two questionnaires designed for children, but with no verbal questions about any particular problem.

The information your child gives will be strictly confidential and his/her scores will become anonymous when added to others and written up within a report.

I (name) ____________________________
of (address) ________________________________

hereby consent that my child _____________ may take part in the above investigation, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw my child from the investigation at any stage without giving a reason for doing so and that this will in no way affect the care my child will receive as a patient.

SIGNED (Parent) ____________________________ Date ____________
(Researcher) ____________________________ Date ____________
(Witness) ____________________________ Date ____________

180
CONSENT FORM FOR PARTICIPANT IN RESEARCH PROJECTS AND CLINICAL TRIALS

CHILD FORM (PAED/ENURESIS GROUP)

Organisation
Research as part of requirements of Psych.D Clin. Course at Surrey University, Guilford

Title of Project
Perception of control, self perception and global self-worth in children with Primary Enuresis

Investigator: Zena Dowling, Psychologist in Clinical Training, Surrey University
Supervisor: Linda Dowdney, Course Director/ Senior Lecturer, Surrey University

About the survey (Actual size print was 14 point font)

My name is Zena and I am doing a survey to see how children think their problems like bed wetting, stomach or head aches will get better. I am also interested in finding out why children think they do well or not so well at different things. For example some children think they get good marks at school because of their teacher, and others think it is because they are clever. I would also like to find out how children feel about themselves.

I will spend a short time with you and ask you a few questions about your bed wetting/stomach/ headaches. Then I have some special questions written down on paper which I would like you to answer. It is not a test so there are no right or wrong answers. You can ask me any questions you like if you do not understand. Also, if you want to stop or take a break, that's fine.

I will be asking lots of children these questions but what you think is really important. You can tell anyone you like about your answers but I will not show people what you have written. If you want, I can show the doctor your answers because it might help him to understand you better. But I will only do this if you say I can.

Your answers might help doctors to understand children better. Then they will know even more about helping children with their problems.

My name is: ________________________________________________
I live at: ______________________________________________________

I am happy for Zena to ask me some questions. Zena has explained what the survey is about and I understand it. I know I can stop or take a break if I want to.

Signature: (Child) __________________________ Date __________
(Parent) __________________________________________ Date __________
(Researcher) __________________________ Date __________

181
CONSENT FORM FOR PARTICIPANT IN RESEARCH PROJECTS AND CLINICAL TRIALS

CHILD FORM (SIBLING GROUP)

Organisation
Research as part of requirements of Psych D Clin. Course at Surrey University, Guilford

Title of Project
Perception of control, self perception and global self-worth in children with Primary Nocturnal Enuresis

Investigator: Zena Dowling, Psychologist in Clinical Training, Surrey University
Supervisor: Linda Dowdney, Course Director/ Senior Lecturer, Surrey University

About the survey (Actual size print was 14 pont font)

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Your answers might help doctors to understand children better. Then they will know even more about helping children with their problems.

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I live at: _________________________________________________________

I am happy for Zena to ask me some questions. Zena has explained what the survey is about and I understand it. I know I can stop or take a break if I want to.

Signature: (Child) _________________________ Date _____
( Parent) _______________________________ Date _____
(Researcher) __________________________ Date _____

182
Appendix 12

Rapport gaining questions (For all three groups of children)

1. Can you tell me how old you are?
2. When is your birthday?
3. Do you have any brothers or sisters?
4. How old are they?
5. Where do you go to school?
6. What's your favourite subject at school?
7. What's your favourite television program?
Appendix 13

GP Letter

Address

Date

Re:- (child's name and D.O.B, and why referred to clinic)

My name is Zena Dowling and I am a Psychologist in Clinical Training at Surrey University.

I am currently carrying out a study within the Paediatric Out-Patient/ Enuresis Clinic which aims to investigate children's perception of control with regard to their identified problem, and also more generally in their lives. The primary objective is to explore the perceptions of children with Primary Nocturnal Enuresis and compare them to children referred for stomach/head aches and healthy children. Areas of their self esteem will also be explored. It is hoped that the findings will guide assessment and intervention procedures. The study has received ethical approval and has been approved by the Clinical Management Group at Kingston Hospital.

I have explained the aims and objectives of the study to Mr and Mrs X and they have agreed for _________ to take part in the study. I have also explained the study in language meaningful to _________ and obtained his/her informed consent. In order to take part in the study the participant simply completes two questionnaires designed specifically for children of _________'s age and answers some questions about their enuresis/ stomach/ head ache.

All names and answers will be held in strictest confidence unless _________ and his/her parents have agreed that useful information gathered form the questionnaires may be passed on the Enuresis/Paediatric Clinic. Scores will remain anonymous in the report which will be written as a result of the study.

If you have any queries about the study I would be happy to discuss them with you.

Yours sincerely

Zena Dowling
Psychologist in Clinical Training
Appendix 14

Semi-structured interview

Group: Enuresis

"Do you mind if I ask you some questions about your bedwetting? Remember, there are no right or wrong answers. Just tell me what is true for you. We can stop or take a break when you want. Just let me know."

1. Could you tell me a bit about your bed wetting? 
   Prompts: - Do you have a special sheet to keep the mattress dry?

2. On nights that you wet the bed, do you ever wake up?
   Card choices =
   Yes    No    Sometimes

   If answers yes or sometimes, ask question 3
   If answers no, ask question 4

3. If you do wake up, what happens next?

   Prompts to elicit whether the child takes control of the consequences of bed wetting or not: - Do you get out of bed?
       Do you change your pyjamas?
       Do you change your bed sheets?
       Does someone else change your bed sheets?
       Do you turn over and go to sleep?
       Do you call for someone else to help you?

4. What sort of things make you more likely to wet the bed on some nights than on others?

   Card choices =
   Things that other people around me say or do
   Things that I do for myself
   There are things but I am not sure what they are
   I don't know

   N.B. For all choices, ask child to provide examples

185
5. You’ve told me a bit about the times that you wet the bed, how about those nights when you don’t wet the bed? Can you tell me about any times when you manage to stay dry at night?
prompts:- Are you able to stay dry some nights?

6. Who would be best at helping you to become dry at night?
(Children will have a choice of answers written on cards laid out before them. One of the cards will be blank so that they may fill it in (for example 'My sister'). They will choose the card with their choice of answer and place it in a box before them).

Choices =
A) My Parents   B) The doctor   C) Blank   D) Me   E) Not sure

If child answers D ask only question 7.
If child answers A, B, C, or E ask only question 8.

7. How could you help yourself to become dry at nights?
prompts:- Tell me about something you do to help yourself.
            What do you do?

8. Do you think you can help yourself to become dry at night?
Card choices =
Yes
No
If yes prompt 'How?', 'What would you do?'
Appendix 15

Semi-structured Interview

Group: Paediatric

"Do you mind if I ask you some questions about your head/stomach aches? Remember, there are no right or wrong answers. Just tell me what is true for you. We can stop or take a break when you want. Just let me know."

1. Could you tell me a bit about your head/stomach aches?
   prompts: - What do they feel like?

2. When you feel a stomach/headache coming on, what do you do next?
   Prompts to elicit whether the child takes control of the situation or not:
     - Do you ask someone for a tablet?
     - Do you lie down to take a rest?
     - Do you try to relax yourself?
     - Do you wait for your mum/dad to notice you are not well?
     - Do you wait for it to just go away all by itself?

3. What sort of things make you more likely to get a stomach/headache on some days?

   Card choices =
   
   Things that other people around me say or do
   
   Things that I do for myself
   
   There are things but I am not sure what they are
   
   I don't know

   N.B. For all choices ask child to provide examples.

4. You've told me a bit about the times when you do get stomach/headaches. How about those times when you don't get them? Can you tell me about any times when you do not have a stomach/headache?
   prompts: - Are there some times when you don't have a head/stomach ache?

5. Who would be best at helping you to get rid of your head/stomach aches?
   (Children will have a choice of answers written on cards laid out before them. One of the cards will be blank so that they may fill it in (for example 'My sister'). They will choose the card with their choice of answer and place it in a box before them).

   Choices =
A) My Parents    B) The doctor    C) Blank    D) Me    E) Not sure

If child answers D ask only question 6.
If child answers A, B, C or E ask only question 7.

6. How could you help yourself to get rid of your stomach/ head aches?
   prompts:- Tell me about something you do to help yourself.
             What do you do?

7. Do you think you can help yourself to get rid of your stomach/ head aches?

   Card choices =

   Yes       No
   If yes prompt 'How?'
Appendix 16

Multi-dimensional measure of children's perception of control

**What I think about things**

Example:-

I can be good at any subject at school If I try hard enough.

Not at all true Not very true Sort of true Very true

Circle the answer which is most like you

1. When I win at sport, a lot of times I can't work out why I won.
Not at all true Not very true Sort of true Very true

2. When I am unsuccessful, it is usually my own fault.
Not at all true Not very true Sort of true Very true

3. The best way for me to get good marks is to get the teacher to like me.
Not at all true Not very true Sort of true Very true

4. If somebody doesn't like me, I usually can't work out why.
Not at all true Not very true Sort of true Very true

5. I can be good at any sport if I try hard enough.
Not at all true Not very true Sort of true Very true

6. If an adult doesn't want me to do something I want to do, I probably won't be able to do it.
Not at all true Not very true Sort of true Very true

7. When I do well in school, I usually can't work out why.
Not at all true Not very true Sort of true Very true

8. If somebody doesn't like me, it's usually because of something I did.
Not at all true Not very true Sort of true Very true
9. When I win at sport, it's usually because the person I was playing against played badly.
   Not at all true  Not very true  Sort of true  Very true

10. When something goes wrong for me, I usually can't work out why it happened.
    Not at all true  Not very true  Sort of true  Very true

11. If I want to do well in school, it's up to me to do it.
    Not at all true  Not very true  Sort of true  Very true

12. If my teacher doesn't like me, I probably won't be very popular with the kids in my class.
    Not at all true  Not very true  Sort of true  Very true

13. Many times I can't work out why good things happen to me.
    Not at all true  Not very true  Sort of true  Very true

14. If I don't do well in school, it's my own fault.
    Not at all true  Not very true  Sort of true  Very true

15. If I want to be an important member of my class, I have to get the popular kids to like me.
    Not at all true  Not very true  Sort of true  Very true

16. Most of the time when I lose a game in athletics, I can't work out why I lost.
    Not at all true  Not very true  Sort of true  Very true

17. I can pretty much control what will happen in my life.
    Not at all true  Not very true  Sort of true  Very true

18. If I have a bad teacher I won't do well in school.
    Not at all true  Not very true  Sort of true  Very true

19. A lot of times I don't know why people like me.
    Not at all true  Not very true  Sort of true  Very true

20. If I try to catch a ball and I don't, it's usually because I didn't try hard enough.
    Not at all true  Not very true  Sort of true  Very true
21. If there is something that I want to get, I usually have to please the people in charge to get it.
   Not at all true  Not very true  Sort of true  Very true

22. If I get a bad mark in school, I usually don't understand why I got it.
   Not at all true  Not very true  Sort of true  Very true

23. If somebody likes me, it is usually because of the way I treat them.
   Not at all true  Not very true  Sort of true  Very true

24. When I lose at an outdoor game, it is usually because the kid I played against was much better at that game to begin with.
   Not at all true  Not very true  Sort of true  Very true

25. When I win at an outdoor game, a lot of times I don't know why I won.
   Not at all true  Not very true  Sort of true  Very true

26. When I don't do well at something, it is usually my own fault.
   Not at all true  Not very true  Sort of true  Very true

27. When I do well in school, it's because the teacher likes me.
   Not at all true  Not very true  Sort of true  Very true

28. When another kid doesn't like me, I usually don't know why.
   Not at all true  Not very true  Sort of true  Very true

29. I can be good at any sport if I work on it hard enough.
   Not at all true  Not very true  Sort of true  Very true

30. I don't have much chance of doing what I want if adults don't want me to do it.
   Not at all true  Not very true  Sort of true  Very true

31. When I get a good grade in school I usually don't know why I did so well.
   Not at all true  Not very true  Sort of true  Very true
32. If someone is mean to me, it's usually because of something I did.
Not at all true  Not very true  Sort of true  Very true

33. When I play an outdoor game against another kid, and I win, it's probably because the other kid didn't play well.
Not at all true  Not very true  Sort of true  Very true

34. A lot of times I don't know why something goes wrong for me.
Not at all true  Not very true  Sort of true  Very true

35. If I want to get good marks in school, it's up to me to do it.
Not at all true  Not very true  Sort of true  Very true

36. If the teacher doesn't like me, I probably won't have many friends in that class.
Not at all true  Not very true  Sort of true  Very true

37. When good things happen to me, many times there doesn't seem to be any reason why.
Not at all true  Not very true  Sort of true  Very true

38. If I get bad marks, it's my own fault.
Not at all true  Not very true  Sort of true  Very true

39. If I want the kids in my class to think that I am an important person, I have to be friends with the really popular kids.
Not at all true  Not very true  Sort of true  Very true

40. When I don't win at an outdoor game, most of the time I can't work out why.
Not at all true  Not very true  Sort of true  Very true

41. I can pretty much decide what will happen in my life.
Not at all true  Not very true  Sort of true  Very true

42. If I don't have a good teacher, I won't do well in school.
Not at all true  Not very true  Sort of true  Very true

43. A lot of times there doesn't seem to be any reason why somebody likes me.
Not at all true  Not very true  Sort of true  Very true

192
44. If I try to catch a ball and I miss it, it's usually because I didn't try hard enough.
Not at all true Not very true Sort of true Very true

45. To get what I want, I have to please the people in charge.
Not at all true Not very true Sort of true Very true

46. When I don't do well in school, I usually can't work out why.
Not at all true Not very true Sort of true Very true

47. If somebody is my friend, it is usually because of the way that I treat him/her.
Not at all true Not very true Sort of true Very true

48. When I don't win at an outdoor game, the person I was playing against was probably a lot better than I was.
Not at all true Not very true Sort of true Very true

The End

Thank you very much for your help
Appendix 17
Self Perception Profile for Children –
What I am like

<table>
<thead>
<tr>
<th>WHAT I AM LIKE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Name ______________________</td>
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<tr>
<td>Class ______________________</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids would rather play outdoors in their spare time</td>
<td>BUT Other kids would rather watch TV.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids feel that they are very good at their school work</td>
<td>BUT Other kids worry about whether they can do the school work set for them.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids find it hard to make friends</td>
<td>BUT Other kids find it's pretty easy to make friends.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids do very well at all kinds of sports</td>
<td>BUT Other kids don't feel that they are very good when it comes to sports.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
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<tbody>
<tr>
<td>□ □</td>
<td>Some kids are happy with the way they look</td>
<td>BUT Other kids are not happy with the way they look.</td>
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<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids often do not like the way they behave</td>
<td>BUT Other kids usually like the way they behave.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids are often unhappy with themselves</td>
<td>BUT Other kids are pretty pleased with themselves.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids feel like they are just as clever as other kids their age</td>
<td>BUT Other kids aren't so sure and wonder if they are as clever.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>□ □</td>
<td>Some kids have a lot of friends</td>
<td>BUT Other kids don't have very many friends.</td>
</tr>
<tr>
<td></td>
<td>Really True</td>
<td>Sort of True</td>
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<td>9</td>
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<tr>
<td>19</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

- Some kids wish they could be a lot better at sports.
- Other kids feel they are good enough at sports.
- Some kids are happy with their height and weight.
- Other kids wish their height and weight were different.
- Some kids usually do the right thing.
- Other kids often don't do the right thing.
- Some kids don't like the way they are leading their life.
- Other kids do like the way they are leading their life.
- Some kids are pretty slow in finishing their school work.
- Other kids can do their school work quickly.
- Some kids would like to have a lot more friends.
- Other kids have as many friends as they want.
- Some kids think they could do well at just about any new sports activity they haven't tried before.
- Other kids are afraid they might not do well at sports they haven't every tried.
- Some kids wish their body was different.
- Other kids like their body the way it is.
- Some kids usually act the way they know they are supposed to.
- Other kids often don't act the way they are supposed to.
- Some kids are happy with themselves as a person.
- Other kids are often not happy with themselves.
- Some kids often forget what they learn.
- Other kids can remember things easily.
<table>
<thead>
<tr>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
<th>Really True For Me</th>
<th>Sort of True For Me</th>
</tr>
</thead>
<tbody>
<tr>
<td>20</td>
<td>Some kids are always doing things with a lot of kids</td>
<td>BUT Other kids usually do things by themselves.</td>
<td></td>
</tr>
<tr>
<td>21</td>
<td>Some kids feel that they are better than others their age at sports</td>
<td>BUT Other kids don't feel they can play as well.</td>
<td></td>
</tr>
<tr>
<td>22</td>
<td>Some kids wish their physical appearance (how they look) was different</td>
<td>BUT Other kids like their physical appearance the way it is.</td>
<td></td>
</tr>
<tr>
<td>23</td>
<td>Some kids usually get in trouble because of things they do</td>
<td>BUT Other kids usually don't do things that get them in trouble.</td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Some kids like the kind of person they are</td>
<td>BUT Other kids often wish they were someone else.</td>
<td></td>
</tr>
<tr>
<td>25</td>
<td>Some kids do very well at their classwork</td>
<td>BUT Other kids don't do very well at their classwork.</td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Some kids wish that more people their age liked them</td>
<td>BUT Other kids feel that most people their age do like them.</td>
<td></td>
</tr>
<tr>
<td>27</td>
<td>In games and sports some kids usually watch instead of play</td>
<td>BUT Other kids usually play rather than just watch.</td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Some kids wish something about their face or hair looked different</td>
<td>BUT Other kids like their face and hair the way they are.</td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Some kids do things they know they shouldn't do</td>
<td>BUT Other kids hardly ever do things they know they shouldn't do.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Really True For Me</td>
<td>Sort of True For Me</td>
<td>Really True For Me</td>
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<td>30</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids are very happy being the way they are</td>
<td>Other kids wish they were <strong>different</strong>.</td>
<td></td>
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<td>31</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids have <strong>trouble</strong> working out the answers in school</td>
<td>Other kids almost <strong>always</strong> can work out the answers.</td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids are <strong>popular</strong> with others their age</td>
<td>Other kids are <strong>not</strong> very popular.</td>
<td></td>
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<tr>
<td>33</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids <strong>don't do</strong> well at new outdoor games</td>
<td>Other kids are <strong>good</strong> at new games <strong>straight away</strong>.</td>
<td></td>
</tr>
<tr>
<td>34</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids think that they are <strong>good looking</strong></td>
<td>Other kids think that they are <strong>not very good looking</strong>.</td>
<td></td>
</tr>
<tr>
<td>35</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids behave themselves <strong>very well</strong></td>
<td>Other kids often find it <strong>hard</strong> to behave themselves.</td>
<td></td>
</tr>
<tr>
<td>36</td>
<td>□</td>
<td>□</td>
<td>BUT</td>
</tr>
<tr>
<td></td>
<td>Some kids are <strong>not very happy</strong> with the way they do a lot of things</td>
<td>Other kids think the way they do things is <strong>fine</strong>.</td>
<td></td>
</tr>
</tbody>
</table>
Appendix 18

Cohen’s Kappa Calculations

Tabulation table for categorisation of responses for Table 1.

<table>
<thead>
<tr>
<th></th>
<th>Enur.1</th>
<th>Enur.2</th>
<th>Enur.3</th>
<th>Enur.4</th>
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<th>Paed.2</th>
<th>Paed.3</th>
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<td></td>
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<td>4</td>
</tr>
</tbody>
</table>

\[ k = \frac{nD - \sum t_i u_i}{n^2 - \sum t_i u_i} \]

1= Things that I do for myself  
2= Things that other people around me say or do  
3= There are things but I'm not sure what they are  
4= Don't know  

= 528-98  
576-98  

= 430  
478  

k= 0.89
# Tabulation table for categorisation of responses for table 2.

<table>
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<tr>
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<th>Enur 2</th>
<th>Enur 3</th>
<th>Enur 4</th>
<th>Enur 5</th>
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<th>Paed 2</th>
<th>Paed 3</th>
<th>Paed 4</th>
<th>Paed 5</th>
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<tr>
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</tr>
</tbody>
</table>

\[ k = \frac{nD - \sum_{i=1}^{u} t_{i}}{n^2 - \sum_{i=1}^{u} t_{i}} \]

1 = The self
2 = Doctor/parents
3 = Joint effort between self and doctor/parents
4 = Unknown control
5 = No one can

= 528-124
576-124
= 404
452

\[ k = 0.89 \]
Tabulation table for categorisation of responses for table 3.

<table>
<thead>
<tr>
<th>Enuresis 1</th>
<th>Enuresis 2</th>
<th>Enuresis 3</th>
<th>Enuresis 4</th>
</tr>
</thead>
<tbody>
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<td></td>
</tr>
<tr>
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</tr>
<tr>
<td>Enuresis 3</td>
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<td></td>
<td>3</td>
</tr>
<tr>
<td>Enuresis 4</td>
<td></td>
<td></td>
<td>3</td>
</tr>
</tbody>
</table>

\[ k = \frac{nD - \sum t_1 u_1}{n^2 - \sum t_1 u_1} \]

= \frac{225-59}{225-59} = \frac{166}{166} = 1

Tabulation table for categorisation of responses for table 4.

<table>
<thead>
<tr>
<th>Paed. 1</th>
<th>Paed. 2</th>
<th>Paed. 3</th>
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</table>

\[ k = \frac{nD - \sum t_1 u_1}{n^2 - \sum t_1 u_1} \]

= \frac{182-39}{196-39} = \frac{143}{157} = 0.91
Tabulation table for categorisation of responses for table 5.

<table>
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<th>En. 3</th>
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<td>9</td>
</tr>
</tbody>
</table>

\[ k = \frac{nD - \Sigma t \Sigma u}{n^2 - \Sigma t \Sigma u} \]

1 = Child takes responsibility  
2 = Parent takes responsibility  
3 = Parent and child take joint responsibility

\[ = 360-113 \]
\[ = 400-113 \]

\[ = 247 \]
\[ = 287 \]

\[ k = 0.86 \]

Therefore mean Kappa = \[ 0.89 + 0.89 + 1 + 0.91 + 0.86 \]

\[ = k = 0.91 \]
Dear Zena,

Thank you for the copy of your Research Project: Perception of control, self perceptions and global self-worth in children with Primary Nocturnal Enuresis, which I received today.

I have only had a brief glance at it but it looks very interesting and am looking forward to reading it more fully.

Thank you for all your excellent liaison, am only sorry the sample was not larger. It seems strange, but it appears from our audit numbers that we have been more children in the last 6 months than we have for the previous year!! I can't say they all have PNE though!

Kind regards

Pat Purchard
Appendix 20
Acknowledgement of feedback letter
from St. Helier NHS Trust

Dear Ms Dowling

Research project: Perception of control, self perceptions and global selfworth in children with Primary Nocturnal Enuresis

I was very pleased to receive a copy of your Research Project completed on the above topic. I shall indeed make it available to other Consultants within the department.

I hope that this letter provides the appropriate evidence for your course requirements.

With kind regards.

Yours sincerely

[Signature]

Dr Christine P Burren, MBBS, MD, FRACP
Consultant Paediatrician and Endocrinologist

c.c. CHS
Appendix 21
Acknowledgement of feedback letter from
Royal Surrey County Hospital

Paediatric Department - Children's Unit

Our ref. MRR/ajm

23rd July 1999

Ms Zena Dowling
Psychologist in Clinical Training
32 D Copenhagen Gardens
Chiswick
LONDON W4 5NN

Dear Zena

Re: Research project: Perception of control, self perceptions and global self worth in children with Primary Nocturnal Enuresis

I write to acknowledge receipt of your project. Have you sent a copy to the Research Ethics Committee at Royal Surrey?

With best wishes.

Yours sincerely,

[Signature]

Dr M R Ryan
Consultant Paediatrician
Expressed Emotion, attributions and knowledge in carers of people with dementia

(Large scale research project)

August 1999
Year 3
Abstract

Background:
Numerous studies have explored the concept of Expressed Emotion among carers of people with schizophrenia. More recently, Expressed Emotion has been explored among carers of people with other conditions including dementia, but with little investigation into the factors which might help explain varying levels of Expressed Emotion in such carers. This study investigated factors which have been found to be associated with Expressed Emotion in carers or relatives of people with schizophrenia; carers’ attributions about cause and control of care-recipients’ behavioural disturbance and carers’ knowledge about the disorder.

Aims:
The aims of this study were to explore the relationships between carer levels of Expressed Emotion and the attributions they made about the cause of their care-recipients’ behaviour and mood disturbance, as well as the degree of control they perceived their care-recipient to have over these behaviours. Additionally, the relationships between carer knowledge and Expressed Emotion, and knowledge and carer attributions were explored. Finally, relationships between Expressed Emotion and other variables such as carer minor psychiatric morbidity, perceptions of the pre-morbid relationship with their care-recipient, and care-recipient levels of behaviour and mood disturbance were investigated.

Method:
Forty three informal carers (relatives) of people with dementia participated in this study. Data were collected with the use of self-report questionnaires.

Results:
Carers tended to perceive their care-recipients as not being able to control their behaviour and mood disturbance, and generally viewed it as caused by their dementia illness. At a more specific level, significant results included the following; 1. Carers perceived their care-recipients’ apathetic-withdrawn behaviour to be under their care-recipients’ control to a higher degree than other behaviour and mood disturbance.
2. Carers with higher levels of Expressed Emotion tended to attribute lower proportions of their care-recipients' behaviour and mood disturbance to illness and higher proportions to a mixture of both illness and personality than carers with lower levels of Expressed Emotion. 3. Carers who attributed behaviour and mood disturbance to the personality of their care-recipient or to a mixture of both illness and personality tended to perceive them to have more control over their illness, whereas carers who attributed behaviour and mood disturbance to their care-recipients' illness only, tended to perceive them to have less control over their behaviour. 4. Carers with more knowledge about dementia tended to attribute lower proportions of their care-recipients' apathetic-withdrawn behaviour to personality than carers with less knowledge. 5. Carers who reported higher levels of Expressed Emotion also tended to report that their care-recipient exhibited more mood disturbance than carers with lower levels of Expressed Emotion. 6. Carers who perceived the pre-morbid relationship with their care-recipient to be of a better quality also tended to report lower levels of Expressed Emotion, perceive their care-recipients to have less control over their behaviour and mood disturbance, and to attribute the disturbance to their care-recipients' illness more than carers who perceived a poorer pre-morbid relationship.

Significant results with regard to causal attributions for active-disturbed behaviour were not in the expected direction, and are discussed.

Conclusions:
It was concluded that an attributional model has a limited ability to help in the understanding of Expressed Emotion in this sample of carers (particularly with regards to perceptions of controllability), and that knowledge did not seem to be a pertinent factor in explaining Expressed Emotion. Difficulties experienced in the measurement of elicited attributions are discussed, and the importance of looking at care-recipients' mood disturbance and the pre-morbid relationship between carer and care-recipient is highlighted. Suggestions for future research incorporate further investigation of the above points.
Guide to the introduction

Within the general introduction the reader will be introduced to the general background of people with dementia and their carers. The concept of Expressed Emotion will then be introduced, firstly with a discussion of its origin in studies of families of people with schizophrenia, and then with an acknowledgement of its relevance for relatives of people with other conditions. The Expressed Emotion concept and its relationship with behavioural interactions will be explored, and a discussion of the need to view Expressed Emotion as a reciprocal dynamic between carer and care-recipient will follow. Methods of measuring Expressed Emotion will then be compared, and a summary of psycho-education aimed to reduce levels of Expressed Emotion in relatives will be given. Finally, before studies of Expressed Emotion are reviewed, its theoretical basis will be briefly critiqued.

Nine published studies investigating Expressed Emotion in carers of people with dementia will be discussed in detail. This will lead onto a summary of the findings, and a discussion of criticisms in relation to the studies. A discussion of an attributional model to account for the mechanisms of Expressed Emotion will follow, leading to a review of studies offering empirical evidence for the model in the area of schizophrenia. A summary of these findings will then be given. Finally, the utility of the attributional model in exploring Expressed Emotion in carers of people with dementia will be considered, leading to a presentation of the current study’s objectives.
Introduction

General introduction

It is estimated that approximately 5% of people over the age of 65 and 15% of people over the age of 80 suffer from some form of dementia (Terry & Katzman, 1983). Although the clinical presentation of different types of dementia vary slightly, the usual fate of a dementia sufferer is progressive global deterioration of cognitive functions, until all care needs are met by another person. In addition, the sufferer can experience psychotic symptoms (hallucinations and delusions), depressive symptoms, and behavioural disturbances (aggressiveness or wandering) (Martinson, Muswascues, Gillis, Doyle & Zimmerman, 1995). Due to the current emphasis on community care, the task of looking after a person with dementia usually resides with a close relative (spouse or grown-up child) until the demands become unmanageable. More recently, researchers in the field of dementia have become interested in investigating the importance of carers’ emotional attitudes toward their care-recipients within the community, specifically the relationship between negative attitudes, and different aspects of carer and care-recipient well being. These emotional attitudes have been explored within the framework of the Expressed Emotion concept (Brown, Birley & Wing, 1972).

Expressed Emotion

Expressed Emotion (EE) is an empirically validated concept thought to reflect the emotional attitudes of a close relative toward a family member who is ill (Weisman, Lopez, Karno & Jenkins (1993). It measures criticism, hostility and emotional over-involvement (EOI) in the family member. EOI includes exaggerated affect and overly self-sacrificing behaviour (Vaughn & Leff, 1976a). The concept is described as a “research tool”, measuring the “blood pressure” of family life, representing the emotional attitudes which may be contributing to a poor outcome (namely relapse of illness symptoms) in the family member who is unwell (Kuipers, 1994).
Expressed Emotion in relatives of people with schizophrenia

EE originated from research with males who had been diagnosed with schizophrenia (Brown, Carstairs & Topping, 1958). It appeared that patients’ prognoses were related to the emotional atmosphere within the families to which they were returning to live after discharge from hospital. A family with a high level of EE (High-EE) would be particularly critical and hostile about their care-recipient, holding a blaming attitude toward him/her. In such families the care-recipient’s deterioration was more apparent. In contrast, a family with a low level of EE (Low-EE) who did not express such criticism and hostility, would be more accepting, and their care-recipient was likely to experience less deterioration.

This logical relationship between patient prognosis and family atmosphere led to a large number of studies on the relationship between EE, and symptom relapse in people with schizophrenia. A review of 25 such studies (n=1346) confirmed that High-EE in a relative (n=705) was associated with a higher risk of relapse (50%), and Low-EE (n=641) was associated with a lower relapse rate (21%) (Bebbington & Kuipers, 1994). Along with further outcome studies in Spain, Denmark, Czechoslovakia and Japan, the strength of EE as a predictor in relapse for schizophrenia has been confirmed, and the multi-cultural sensitivity of the concept as a measure has become evident (Bechgaard, 1991; Bertando, Beltz, Bressi, Clerici, Farma, Invernizzi & Gazullo, 1992; Mino, Tanaka, Tsudo, Babazono, Kiok, Shigemi, Ogawa, Inoue & Aoyama, 1994; Mozny, Votypka, 1992; Pumar, Espina, Yerbe, Santos, Garcia & Bel, 1991; cited in Kuipers, 1994).

Expressed Emotion in relatives of people with other conditions

Researchers have increasingly speculated that EE may be a generalised risk factor for poor outcome or relapse in other mental or physical conditions. This speculation has resulted in studies of the relationship between EE and a variety of other conditions including; anorexia (Asarnow, Tompson, Hamilton & Goldstein, 1994; Le Grange, Eisler, Dare & Hodes, 1992), depression (Florin, Nostadt, Reck & Franzen, 1992; Hooley & Teasdale, 1989), manic depression (Priebe, Wildgrube & Muller-
Oerlinghausen, 1989), brain injury (Flanagan, 1998), diabetes (Koenisberg, Klausner, Pelino, Rosnick & Campbell, 1993; Sensky, Stevenson, Magrill & Petty, 1991), obesity (Flanagan & Wagner, 1991) and dementia (e.g. Vitaliano, Young, Russo, Romano & Magana-Amato, 1993) among others. In some of these studies, High-EE has been associated with poor outcome (e.g. Vitaliano et al., 1993) or poor prognosis for compliance with treatment (e.g. Flanagan & Wagner, 1991; Le Grange et al., 1992).

Expressed Emotion and its relationship with behavioural interactions

The underlying assumption of EE is that there is an association between the emotional attitudes expressed within assessment, and the verbal communication or behaviours of the relative toward the care-recipient on a day to day basis. This assumption has now been supported by a number of studies investigating families with a relative who has Schizophrenia. The studies revealed High-EE parents expressed significantly more criticism than Low-EE parents (Valone, Norton, Goldstein and Doane, 1983), High-EE parents used more intrusive and invasive statements (Miklowitz, Goldstein, Falloon & Doane, 1984), and High-EE relatives were poorer listeners and talked for longer than Low-EE relatives (Kuipers, Sturgeon, Berkowitz & Leff, 1983). In a study of EE in spouses where one suffered with depression, High-EE spouses were much more critical, disagreed more and were much less likely to accept what their spouse said to them than were Low-EE spouses (Hooley, 1984; cited in Hooley, 1985).

There do not appear to have been studies exploring the specific association between EE levels and the communication and behaviour of relatives of people with dementia. However, one study has compared relatives of people with dementia with relatives of three individual groups of younger and older psychiatric patients, and physically ill patients. The study found that the carers of people with dementia described themselves as significantly more dominant and protective, and less submissive toward their care-recipient than relatives of the other three groups of patients (Orford, O'Reilly & Goonatilleke, 1987). One might speculate that due to the progressively dependant and cognitively impaired position of the person with dementia, there is
potential for very high EE relatives to become abusive or neglectful in their caring role, in addition to being generally more critical in their verbal interactions with their care-recipient.

**Expressed Emotion and reciprocity**

Although it is valuable to discover that negative emotional attitudes are expressed behaviourally, these findings may lead to the assumption that relatives are solely responsible for the family atmosphere, and perhaps should be blamed for their influence on poor outcome in their family member who is ill. One study investigating transactional processes between relatives and family members with schizophrenia (n=36) revealed that EE gives rise to a transactional process between relative and patient. The study found that High-EE attitudes are associated with reciprocal levels of criticism by patient and relative, and Low-EE attitudes are associated with neutral, non critical behaviour in relatives and frequent autonomous statements by patients (Strachan, Feingold, Goldstein, Miklowitz & Nuechterlain, 1989). Orford et al. (1987) found that relatives of people with dementia in general, reported experiencing their care-recipients as ignoring them, being rebellious and not showing affection, more than relatives of people with other psychiatric or physical illness.

This evidence fits with Kavanagh’s assertion that one should take a family systems view of EE, whereby there are reciprocal influences between reactions and symptoms of the disturbed family member, and reactions such as frustration, distress and concern which affect the emotional atmosphere of the family or dyad (Kavanagh, 1992). With regards to a person with dementia, an inability to cope with stressful interactions with their carers (Silliman, Sternberg, & Fretwell, 1988) may lead to more aggressive or difficult to manage behaviour as a way of expressing distress, and this could lead in turn to an increase in negative attitudes in the carer.

**Measurement of Expressed Emotion**

Traditionally, EE has been measured using the brief version of the Camberwell Family Interview (CFI; Vaughn and Leff, 1976a). This is a semi-structured interview
lasting approximately 1.5 hours. The interviewer makes frequency ratings of remarks regarding criticism and positivity, and global ratings of hostility, warmth and emotional over-involvement. Vocal aspects such as speed, pitch and emphasis of delivery are also considered. Relatives rated as high in EE (High-EE) will have made six or more critical comments, or exhibited a moderate amount of either emotional over-involvement (EOI) or hostility (Kuipers, 1994). Thus Low EE is a 'negative' definition whereby an absence of significant criticism, hostility and EOI is noted. Most studies do not even discuss the presence or absence of warmth or positivity in their sample (Kuipers, 1994). Perhaps this is because a significant presence of criticism and hostility is simply assumed to reflect a lack of warmth and positivity, so the latter is not perceived as any more informative. A recent study using the CFI confirmed that criticism and positivity were strongly negatively correlated (Chambless, Bryan Aiken, Steketee & Hooley, 1999).

Due to the length of time and training required to administer the CFI, The Five Minute Speech Sample (FMSS), was developed and then adapted as a brief alternative measure (Magana, Goldstein, Karno, Milkowitz, Jenkins & Falloon, 1985). The relative is instructed to speak uninterrupted into an audio-tape for five minutes about their ill family member. Expressed attitudes and feelings are then rated on dimensions analogous to those of the CFI. Magana et al., (1985) demonstrated a reasonably high level of correspondence between the FMSS and the CFI among carers of people with schizophrenia (p<0.001 using a Chi Squared test). Both the CFI and the FMSS require specific training in order to reliably score relatives as High- or Low-EE. Additionally, relatives may find speaking in a monologue anxiety provoking.

An alternative measure is the Patient Rejection Scale (PRS; Kreisman, Simmons & Joy, 1979). The scale was developed from an eleven item questionnaire to twenty four items in 1980, and consists of both positively and negatively worded items reflecting feelings of love and acceptance, criticism, disappointment and rejection. It is considered an analogue of the critical comments and hostility factors of EE (Kreisman, Blumenthal, Borenstein, Woerner, Kane, Rifkin & Reardon, 1988). McCreadie and Robinson (1987) used the questionnaire with a group of carers of people with Schizophrenia (n=58) and compared it to the CFI. They found that the
PRS could statistically differentiate between groups of High- and Low-EE relatives as identified by the CFI, although they remarked upon the wide range of scores in the high EE category making it difficult to find a cut off point for individuals (mean score=68, standard deviation=27). Another study found a strong correspondence between traditionally rated EE levels and PRS scores, concluding that the high degree of correspondence between the two scales was sufficiently high for the two measures to be considered interchangeable (Snyder, Jenkins, Nuechterlein & Mintz, 1988; cited in Whittick, 1992).

Until very recently, items measuring emotional over-involvement (EOI) were not included in the PRS. However the absence of EOI items has not appeared to interfere with the identification of relatives with higher or lower EE (e.g. McCreadie & Robinson (1987). Indeed there has been longstanding controversy about how useful EOI as a dimension really is in identifying levels of EE. Whilst studies have largely confirmed the durability of critical comments and their relationship to relapse in families with a Schizophrenic member, EOI has shown a weaker relationship, perhaps being predictive of outcome only when tied with a classification of high EE on the basis of the necessary number of critical comments (Kreisman & Blumenthal, 1995). EOI has played a minor role in classifying carers of people with dementia when using the CFI or FMSS in studies involving such participants (e.g. Bledin, MacCarthy, Kuipers & Woods, 1990; Vitaliano et al., 1993; Wagner, Logsdon, Pearson & Teri, 1997) and has been viewed as inappropriate in its measurement because of the caring demands of a person with dementia (Orford et al., 1987).

It appears that the PRS without its additional items measuring EOI, is a useful research tool in the measurement of hostility and criticism, and that it seems to reflect higher and lower levels of the EE concept. Due to its non-threatening nature, it provides a good alternative measure to the CFI and FMSS.

Expressed Emotion and psycho-educational intervention

EE research has enabled identification of patients at risk of relapse or who are living in stressful environments. Inevitably this recognition has lead to psycho-educational
interventions emphasising specific strategies designed to reduce high levels of criticism, hostility or EOI within families with a schizophrenic member. In studies measuring the efficacy of psycho-educational intervention, four-fold decreases in relapse in the person with schizophrenia have been observed nine months after intervention, with relapse rates of less than 10% compared with 40-50% in control groups (Fadden, 1998). Conclusions drawn from reviews on psycho-educational intervention for families who live with a person with schizophrenia suggest that the approaches all share a number of common features which seem to underlie their effectiveness. These include:-

1. Establishing a collaborative working relationship with all family members, including the person with schizophrenia.
2. A positive non-blaming attitude on the part of the therapist.
3. Helping the family to find new ways of coping and solving problems.
4. Sharing information about the disorder (e.g. aetiology, prognosis and symptomology).
5. Emphasising communication in an attempt to help family members learn more constructive methods of interacting.
6. Encouraging both family and individual goals and interests.

(Fadden, 1998)

Expressed Emotion and its theoretical basis

Finally, EE has been criticised for being solely a measurement, which has not been derived from theory (Kuipers, 1994). Indeed there have been observations from researchers that an early pre-occupation with linking EE levels with relapse (which in itself is rather a crude outcome measure) has led researchers to neglect investigation of factors which may influence why some families express high levels of emotion and others low (e.g. Harrison & Dadds, 1992; Harrison, Dadds & Smith, 1998; Kuipers, 1994). A few early studies within the area of schizophrenia have highlighted at least two factors which appear to be associated with higher levels of EE or relapse. For example higher levels of behavioural disturbance in the patient (e.g. Brown et al., 1972) and more hours per week face to face contact with the patient (Vaughn & Leff,
Additionally, there is uncertainty about whether EE levels are a reflection of a carer’s longstanding trait, or simply a temporary state. Reports that high levels of EE are more evident on the CFI during the relative’s admission, than 6-12 months later after discharge (Kavanagh, 1992) suggest that levels of EE are not stable over time. This would also fit with improvements noted after family intervention. However Hooley (1998) suggested that the construct has a continuum of state-like and trait-like properties and viewed such a debate as “unproductive”. She maintains it is more important to recognise EE as a dynamic construct resulting from the interaction between carer and care-recipient.

As will be evident in the literature review which follows, research in the area of EE and dementia has thus far failed to adequately investigate the mechanisms of why some relatives are high in EE and others are low. It will become evident that it is necessary to draw upon a cluster of more recent studies within the schizophrenia literature to provide some hypotheses around this question.

**Studies of EE in carers of people with dementia**

To the author’s knowledge, there have been a total of nine published studies investigating EE in carers of people with dementia (search sources included Psych. Lit. and Med. Line). These are more recent papers, which originated from a recognition that there were significant similarities in the chronic nature of demands associated with caring for a relative with dementia, and those demands posed by relatives with schizophrenia. Vitaliano et al. (1993) posited that “there is potential for dysfunctional caregiver behaviour such as those categorised as High-EE responses at any time during the course of the care-recipient’s disease for both types of caregivers”.

As a note of caution however, it should be noted that there are qualitative differences between the disorders of schizophrenia and dementia, which might jeopardise the
generalisability of the EE concept. For example, the course of most types of dementia (e.g. Alzheimer’s Disease) involves progressive deterioration, with little or no reprieve of symptoms. In contrast, a person with schizophrenia may function well for significant periods of time. Thus outcome measured by relapse is not valid in people with dementia. The concept may however be of use in furthering our understanding of negative attitudes and their associated factors in carers of people with dementia.

Each of the nine studies will be discussed, as the small body of conclusions give rise to a logical focus for the current study.

The first study investigating EE in carers of people with dementia (Orford et al., 1987) explored twelve relatives’ levels of EE (relationship to care-recipient unspecified) as part of a larger study of relatives (n=65) caring for psychiatric patients (aged 18-59 years, and 60+ years) and physically ill patients (aged 60+ years). Using a “measurement of EE… based closely upon the previous work of the MRC Social Psychiatry Research Unit group”, but which was not specified as the CFI, the authors found that only one relative was rated as High-EE (8%), using the traditional cut-off point of six critical comments or a “moderate” amount of EOI (Kuipers, 1994). However the authors chose to compare the level with other levels in the remaining groups of carers by lowering the cut-off point to “include those who expressed two or more critical remarks”. They then quoted the level of EE in carers of people with dementia at 17%, compared to relatives of younger (52%) and older (42%) psychiatric patients, and physically ill patients (17%).

Thus the levels of EE were low in this sample of relatives. However, the sample was too small to base firm conclusions upon. Additionally, it is not clear from the paper whether the shortened CFI was utilised or not. This, in addition to the fact that the authors finally quoted 17% as the percentage of High-EE relatives, makes later comparisons with other studies rather difficult. The validity of their EE measure is reduced because they categorised carers with only two or more critical comments as High-EE. Finally, the study did little more than to demonstrate the logical assumption that high EE levels do exist in some relatives of people with dementia, as it failed to explore associations with any other variables.
Building upon this initial study, Gillhooly and Whittick (1989) explored associations between EE and a number of factors previously investigated in relation to carers of people with dementia. These included age and sex of both carer and care-recipient, care-recipient’s level of impairment and functioning, carers’ social contact with others, satisfaction with help received, presence of dependant children at home, and psychological wellbeing. A total of 48 carers were interviewed over multiple meetings for a total of between three to twelve hours. The authors counted the number of critical comments made by the carer as a measure of EE (mean=12.7, standard deviation = 17.5, range = 0-78) and correlated them with scores obtained on the remaining measures.

Results revealed that higher levels of EE were significantly associated with carers’ poorer psychological wellbeing (measured by The Kutner Morale Scale; Kutner, Fanshel, Togo & Langner, 1956) and poorer mental health (measured by the OARS Multidimensional Functional Assessment Questionnaire’s ‘mental health’ scale; Duke University Centre for the Study of Ageing & Human Development, 1978). Females had significantly higher EE scores, and carers with higher EE scores had significantly less contact with their friends. Higher EE scores were also found to be significantly correlated with poorer ratings of the pre-morbid relationship between carer and care-recipient (on a scale of one to five; very poor-very good). No care-recipient characteristics were correlated with EE including age, sex, or level of impairment. Additionally, there were no significant correlations between EE levels and help from services and professionals, with carer satisfaction with help from relatives, presence of a dependant child living at home, relationship to care-recipient, or preference for institutionalisation of the care-recipient.

Although there were clearly a number of people who expressed higher levels of criticism (mean number of critical comments = 12.7) it is not possible to compare the exact percentage either to Orford et al.’s study, or previous schizophrenia studies because they did not standardise their interviews and thus their measurement of EE. Interviews of varying lengths of time cannot be compared either to each other, or to the CFI. The study did however highlight carer factors associated with higher levels
of criticism (morale/ psychological wellbeing, mental health, gender, social contact and quality of pre-morbid relationship). However the measures used could be criticised for being too crude in their assessment, and lacking specificity (e.g. rating the pre-morbid relationship only on the dimension of ‘goodness’).

Vitaliano, Becker, Russo, Magana-Amato and Maiuro (1989) were more interested in the relationship between EE and carers’ coping styles, expression of anger, and experience of distress and burden. Thus they initiated an exploration of the differences in other psychological variables in relation to carers. EE levels in seventy-nine spouses of people with dementia who fulfilled the role of primary carer were measured using the FMSS. 17% of spouses were classified as high EE on the basis of making either an initial negative statement, receiving a negative relationship rating, or making one or more criticisms. Three spouses were rated as High-EE on the basis of EOI; “displaying excessive overprotective behaviour and/or broke down in tears during the interview”. However as this number was so low, they were excluded from further analysis.

Significant differences between High- and Low- EE spouses were obtained for ratings of; carer depression (using The Beck Depression Inventory; Beck, Ward, Medelson, Mock & Erbaugh, 1961); spouses’ experienced burden (using a Burden Scale developed by the authors); spouses ‘holding anger inside’ (hostility) and anger control (The Anger Expression Scale; Spielberger, Johnson, Russell, Crane, Jacobs & Worden, 1985); and avoidance, blaming others and counting one’s blessings as coping strategies (The Ways of Coping Checklist; Folkman and Lazarus, 1981). In other words, High-EE spouses were more depressed, reported experiencing more burden, held their anger inside more, were less likely to be able to control their anger, tried to forget problems more, took their problems out on others more, and counted their blessings less than Low-EE spouses. There were no associations between EE levels and spouse or care-recipients’ age, education or gender, or the care-recipients’ cognitive ability or depression ratings.

This study was an improvement upon earlier studies as it used a standardised measure and categorisation system of EE, used a large number in its sample which was
selected from the general population, and attempted to look more specifically at why some carers may differ in their levels of EE, based upon psychological variables. It indicated that styles of coping and dealing with anger may be important factors in EE, which in turn suggested that EE may be associated with carers' personality styles, rather than care-recipients' factors. It also revealed only a small percentage of carers with high EE. This may be because the sample was drawn from the general population, and thus from a sample of carers who were not necessarily in need of input from services.

The Vitaliano et al. (1989) study was continued within a longitudinal design, in line with many previous studies within the schizophrenia and EE literature in order to explore whether EE levels in spouses would predict subsequent problems among care-recipients with Alzheimer's Disease (Vitaliano et al., 1993). Carers were asked to indicate the presence or absence of nine negative behaviours derived from the Screen for Caregiver Burden (Vitaliano, Russo, Young, Becker & Maiuro, 1991). These behaviours included being unco-operative, threatening, physically abusive, angry, ungrateful, paranoid (hiding things) and prone to wander. At a 15-18 month follow-up, High-EE carers reported almost twice the number of care-recipient negative behaviours than did the Low-EE carers (p<0.001). However, the authors noted that the High-EE carers lived with care-recipients who had more negative behaviours than the low-EE carers at the original time point (p<0.01). There were no differences in cognitive functioning or activities of daily living at time one.

The authors concluded that carer EE was predictive of care-recipients' negative behaviour over time, and suggested that such behaviours may be more readily influenced by carer affect than functional or cognitive ability, because of their sensitivity to interpersonal dynamics. They also suggested that because High-EE carers were living with care-recipients whose behaviours were more difficult to manage than those in the Low-EE group in the first place, high EE itself may be a reaction to more disruptive care-recipient behaviours, more so than cognitive impairment or limited functioning. This study highlighted the importance of identifying carers with high EE levels, with the goal of intervening in an attempt to help lower the levels.
Bledin et al. (1990) focused upon exploring EE within a specific sample of grown-up children. They studied twenty-five daughters who cared for a parent with dementia, using the brief version of the CFI. The daughters were already known to local mental health or voluntary services (e.g. MIND, Age Concern, Alzheimer's Disease Society) and had four or more contacts per week with their parent. They looked at associations of EE with levels of reported strain, minor psychiatric morbidity, use of coping strategies and support. Daughters were categorised as High-EE if they had made four or more critical comments (the median). Fourteen daughters (58%) were rated as High-EE. Critical Comments referred most frequently to the care-recipient’s repetitious speech and behaviour (15% of the total), messiness (11%) and aggressive argumentative behaviour (11%).

High-EE daughters reported more strain (Relative’s Stress Scale; Greene, Smith, Gardiner & Timbury, 1982) and distress (General Health Questionnaire; GHQ; Goldberg, 1978) than Low-EE daughters, though these differences were not significant at p<0.05. High-EE daughters did however score over the threshold for GHQ ‘caseness’ significantly more than Low-EE daughters. Also, daughters making one or more positive remarks reported a greater use of positive coping strategies than those who did not make positive remarks. Interestingly, significantly more High-EE daughters (85.7%) than Low-EE daughters (45.5%) had had a respite break during their time as a carer. One might have speculated that daughters who had more support might be under less strain. Consistent with previous studies (with the exception of Vitaliano et al., 1993) EE was not associated with measures of cognitive impairment or behaviour and mood disturbance (as measured by the Behaviour Rating Scale and Cognitive Assessment Scale of the Clifton Assessment Procedures for the Elderly; Pattie & Gilleard, 1979; and the Behaviour and Mood Disturbance Scale; Greene et al., 1982). At a nine month follow-up, there were no significant differences between High- and Low-EE daughters in the numbers whose status as primary carer had changed, and so EE levels were not associated with continuing care in the community in the short term.

This study highlighted specific behaviours associated with critical comments, and thus added new information to the previous studies. It is consistent with findings in
schizophrenia studies which have identified specific behaviours as being linked to high EE (Harrison & Dadds, 1992; Harrison et al., 1998). Interestingly, criticism seemed to be evoked by behaviour perceived to be more deliberate and under the person’s control. However, it was a small sample, which was probably not representative of the general population as all were already known to services. A high percentage (58%) were categorised as High-EE, which suggests that daughters may be a particularly vulnerable group of carers, possibly because of additional demands such as work and responsibilities to their own partners and children. However this percentage would not be so high if the traditional cut-off point of six or more critical comments had been applied. Once again, it is difficult to compare these EE levels with those in other studies due to the inconsistency in EE measurement criteria.

A study described by Whittick (1992), using a small sample of twenty carers of resident and non-resident patients, used the Patient Rejection Scale (PRS) to measure EE, obtaining a mean score of 68 (range 47-99) which is the same mean score found in a sample of carers of schizophrenic patients (McReadie & Robinson, 1987). Carers who self-rated higher levels of criticism and hostility, were stated to have had a significantly poorer pre-morbid relationship (assessed within semi-structured interview) and higher depression ratings (using Beck Depression Inventory; Beck & Beamesderfer, 1974). The authors also noted that lower ratings of hostility and criticism were associated with a wider repertoire of coping strategies. Unfortunately no description of the analyses or statistics were given and therefore the significance and specificity of the findings cannot be evaluated. The authors stated that there were no associations between the PRS and frequency or range of problem behaviours, however the “more demented” the patient, the lower the ratings of hostility and criticism. They concluded that perhaps in the early stages, when the carer is struggling to understand the dementia process, they are more inclined to be rejecting and hostile. Unfortunately this study cannot be deemed to be very helpful in furthering our understanding, due to its small sample size and incomplete descriptions of findings.

A similarly incomplete description of a study is given within a paper by Gilhooly, Sweeting, Whittick & McKee (1994). A large sample of 100 carers were assessed
using the PRS. Higher PRS scores were not associated with any particular coping techniques (using The Ways of Coping Check-list; Folkman & Lazarus, 1981), carers’ “psychological wellbeing”, or breakdown of continuing care in the community at one year follow-up. However, they analysed “in-depth” interviews qualitatively, and described various ways of coping. Despite its impressive sample size, this study did little more than to describe various ways of effective and ineffective coping, without linking them with any other factors.

Wagner et al. (1997) aimed to explore levels of EE in carers (n=57) of people with both Alzheimer’s Disease and depression, hypothesising that high EE would be associated with a presence of depression in the patient, because such patients have been perceived by carers as less communicative (Fitz & Teri, 1994; cited in Wagner et al., 1997). Using the Five Minute Speech Sample (Magana et al., 1985), 40% were categorised as High-EE on the basis of critical comments (with the exception of one categorised on the basis of EOI). Results revealed that High-EE carers were more likely than Low-EE carers to receive a diagnosis of depression (using the Centre of Epidemiological Studies – Depression Scale; Radloff, 1977), to rate themselves as feeling more burdened (using the Burden Inventory; Zarit, Reever & Bach-Peterson, 1980) and to endorse fewer aspects of caring as positive (using a scale devised by the authors). There were no significant correlations between EE and carer and patient age, education or gender, carer relationship to patient, or patient’s cognitive functioning, functional status or behavioural problems.

These EE ratings were higher than previous studies (e.g. Orford et al., 1987; Vitaliano et al., 1993), suggesting that carers of people with both Alzheimer’s Disease and depression, may be at risk of developing higher EE ratings than carers of non-depressed care-recipients. It is possible that the results are more specific to spousal carers as this category accounted for the majority of carers in this sample (79%)

The most recent study (Fearon, Donaldson, Burns & Tarrier, 1998) explored EE and its association with past and current intimacy between carers and their care-recipients. In a sample of 99 spouses or off-spring, EE was measured using the CFI, with High EE defined as six or more critical comments, any degree of hostility, or a score of four
or more on EOI. Intimacy was measured with a 22 item questionnaire developed from a questionnaire by Morris, Morris and Britton (1988), which explored affection, cohesion, expressiveness, compatibility and conflict resolution. 34.3% of carers were classed as High-EE, and they reported significantly lower levels of past and current intimacy than Low-EE carers.

The authors suggested that carers who had had difficult pre-morbid relationships with their care-recipients may not perceive caring as an opportunity to repay past kindness, or consider that they are helping the person as that person would help them if the situation were reversed. This study used a large sample of carers with standardised measures of EE, thus the findings may be less tentative than previous explorations into EE and the pre-morbid relationship between carer and care-recipient (e.g. Gillhooly & Whittick, 1989; Whittick, 1992).

**Summary of findings within studies exploring Expressed Emotion in carers of people with dementia**

These studies collectively reveal that levels of High EE in carers of people with dementia range from 17% (e.g. Orford et al., 1987; Vitaliano et al., 1989; 1993) to 58% (Bledin et al., 1990), and that in some studies (e.g. Bledin et al., 1990; Whittick, 1992) high EE levels are comparable to the overall prevalence in samples of carers who look after a person with schizophrenia (McCreadie & Robinson, 1987). This presence of high EE levels, indicates that EE is a concept which justifies further investigation within the field of caring in dementia. Although high EE levels in carers of people with dementia do not appear to be associated with carers’ preference for institutionalisation (Gillhooly & Whittick, 1989), or indeed increased rates of institutionalisation (Bledin et al., 1990; Gilhooly et al., 1994), they may be associated with an increase in negative or difficult to manage behaviours in the longer term (Vitaliano et al., 1993). This finding suggests that such behaviours may be more sensitive to, and thus more influenced by, interpersonal dynamics. This conclusion should however be treated with caution as people with dementia who had High-EE carers were originally more disturbed anyway.
The most consistent finding is that high EE levels are associated with poorer psychological wellbeing and mental health in the carer (Bledin et al., 1990; Gilhooly & Whittick, 1989; Vitaliano et al., 1989; Wagner et al., 1997; & Whittick, 1992). However, the direction of causality within this relationship is unclear. One could hypothesise that consistently holding critical and hostile attitudes toward a care-recipient may have a damaging impact on the carer’s sense of wellbeing and mental health generally. It is equally plausible that a damaged sense of psychological wellbeing and presence of depressive and anxiety symptoms may cause specific negative affect toward a source of stress (the care-recipient). Whichever the direction of causality, if any, it could be hypothesised that a carer with poorer psychological wellbeing or mental health may be struggling to provide the quality of care they might otherwise be providing.

Another association which receives support from two studies is that between carers’ high EE, and greater experienced burden (Vitaliano et al., 1989; Wagner et al., 1997). Again, direction of causality is unclear. Holding negative emotional attitudes toward the care-recipient may distort perceptions of the impact of care giving on the carer. Equally, perceptions of greater burden may influence the carer to feel more resentment toward their care-recipient, and thus influence them in being critical.

Suggestions of how High- and Low-EE relatives differ in the way they approach stressful situations come from Bledin et al. (1990) and Vitaliano et al. (1989), who have indicated that certain coping styles and ways of dealing with feelings of anger are associated more with High-EE relatives than with Low-EE relatives. These two studies thus begin to touch upon the crucial issue of why some relatives may be particularly critical and hostile toward their care-recipient, while others faced with the same stressors are less so. Another tentative conclusion is that the quality of the pre-morbid relationship between carer and care-recipient may in some way influence carers’ emotional attitudes (Fearon et al., 1998; Gilhooly & Whittick, 1989; Whittick, 1992), suggesting that perhaps negative attitudes toward the care-recipient simply continue as they have before, or that resentment builds from the carer’s recognition of their forced role as carer, in the face of an already tenuous relationship. Other less well supported associations with high EE have included female gender of carer, carers’ decreased contact with friends, and care-recipients receiving respite care.
Finally, the additional diagnosis of depression in the care-recipient, or the carer’s relationship to the care-recipient being a daughter, both seem to be associated with elevated EE levels (Bledin et al., 1990; Wagner et al., 1997). Interestingly, the care-recipient’s level of cognitive, functional, and usually behavioural impairment, does not generally share a relationship with EE, indicating that the mechanisms of EE might reside within the carer and their stable personality characteristics, or processes more specific to their role as carer, such as appraisal of challenges presented to them, or their perceptions or understanding of the illness process.

Criticisms of EE studies within the field of dementia

On the whole, the studies fail to adequately investigate why some carers have high EE levels and others low, other than touching upon ways of expressing anger, and ways of coping. Neither of these variables have been given much attention in the schizophrenia literature in efforts to refine the theoretical basis of EE. Sample sizes are often too small to allow firm conclusions to be drawn from findings (e.g. Bledin et al., 1990; Orford et al., 1987; Whittick, 1992). Comparisons of studies are made difficult by researchers choosing unstandardised methods of EE measurement (e.g. Gilhooly & Whittick, 1989) or deviating from the use of traditional cut-off scores to define levels (e.g. Bledin et al., 1990; Orford et al., 1987). Finally, with the exception of Vitaliano et al. (1993), it is not possible to define the direction of causality within relationships between variables. However, as studies into EE and its relationships with other variables within carers of people with dementia are relatively recent and thus constitute a ‘fledgling’ body of evidence, they do offer a base from which to refine hypotheses for future research.

It is the author’s deduction that since associations between high EE and undesirable outcome have been demonstrated (poorer psychological wellbeing and mental health in the carer, increase in negative behaviours in the care-recipient), the next step within research is to explore more fully the processes or mechanisms which may influence the presence of high EE in carers of people with dementia. Due to significant associations with variables residing in the carer rather than in the care-recipient, it seems logical to begin that process by exploring carer attributes. In order to do this, it is helpful once again to examine studies conducted with carers of people with
schizophrenia, since this is where explorations of EE originated and where the concept continues to be refined.

**Toward an explanation of Expressed Emotion**

Explorations attempting to form an understanding of the mechanisms of EE among carers of people with people with schizophrenia draw primarily and most consistently upon attribution theory (e.g. Brewin, MacCarthy, Duda & Vaughn, 1991; Harrison & Dadds, 1992; Harrison, Dadds & Smith, 1998; Hooley, 1987; Weisman et al., 1993; Weisman, Neuchterlein, Goldstein & Snyder, 1998). Hooley (1987) was among the first to formally hypothesise the link between EE and attribution theory (the process of explaining the cause of people’s behaviour) in the context of partner/spouse relationships, despite earlier speculations (e.g. Vaughn & Leff, 1976a). She based her hypotheses upon Weiner’s Attribution-Affect Theory of behaviour, whereby causes of others’ behaviour which are perceived as controllable elicit pity or sympathy in a person, whereas causes perceived as controllable elicit anger (Weiner, 1986). These processes were empirically supported by Schmidt and Weiner (1988) within the context of experimental conditions of help-giving.

In line with Weiner, Hooley suggested that when faced with the unusual behaviour of a family member, relatives generally have two choices; they can make an internal attribution (blame the care-recipient) or an external attribution (blame the illness for which the care-recipient is not perceived to be responsible, or a situational factor). She suggested that the willingness or ability of a relative to accept their care-recipient is genuinely ill, may be crucial in determining their acceptance or tolerance for their care-recipient’s disturbed behaviour or symptoms. This hypothesis has received support from studies in other areas. For example, mothers’ emotional reactions to their children with Nocturnal Enuresis, whereby mothers perceiving their child to have greater control over their wetting were less tolerant (Butler, Brewin & Forsythe, 1986), and marital distress (Fincham, Beach & Nelson, 1987), whereby distress was associated with partners viewing each other’s negative behaviour as intentional.

Hooley (1987) went further to illustrate the explanatory power of the attribution model in demystifying the mechanisms of EE. She proposed that High-EE and Low-EE relatives may be making different attributions about the cause of disturbed behaviour
in their care-recipient. High-EE relatives may view the behaviour as due to the care-
recipient’s character or personality, and thus believe it to be under their voluntary
control. This would predict that the relative would not feel sympathy, but rather
annoyance or even anger toward them (Weiner, 1986). She proposed that criticism,
by its very nature, implies the relative would like the care-recipient to behave
differently, and that if the relative desires them to change and also considers them
capable of changing, they will attempt to modify elements of the behaviour (she draws
upon evidence that High-EE relatives tend to be more socially controlling in their
interactions with their care-recipient than Low-EE relatives; Hooley, 1985; Greenley,

If the carer’s efforts to influence such behaviours fail, the relative may accept their
care-recipient is incapable of change and thus that their behaviour is due to an illness
(and hence reflect low EE attitudes). Alternatively they may become more frustrated
by their lack of impact, causing them to become hostile. Thus high EE on the basis of
criticism and hostility can be explained. Hooley also proposed that relatives may
become emotionally over- involved when they make attributions which are entirely
consistent with the medical model, so that care-recipients are in no way held
responsible for their behaviour. The relative then develops an overly protective
emotional attitude. She suggested that it is most helpful to attribute behaviours to
illness at a general level, thus viewing them as uncontrollable, but also expecting
some degree of responsibility (e.g. for taking medication).

This model appears to fit nicely with the aim of educational interventions with
relatives of people with schizophrenia, which emphasise the care-recipient’s
behaviour as symptoms of an illness whereby they are unable to control much of their
behaviour but are encouraged to take responsibility for their medication. Generally, it
has high face validity. Its implications for clinical intervention make it a particularly
attractive model, because attributions about cause and controllability of symptoms
may be more specific to the caring situation, than a reflection of a stable personality
characteristic. Thus it is clear to see how intervention packages could be targeted
specifically to change attributions about their care-recipient’s behaviour, rather than
for example concentrating upon changing ways of dealing with anger (Vitaliano et al.,
1989) which may reflect more stable personality characteristics and require more
individualised intervention. Brewin (1994) reported that reductions in relative’s criticism and hostility following intervention were accompanied by more use of attributions to the illness, and uncontrollability on the patient’s part. However Hooley (1987) suggests that educative input alone is unlikely to reduce Expressed Emotion levels in carers whose pre-morbid relationship with their care-recipient was poor.

In a later paper, Hooley (1998) posits that it is the carers’ attributions about their relatives’ ability to control their behaviour that are central to the attributional model of EE. This indirectly implies that attributions specific to cause (e.g. illness or personality) are less important than attributions about controllability. In fact, according to Hooley’s descriptions, it appears that she sometimes subsumes attributions about cause under the heading of controllability, rather than separating the two out. This lack of clarity, and attention in separating cause from controllability is reflected in selected studies examining EE and attributions among relatives of people with schizophrenia (e.g. Weisman et al., 1993; 1998). Other studies (e.g. Harrison and Dadds, 1992; Harrison et al., 1998) look at both types of attributions.

The following studies involving carers of people with schizophrenia have provided some support for Hooley’s model, and may be relevant in increasing our understanding of the mechanisms of EE within carers of people with dementia.

Brewin et al. (1991) studied EE and the attributions of 58 relatives of people with schizophrenia (64% were parents) using the CFI, and The Leeds Attributional Coding System (LACS; Stratton, Heard, Hanks, Munton, Brewin & Davidson, 1986). The LACS measures spontaneous attributional statements along five binary dimensions; stable-unstable, global-specific, internal-external, personal-universal and controllable-uncontrollable. Critical relatives were more likely to make statements attributing behaviours to the person, and to volitional control. Low-EE relatives, and relatives categorised as High-EE on the basis of EOI only, did not differ significantly from each other. Negative symptoms (e.g. apathy and self-neglect) were also perceived as more controllable by relatives. The main criticism of this study, as noted by the authors, is its measurement of spontaneous attributions. As not all relatives generated the same quantities or types of data, it is not known whether their spontaneous
attributions always reflected equally well the structure of their causal beliefs. The authors noted that longer interviews lead to greater numbers of attributions and were perhaps associated with more unstable, external, universal and uncontrollable attributions (Brewin et al., 1991).

A study by Barrowclough, Johnston and Tarrier (1994; n=60 relatives) used the same methodology as Brewin et al. (1991), and found highly critical relatives gave more attributions internal to the patient than those who were less critical, and hostile relatives also tended to perceive causes to be controllable by and personal to the patient. Again, EOI was associated with beliefs similar to Low-EE relatives. The same criticisms can be applied to the methodology of this study.

Weisman et al. (1993) compared a sample of 23 High-EE relatives, and 23 Low-EE relatives of Mexican-American origin (on the basis of critical comments only). EE was measured using the CFI, and spontaneous attributions were coded with regards to controllability by using global ratings of perceived controllability on a five point scale (1= no perceived control and 5= a great deal of perceived control). Relatives’ positive affect (love, warmth, affection, sympathy and sadness) and negative affect (frustration, annoyance, disgust and hate) were also assessed. High-EE relatives made significantly higher controllability ratings than Low-EE relatives. Also relatives with a tendency to perceive the disorder and its symptoms as under the patient’s volitional control, emitted proportionally more negatively charged statements about the patient than did relatives who viewed the symptoms as less controllable.

The evidence from these two studies again supports Hooley’s attributional model of EE. Additionally, the finding that negative symptoms are perceived as more controllable than positive symptoms replicates the finding in Brewin et al.’s study (1991). However, there are three main criticisms of this study. Firstly, as with the Brewin et al. study, reliance upon spontaneous attributions does not allow standardised measurement across all participants. Secondly, making global ratings of controllability may make findings less accurate as it may encourage more rater subjectivity, and a lack of specificity with regards to comments. Finally, as with the previous study, it fails to explore which factors might influence the attributions relatives make. Of course, neither study confirms direction of causality. As Weisman
et al. point out, it is possible that relatives’ emotions influence their perception of causality.

Harrison and Dadds (1992) went some way to address the criticisms highlighted above. Examining a sample of 31 relatives of people with schizophrenia with the CFI, they measured elicited attributions, by devising a questionnaire which required the respondent to rate how often and how severely their ill family member demonstrated a number of negative and positive symptoms. They then rated on a scale of 1-5 how much they thought each symptom was under their care-recipient’s volitional control, and whether they thought it was caused by illness, the care-recipient’s personality, or by some other factor. Thus the authors moved away from measuring spontaneous attributions, to elicited ones. Additionally, they hypothesised a link between the amount of understanding the person possessed about schizophrenia (knowledge) and the type of attributions they made about symptoms.

Results revealed that High-EE relatives (defined on a basis of criticism and EOI) possessed significantly less knowledge or understanding of the illness (its diagnostic name, clinical symptoms, available treatments and prognosis) than relatives defined as High-EE on the basis of EOI only, or relatives defined as Low-EE. They also made a significantly higher mean percentage of attributions of negative symptoms to personality than the emotionally over-involved group, but not the low EE group. There were no differences between groups of relatives on perceived controllability of negative symptoms, or cause/controllability for positive symptoms. Finally, knowledge was significantly negatively correlated with attributions of negative symptoms to personality, and the percentage of symptoms judged as controllable was positively correlated with the percentage of symptoms attributed to personality.

This study therefore added support to the link between attributions about cause, and then perceptions of controllability of symptoms, between knowledge of the dementia disease and attributions made, and between negative symptoms such as apathy, and High-EE. The understanding a relative possesses about the disorder may be an important factor associated with attributions made about behaviour. The measure of knowledge and attributions was not however standardised, and as the authors point out, forcing relatives to attribute the cause of symptoms to one of three categories, may be too global. In fact, forcing carers to make attributions when they may feel
undecided in their position may not be helpful. This study suggests that investigating attributions about cause and controllability separately may be important, since significant findings were established for attributions about cause and negative symptoms, but not attributions about controllability and negative symptoms.

Harrison et al. (1998) replicated the study with a larger sample (n=84) and again found that carers’ knowledge of the illness was negatively correlated with the percentage of negative symptoms attributed to personality. Multiple regression analysis between the number of criticisms and the proportion of negative symptoms, carer knowledge, and percentage of negative symptoms to attributions to personality was performed. When the proportion of negative symptoms was smaller than the positive ones, and when carers knew little about the illness and attributed symptoms to the personality of the patient, rather than to the illness, carers were more likely to be critical of the patient.

Weisman et al. (1998) sought to replicate and evaluate the ethnic generalisability of Weisman et al.’s original study with Mexican-American relatives. In addition, they were interested in the difference in attributions made about positive and negative symptoms. Comparing a sample of High-EE relatives (n=11) and Low-EE relatives (n=29) with the same methodological design, they also found that High-EE relatives viewed their family members’ symptoms as residing more under their personal control compared with Low-EE relatives. Also symptoms reflecting behavioural deficits (e.g. lack of communication and apathy) were found to be criticised more often than were positive symptoms (e.g. hallucinations).

Summary of findings about EE, attributions and knowledge in carers of people with schizophrenia

Hooley’s (1987) attributional model explaining the mechanisms of EE in relatives of people with schizophrenia has received some empirical support. Taken together, the findings suggest the following:-

- Critical relatives are more likely to attribute their care-recipient’s unusual behaviour to personality characteristics than to genuine illness (Barrowclough et al., 1994;
Brewin et al., 1991) and to perceive their care-recipient’s behaviour as under volitional control (Brewin et al., 1991; Weisman et al., 1993; 1998).

- Furthermore, negative symptoms such as self neglect and apathy (which can be viewed more as an extension of normal behaviour than hallucinations) are more likely to be attributed to the care-recipient’s personality by High-EE relatives (defined by criticism only, or criticism and EOI) than are positive symptoms (Harrison & Dadds, 1992).

- Such negative symptoms are also perceived to be more controllable by relatives (Brewin, 1991; Weisman et al., 1998).

- When symptoms are judged as part of the care-recipient’s personality characteristics, they are more likely to be perceived as under volitional control (Harrison & Dadds, 1992).

- Relatives who are both critical and emotionally over-involved, tend to possess less knowledge about the schizophrenia illness than relatives who are only emotionally over-involved (Harrison & Dadds, 1992).

- The less knowledge a relative possesses, the more likely they are to be attributing negative symptoms to their care-recipient’s personality, and the more likely they are to be feeling critical and hostile toward their care-recipient (Harrison & Dadds, 1992; Harrison et al., 1998).

- On the whole, emotionally over-involved and Low-EE relatives do not tend to differ significantly in their attributions about cause and controllability (Barrowclough et al., 1994; Brewin et al., 1991; Harrison & Dadds, 1992).

- Finally, it may be important to investigate cause and controllability as separate types of attributions (as with Harrison and Dadds, 1992; Harrison et al., 1998), rather than subsuming attributions about cause under attributions about controllability, as some researchers have done (e.g. Weisman et al., 1993; 1998), and as Hooley’s more recent account of her model implies. To highlight this distinction, it seems appropriate to use different terminology when describing the two (e.g. “attributions about cause” and “perceptions of controllability”). This appears to fit more comfortably, as one
logically makes an attribution about cause of a person’s behaviour and judges the
degree of control as a result. Thus the author will discuss in terms of perceptions of
controllability, and attributions about cause. This language is consistent with Harrison
and Dadds (1992).

Despite Hooley’s assumption that attributions may influence emotional attitudes, the
direction of causality remains unconfirmed within these studies. However, Hooley’s
assumption is a logical one, and fits with reductions in relative’s EE levels following
family interventions including educational input. Her assumption also sits
comfortably with Schmidt and Weiner’s empirical evidence (1988) within
experimental conditions of help-giving behaviour, whereby attributions appeared to
precede affect, and then behaviour. As a final point, Hooley’s model could be
criticised for including only an internal-external dimension of attributions. Some
researchers demonstrate the existence of further dimensions, such as the global-
specific dimension (e.g. Brewin et al., 1991). It appears however that such studies
emphasise the clinical significance of the internal-external dimension and resultant
perceptions of control to a higher degree in their explanation of EE levels, and seem to
add little more understanding than studies including the internal-external dimension
only (e.g. Harrison & Dadds, 1992; Harrirson et al., 1998).

Although the results are in the expected direction and are generally consistent, they
constitute only a small body of evidence which require replication both within the
field of schizophrenia, and within other conditions. Exploring other conditions would
enable researchers to understand whether the findings are specific to mechanisms
within relatives of people with schizophrenia only, or are generalisable to relatives of
people with other disorders. Within these studies it would be helpful to replicate
methodology in the measurement of either spontaneous attributions (using the
standardised LACS) or of elicited attributions using a system in parallel with Harrison
& Dadds (1992) and Harrison et al. (1998). In this way studies may be more usefully
compared.

234
The utility of Hooley’s model in explaining EE in carers of people with dementia

Hooley’s attributional explanation of EE may be useful in understanding levels of EE in carers of people with dementia. Although carers’ coping techniques and ability to deal with anger have been tentatively associated with EE levels (Vitaliano et al., 1989), these may reflect more global personality characteristics than isolated attributions specific to the relationship between carer and care-recipient. Attributions more specific to the care-recipient in his/her role as a patient can logically be seen to be more amenable to modification through education about the illness. Thus it may be clinically useful to examine carers’ attributions systematically as a means of ascertaining the utility of tailoring interventions to change unhelpful attributions in the same way as clinicians working with people with schizophrenia.

A cautionary note as mentioned earlier however, is that one should think carefully when appropriating explanatory models from one condition to another. For example carers may more readily perceive their care-recipients’ symptoms to be as a result of organic damage, than carers of people with schizophrenia. Thus attributions of illness may dominate, and render Hooley’s attributional explanation redundant in the field of dementia. It is however important to test the generalisability of the model in order to further our understandings of the mechanisms of EE, since levels have been found to be comparable to levels among carers of people with schizophrenia in some studies.

The association between knowledge and type of attribution seems important, and requires further exploration. If the tentative conclusion that more knowledge is associated with less criticism, more attributions to illness and perceptions of less volitional control is reliable, it follows that facilitating a good understanding of the dementia illness in carers would be a priority. Possession of knowledge and its association with other variables has been studied recently in carers of people with dementia (Graham, Ballard & Sham, 1997a; 1997b). Lower levels of knowledge have been found to be associated with high levels of carer depression, and fewer expressed feelings of competency and confidence, higher expectations of the care-recipient’s capabilities and making less positive comparisons of their care-recipient. Interestingly, higher levels of knowledge were associated with higher levels of anxiety. This suggests that anxious carers seek more information, or that higher levels of knowledge about the disease’s prognosis and symptoms increase anxiety within the
More investigation of this factor would be helpful to establish the consistency of this particular result. Knowledge seems to hold a position of importance with regard to carer wellbeing and perceptions of difficulties involved in the caring role.

Finally, it seems redundant to explore attributions and knowledge in relation to EOI in carers of people with dementia. The above studies revealed that generally, low EE relatives and emotionally over-involved relatives did not seem to differ significantly. As mentioned in the earlier review of studies on EE and carers of people with dementia, categorisation of relatives on the basis of EOI has not proved very useful. It may be that the debilitating nature of the dementia illness necessitates a very protective attitude within the carer, which makes EOI difficult to measure within this population.

**Objectives of the current study with carers of people with dementia**

The objectives of the study were as follows:-

1. To assess the generalisability of Hooley’s attributional model in understanding the levels of EE in carers of people with dementia (i.e. to assess the relationships between carer levels of EE and carer attributions about cause and perceptions of controllability of care-recipients’ behaviour and mood disturbance, the relationships between carer attributions and carer perceptions of control, and the relationships between care-recipient apathetic/ withdrawn behaviour and carer attributions about cause and perceptions about control).

2. To assess the relationships between carer levels of knowledge and, a) carer levels of EE, b) carer attributions about cause and controllability of care-recipient’s behaviours, and c) carer levels of minor psychiatric symptoms.

3. To explore some of the relationships between variables formerly found to be related with carer levels of EE in other studies within the field of dementia, in order to ascertain if they would be replicated in the current study. These included carer levels of minor psychiatric symptomology, carer perceptions of quality of pre-morbid relationship between carer and care-recipient, and care-recipients’ level of behaviour and mood disturbance.
Hypotheses

The following hypotheses were formed as a result of the researcher’s expectations arising from theoretical implications of the literature reviewed in the introduction, and as a result of previous research findings.

**1. Carer attributions about cause and perceptions of controllability of care-recipient behaviour and mood disturbance (Assessment of generalisability of Hooley’s model)**

**Carer perceptions of controllability**

1.1 Care-recipients’ apathetic/withdrawn behaviour would be perceived by carers to be under the care-recipients’ volitional control to a higher degree than other behaviour/mood disturbance.

1.2 Levels of carer EE would have a positive relationship with carer perceptions of care-recipients’ volitional control over their behaviour and mood disturbance.

**Carer attributions of cause**

1.3 Carers would attribute care-recipients’ apathetic/withdrawn behaviour to the care-recipient’s personality more than they would to the care-recipients’ illness.

1.4 a) Levels of carer EE would have a positive relationship with carer attributions of behaviour and mood disturbance to the personality of the care-recipient, and b) a negative relationship with carer attributions of cause to the care-recipients’ illness.

**Carer attributions of cause and perceptions of controllability**

1.5 a) Carer attributions of behaviour and mood disturbance to the personality of the care-recipient would have a positive relationship with carer perceptions of volitional control on the part of the care-recipient, and b) carer attributions to the care-recipients’ illness would have a negative relationship with carer perceptions of volitional control.
2. Relationships between carer knowledge and carer attributions of cause and perceptions of controllability, carer levels of EE, and carer levels of depression and anxiety

2.1 Carer levels of knowledge would have a negative relationship with carer levels of EE.

2.2 Carer levels of knowledge would have a negative relationship with carer perceptions of care-recipients' behaviour and mood disturbance being under volitional control.

2.3 Carer levels of knowledge would have a negative relationship with carer attributions of care-recipients' behaviour and mood disturbance to the personality with regard to apathetic/withdrawn behaviour.

2.4 a) Carer levels of knowledge would have a negative relationship with carer levels of depression, and b) a positive relationship with carer levels of anxiety.

3. Relationships between carer levels of EE and carer levels of depression and anxiety, care-recipients' level of behaviour and mood disturbance and carer perceptions of pre-morbid relationship

3.1 Carer levels of EE would not have a relationship with levels of behaviour/mood disturbance (null hypothesis)

3.2 Carer levels of EE would have a positive relationship with carer levels of depression and anxiety.

3.3 Carer levels of EE would have a negative relationship with carer perceptions of the pre-morbid relationship.
Method

Participants

Forty three carers (relatives) of people with dementia in the community participated in this study. Power calculations were undertaken prior to recruitment. It was established that to have 80% power with an effect size of .4 (medium to large effect), 44 participants would be required.

Carer inclusion criteria

Carers were included in the study if:-

1. ..their care-recipient had received a formal diagnosis of dementia (of any type) from a psychiatrist or specialist, or a primary diagnosis from a GP.
2. ..their care-recipient lived with them in the community, or spent upwards of seven hours per week in direct contact with them.
3. ..they were a relative of the care-recipient.
4. ..they were the main carer (spent the most time in direct contact) when among a number of carers (with the exception of one instance when two daughters giving equal amounts of care were included).
5. ..they were already aware that their care-recipient had received a diagnosis of dementia.

Carer exclusion criteria

Carers were excluded if:-

1. ..they were diagnosed as suffering from organic cognitive deterioration (such as dementia or effects of head trauma).
Procedures

The procedures for this study were approved by the South West Surrey Local Research Ethics Committee (see appendix 1). Carers were recruited through one of two sources; The Alzheimer’s Disease Society (ADS- four local branches), and a Community Mental Health Team for older adults (CMHT). These sources were located in Surrey (Haslemere and Guildford) and West London (Hammersmith and Hounslow). Carers from the ADS lived with care-recipients who attended one of two ADS day centres, or were simply in contact with one of two local branches. Carers from the CMHT were known by key workers as carers of referred clients.

CMHT key workers, day centre managers from two branches, and ADS representatives from two branches were asked to identify carers on their caseload who met inclusion and exclusion criteria. Identified carers were then sent a letter of invite and an information sheet about the study (see appendices 2-3). The information sheet included a reply slip to be returned to the researcher within a self addressed envelope, only if the carer was interested in the study. An indication of interest was then followed up with a telephone call from the researcher who answered any queries, and arranged a meeting with the carer at their convenience, and in the absence of their care-recipient.

Within the meeting, issues of confidentiality were explained, and permission to notify the carer’s GP of their participation in the study was sought. Any remaining questions about the study were answered, and then informed consent was requested (see appendix 4). If the carer consented, data collection began initially with the researcher asking some questions regarding demographic data. Carers then completed the booklet of questionnaires themselves, and were encouraged to seek help from the researcher if they were unclear about particular items.

When the booklet was completed (time to complete ranged between 35 minutes, and one hour and fifteen minutes) the researcher asked each carer if they had any questions, worries or comments to express as a result of completing the questionnaires. As part of the procedures agreed with the Local Research Ethics
Committee, the researcher asked carers for permission to glance through the completed items. If responses immediately indicated a presence of severe depressive or anxiety symptoms, or very high levels of EE, this issue was raised with the carer as an indication of significant distress. Permission was then sought from the carer to inform an appropriate professional within their support network. This actually occurred on two occasions only. The carers in question agreed that they were under significant stress, and agreed to the researcher asking their key workers to make contact with them in order to discuss this concern.

The carer was then thanked for their time, and a standard letter was sent to the GP (see appendix 5).

**Carer demographic information**

Based on the steps outlined in the procedures section, 43 carers consented to take part in the study out of a total of 71 carers who received letters of invitation, resulting in a response rate of 60.5%. 79% (n=34) of the carers were recruited from branches of the Alzheimer’s Disease Society, and 20.9% (n=9) were recruited from a Community Mental Health Team for the Elderly.

**Age:** The mean age of carers was 65.33 years (s.d. 14.46; range 36 years – 89 years) and the median age was 69 years.

**Gender:** 65.1% of the 43 carers were female (n=28) and 34.9% were male (n=15).

**Relationship:** Table 1. summarises carer relationships to care-recipients.

<table>
<thead>
<tr>
<th>Relationship to care-recipient</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Husband</td>
<td>11</td>
<td>25.6%</td>
</tr>
<tr>
<td>Wife</td>
<td>19</td>
<td>44.2%</td>
</tr>
<tr>
<td>Ex-wife</td>
<td>1</td>
<td>2.3%</td>
</tr>
<tr>
<td>Son</td>
<td>2</td>
<td>4.7%</td>
</tr>
<tr>
<td>Daughter</td>
<td>9</td>
<td>20.9%</td>
</tr>
<tr>
<td>Daughter-in-law</td>
<td>1</td>
<td>2.3%</td>
</tr>
</tbody>
</table>
This table reveals that 69.8% (n=30) of carers were spouses of the care-recipients, and 25.6% (n=11) were grown children of the care-recipients.

**Occupation:** Over half the carers were retired (53.5%; n=23), with the remaining carers working full time (16.3%; n=7), or part time (16.3%; n=7), or not working at all despite being below retirement age (14%; n=6).

**Help received from services providing for people with dementia and their carers (voluntary, social work or NHS):** 65.1% (n=28) of the carers received help from services in the form of respite services, home help and or day centres/ hospitals. The remaining 34.9% (n=15) received no help from services although some contact had been made with them.

**Hours per week spent in direct contact with care-recipients:** Table 2. shows the hours per week spent in direct contact with care-recipients.

<table>
<thead>
<tr>
<th>Hours per week</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>7-14 hours</td>
<td>3</td>
<td>7%</td>
</tr>
<tr>
<td>15-35 hours</td>
<td>6</td>
<td>14%</td>
</tr>
<tr>
<td>36 hours or more</td>
<td>34</td>
<td>79.1%</td>
</tr>
</tbody>
</table>

This table reveals that the majority of carers (79.1%; n=34) spent 36 hours or more a week in direct contact with their care-recipient.

**Care-recipient demographic information**

Despite the participation of a total of 43 carers, there were only 42 care-recipients because data had been gathered from two daughters who lived apart from each other, but had the same mother. The two daughters had different levels of EE, and different perceptions of their care-recipient, therefore they were treated as independent observations. Including data from more than one relative for an individual care-recipient has been viewed as acceptable by at least one other researcher looking at EE in relatives of people with schizophrenia (Brewin, 1994).
Gender: 38.1% (n=16) of the care-recipients were female and 61.9% (n=26) were male.

Diagnosis: Table 3 summarises the diagnostic categories of dementia received by care-recipients as reported by their carers.

<table>
<thead>
<tr>
<th>Diagnostic category</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>23</td>
<td>54.8%</td>
</tr>
<tr>
<td>Multi-Infarct Dementia</td>
<td>9</td>
<td>21.4%</td>
</tr>
<tr>
<td>Dementia (Precise category unknown)</td>
<td>7</td>
<td>16.7%</td>
</tr>
<tr>
<td>Mixed Multi-Infarct &amp; Alzheimer’s Disease</td>
<td>1</td>
<td>2.4%</td>
</tr>
<tr>
<td>Pick’s Disease</td>
<td>1</td>
<td>2.4%</td>
</tr>
<tr>
<td>Korsakoff’s Syndrome</td>
<td>1</td>
<td>2.4%</td>
</tr>
</tbody>
</table>

As can be seen from the table, over half of the care-recipients had been diagnosed with Alzheimer’s Disease (54.8%).

Time lapsed since diagnosis: Table 4 shows the total time lapsed since care-recipients had been diagnosed with dementia (as reported by carers).

<table>
<thead>
<tr>
<th>Time lapsed</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>0-3 months</td>
<td>1</td>
<td>2.4%</td>
</tr>
<tr>
<td>4-12 months</td>
<td>10</td>
<td>23.8%</td>
</tr>
<tr>
<td>13 months-3 years</td>
<td>14</td>
<td>33.3%</td>
</tr>
<tr>
<td>3-5 years</td>
<td>13</td>
<td>31%</td>
</tr>
<tr>
<td>5 years or more</td>
<td>4</td>
<td>9.5%</td>
</tr>
</tbody>
</table>

This table reveals that the majority of care-recipients had been diagnosed with dementia between 1-5 years before data were collected (64.3%; n=27), although a substantial proportion had been diagnosed less than a year before data collection (26.2%; n=11).
Measures

1. Measurement of carer Expressed Emotion

As an approximation to the measurement of EE, the 24 item Patient Rejection Scale (PRS; developed from the 11 item PRS; Kreisman et al., 1979, in order to include positively worded items) was used (see appendix 6). The PRS is designed to tap the extent to which a relative feels hostility and criticism toward their ill family member. Thus emotional over-involvement was not measured (see earlier critique). Raters circle one of seven responses on a Likert scale (1= Always, 2= Almost always, 3= A lot of the time, 4= Sometimes, 5= Once in a while, 6= Almost never, 7= Never) to indicate how often they feel the same way as the statement given. For example “I enjoy being with X” (X= name of care-recipient), or “I am very disappointed in X”.

For the purposes of the current study, the wording of a total of five items were modified slightly to account for cultural differences (measure originates from America) and the deviation from the population for which the scale was originally designed (parents of children with schizophrenia). The changes were as follows:

<table>
<thead>
<tr>
<th>Item number</th>
<th>Changed from</th>
<th>Changed to</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>X is driving me crazy</td>
<td>X is driving me mad</td>
</tr>
<tr>
<td>12</td>
<td>I have to treat X like a much younger kid</td>
<td>I have to treat X like a child</td>
</tr>
<tr>
<td>13</td>
<td>I can help X to get better</td>
<td>I can help X to be more independent</td>
</tr>
<tr>
<td>14</td>
<td>X is not grateful for what we do for X</td>
<td>X is not grateful for what I do for him/her</td>
</tr>
<tr>
<td>23</td>
<td>I wish X had never been born</td>
<td>I wish I had never had any connection with X</td>
</tr>
</tbody>
</table>

These modifications were agreed with Kreisman via personal communication (see appendix 7), and were not expected to change the original psychometric properties of the scale. The alpha estimating the scale’s internal consistency in families of people with schizophrenia is .89. Test-retest after one year was .62 (Kreisman, 1998). Internal consistency for the scale for carers of people with dementia had not been quoted in earlier studies (e.g. Whittick, 1992; Gilhooly et al., 1994). Therefore the internal consistency of the scale with this population in the current study was
calculated using Cronbach’s Alpha. The alpha was calculated at \( r = 0.85 \), indicating a good level of internal consistency.

Validity for the 24 item PRS is said to be the same for the 11-item scale (D.E. Kreisman, personal communication, August 25, 1998). A correlation of the PRS with re-hospitalisation within 18 months did not differ significantly from Vaughn and Leff’s (1976b) original findings when comparing EE levels with re-hospitalisation (Kreisman et al., 1979). McCreadie and Robinson (1987) found statistically significant differences between mean scores in different EE categories (high EE versus low EE; \( p < 0.05 \); hostile versus non-hostile; \( p < 0.001 \); critical versus non-critical; \( p < 0.01 \)). Thus reliability and validity are reasonable.

2. Measurement of carer knowledge of dementia

The Dementia Knowledge Questionnaire (Graham et al., 1997a) was used (see appendix 8). This questionnaire yields a maximum score of 19, and assesses the presence of irrational beliefs (poor rudimentary knowledge of dementia) and general dementia knowledge (epidemiological knowledge, clinical symptoms knowledge and aetiological knowledge). Rudimentary knowledge expects a person to have a very basic grasp of the disorder. If they score poorly on this section, they are perceived as holding irrational beliefs about dementia. This measure was chosen for its attention to both irrational beliefs and awareness of the symptoms caused by dementia. These areas were speculated to be of particular importance with regards to the attributions carers might make about behaviours to illness, person or some other factor.

Scores obtained by a sample population followed a normal distribution (Graham, 1997a). The three categories epidemiological knowledge, clinical symptoms knowledge and aetiological knowledge all showed significant correlations with each other at \( p < 0.01 \), indicating good internal reliability between these three domains. The mean scores for the total measure obtained from carers in contact with mental health care professionals (\( n = 109 \)) and carers attending an Alzheimer’s support group (\( n = 18 \)), were 9.52 and 11.55 respectively.
3. Measurement of carer attributions about cause and perceptions of controllability

There were no available measures of elicited attributions about care-recipients’ behaviour for use with carers of people with dementia. The author therefore used a method of measurement modelled upon the one employed by Harrison and Dadds (1992) and Harrison et al. (1998) (see appendix 9). An established measure of behaviour and mood disturbance devised for relatives of people with dementia was used (Behaviour and Mood Disturbance Scale; Greene et al., 1982) to firstly indicate the frequency of occurrence of behaviour within three sub-scales; Apathetic/Withdrawn, Active/Disturbed, and Mood Disturbance. There are a total of 31 items, and respondents are asked to rate the occurrence of each item on a five point scale (0=Never, 1=Rarely, 2=Sometimes, 3=Frequently, 4=Always). The test-retest reliability coefficient for the total items is r=0.84 and for the sub scales individually; Apathetic/Withdrawn =.90; Active/Disturbed =.87; Mood Disturbance =.73.

If a relative responded that their care-recipient showed the behaviour or mood disturbance indicated by an item to any extent, they were then asked to rate to what extent they believed that behaviour/mood was controllable by the person on a six point scale (0=Not at all controllable, 1=Slightly controllable, 2=Controllable to some extent, 3=Often controllable, 4=Controllable most of the time, 5=Completely controllable). Finally, they were asked to indicate whether they believed the behaviour/mood was caused by their care-recipient’s dementia illness (I), their care-recipient’s personality or nature (P) or some other factor (O). They were verbally informed that they could indicate their care-recipients’ behaviour to be as a result of both illness and personality if they wished by recording I/P. Respondents did not rate cause or controllability for a particular item if they had not indicated that their care-recipient exhibited that behaviour/mood.

A controllability score for each carer was calculated by adding together their controllability rating for each item, and dividing the total by the number of items answered, i.e. the mean.
Causal attribution scores were recorded for each carer by calculating the percentage of attributions made to each of four categories; Illness (I), Personality (P), Other (O), and Illness/Personality (I/P). The percentages were then converted to represent decimals of 0.0-1.0 (0%-100%). Each score represented the proportion of items associated with attributions of the said category. For example, a score of 0.6 for the ‘Total BMD Illness category’ would indicate that a carer had attributed 60% of the total number of behaviour and mood items answered out of 31 on the BMD scale, to their care-recipient’s illness. These two methods of calculation mirror methods used by Harrison & Dadds (1992) and Harrison et al. (1998).

4. Measurement of carer anxiety and depression

The Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) was used to detect anxiety and depression as well severity of emotional disorder (see appendix 10). Despite the use of the word ‘hospital’ in the title, it is valid in community work (Milne, 1992). Severely psychopathological symptoms are not covered. This is thought to make the scale more sensitive to mild forms of psychiatric disorder, avoiding a floor effect (Herrman, 1997).

The scale has 14 items which are rated on a four point scale ranging from the absence of a symptom or the presence of positive features (scoring 0), to maximal symptomatology or the absence of positive features (scoring 3). Seven items measure depression, and seven measure anxiety, yielding a maximum score of twenty-one for each subscale. Scores equal to or greater than eleven on either the anxiety or depression sub-scales are likely to indicate clinical anxiety or depression (Milne, 1992). Concurrent validation with clinician’s interviews of clients (who were blind to HADS scores) yielded significant correlations of 0.54 for anxiety, and 0.79 for depression (Milne, 1992). Studies investigating the internal consistency of the scale (Crohnbach alphas) reveal acceptable levels at r=.80 to r=.93 for the anxiety sub-scale, and r=.81 to r=.90 for the depression sub-scale. Test-retest reliability shows a high correlation (r=.80) after up to two weeks.
The mean score for the anxiety sub-scale obtained from a sample of 1901 adults (mean age = 61.3; s.d. = 2.3) was 3.9 (s.d. = 3.5) and the mean score for the depression sub-scale was 3.7 (s.d. = 3.3) (Spinhoven, Ormel, Sloeckers, Kempen, Speckens & Van Hemert, 1997).

5. **Measurement of carers' perceptions of their pre-morbid relationship**

The author devised three items to assess carers' perceptions of their pre-morbid relationship. This variable was not part of the main hypotheses and so a brief measure was acceptable. The items were designed to tap 'closeness', 'positivity', and 'conflict' on a five point scale; 1= Not at all..., 2= A little..., 3= Somewhat..., 4= Quite..., 5= Very... (see appendix 11). It was considered that these were relationship aspects that carers would be able to make quick judgements about.

6. **Measurement of care-recipient's behaviour and mood disturbance**

This was measured using the **Behaviour and Mood Disturbance Scale** as described earlier. Mean scores obtained from a sample of 38 relatives of day hospital patients diagnosed with dementia were 24.95, 21.37, 10.68 and 51.98 for the Apathetic-Withdrawn, Active-Disturbed and Mood Disturbance sub-scales, and the total scale respectively (Greene et al., 1982).

7. **Measurement of demographic data**

Information about carers' age, gender, relationship to care-recipient, occupational status, presence of children in the home, and help received from services were recorded from carers' verbal information in response to specific questions from the researcher. Information about hours per week in direct contact with care-recipient and time since diagnosis were recorded within 3-5 point response scales (see appendix 12).
Analyses

Analyses were conducted using an SPSS statistical software package (version 7.5). The distribution of data on each variable was checked for normal or skewed distributions. However, due to the ordinal nature of measurement within all of the measures employed (with the exception of the Dementia Knowledge Questionnaire), it was decided that data would be analysed using non-parametric tests as appropriate, regardless of the normality of distribution. This decision was informed by an ongoing debate in the literature about whether ordinal levels of measurement can be treated in the same way as interval levels of measurement for the purposes of statistical tests (e.g. Pearson’s Product Moment correlations) (Fife-Schaw, 1995). The author decided to err on the side of caution in line with more conservative views (Stine, 1989; cited in Breakwell, Hammond & Fife-Schaw, 1995) and use non-parametric tests.

Spearman’s Rank Order correlations were performed to test the strength of relationships between scores, and Friedman analysis of variance or Wilcoxon tests were used to explore differences between scores as appropriate. Chi Squared tests were also performed to explore associations between different groups of carers (e.g. high-EE Vs Low-EE). When expected cell counts were less than five, Fisher’s Exact tests were used. Multivariate analyses such as multiple regression procedures were not necessary in order to test the specific hypotheses in this study. Also, the sample size was more than four times too small to reliably calculate regression analysis (Hammond, 1995).

Due to the exploratory nature of this study (especially the piloting of the assessment of the generalisability of Hooley’s model), Bonferroni’s adjustment was not made to reduce the probability of obtaining Type I errors. Thus significant findings must be interpreted with caution, and with the understanding that replications of the study are essential in order to support their robustness.
Results

The results contain two sections. Section one contains three parts. Section two contains only one part.:-

SECTION ONE

Part one: Carer attributions about cause and perceptions of controllability of care-recipient behaviour and mood disturbance, and their relationships with Expressed Emotion (Hypotheses 1.1-1.5).

Part two: Relationships between carer knowledge and carer levels of EE, carer attributions of cause and perceptions of controllability, and carer levels of depression and anxiety (Hypotheses 2.1-2.4).

Part three: Relationships between carer levels of EE and carer levels of depression and anxiety, care-recipients’ level of behaviour and mood disturbance and carer perceptions of pre-morbid relationship (Hypotheses 3.1-3.5).

A caveat to the interpretation of the results.

SECTION TWO

Further analyses to corroborate findings with regard to carer perceptions of controllability and causal attributions of behaviour and mood disturbance.
SECTION ONE

Part one:

Carer attributions about cause and perceptions of controllability of care-recipient behaviour and mood disturbance, and their relationships with Expressed Emotion (Hypotheses 1.1-1.5).

Carer levels of Expressed Emotion (EE) as measured by the Patient Rejection Scale

The mean Patient Rejection Scale (PRS) score in this sample of carers was 81.5 (s.d. 17.9). The scores ranged from a minimum of 46 to a maximum of 126 and the data was normally distributed (see appendix 13 for histogram, and appendix 14 for Z scores obtained for skewness and kurtosis).

Carer perceptions of controllability for behaviour and mood disturbance as measured by the BMD Scale

Frequency analysis revealed that the modal response for perceptions of controllability of behaviour and mood disturbance for every one of the 31 items of the BMD scale was ‘0’ – ‘Not at all controllable’. The data were positively skewed in their distribution (see appendix 14 for Z scores obtained for skewness and kurtosis).

Table 6. shows carers’ mean controllability scores, standard deviations, and individual score ranges for the BMD sub-scales and total BMD Scale.
Table 6: Means, standard deviations and individual ranges of carers’ perceptions of controllability scores for total BMD scale and sub-scales

<table>
<thead>
<tr>
<th>BMD Scale/ sub-scales</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathetic- Withdrawn</td>
<td>.68</td>
<td>.87</td>
<td>0-2.88</td>
</tr>
<tr>
<td>Active-Disturbed</td>
<td>.18</td>
<td>.33</td>
<td>0-1.64</td>
</tr>
<tr>
<td>Mood Disturbance</td>
<td>.49</td>
<td>.82</td>
<td>0-3.25</td>
</tr>
<tr>
<td>Total BMD scale</td>
<td>.50</td>
<td>.62</td>
<td>0-2.20</td>
</tr>
</tbody>
</table>

This table reveals that the range of individual controllability scores lay between 0 ‘Not at all controllable’ and 3.25 ‘Often controllable’. Although the mean scores lay between 0 ‘Not at all controllable’ and 1 ‘Slightly controllable’. The standard deviations reflect large score variations from the mean (e.g. Mood Disturbance = .82). Behaviours within the Apathetic-Withdrawn sub-scale were perceived to be the most controllable by carers (mean controllability score = .68), and behaviours within the Active-Disturbed sub-scale were perceived to be the least controllable by carers (mean controllability score = .49).

A Friedman Two Way Analysis of Variance test detected significant differences between the mean perceptions of controllability scores of the three sub-scales ($\chi^2 = 21.103$, $p<.001$). Wilcoxon Signed Rank tests were performed on each possible combination of two sub-scales of the BMD scale to establish which sub-scales differed significantly from each other in their scoring. Table 7. shows the Z scores obtained.

Table 7: Differences between perceptions of controllability scores on sub-scales of the BMD scale

<table>
<thead>
<tr>
<th>BMD sub-scale comparisons of controllability scores</th>
<th>Z scores</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathetic-Withdrawn/ Active-Disturbed</td>
<td>-3.906***</td>
</tr>
<tr>
<td>Apathetic-Withdrawn/ Mood Disturbance</td>
<td>-2.006*</td>
</tr>
<tr>
<td>Active-Disturbed/ Mood Disturbance</td>
<td>-3.305**</td>
</tr>
</tbody>
</table>

*** = sig. at $p<0.001$ (2-tailed); ** = sig. at $p<0.01$ (2-tailed); * = sig. at $p<0.05$ (2-tailed)

Controllability scores for each comparison of sub-scales on the BMD were significantly different from each other. Carers perceived Apathetic-Withdrawn behaviour to be significantly more controllable than Active-Disturbed behaviour ($Z = -3.906, p<0.01$) or Mood Disturbance ($Z = -2.006, p<0.05$), and they perceived Active-
Disturbed behaviour to be significantly less controllable than Mood Disturbance ($Z=-3.305, p<0.01$).

Thus, findings were consistent with hypothesis 1.1 (Carers would perceive care-recipients’ apathetic-withdrawn behaviour to be under the care-recipients’ volitional control to a higher degree than other behaviour and mood disturbance).

**Relationship between carer levels of EE and carer controllability scores**

Spearman’s Rank Order correlations were performed to assess the relationship between carer PRS scores and carer controllability scores.

Table 8. shows the values for correlations between PRS scores and controllability scores for each sub-scale of the BMD and the total BMD scale.

<table>
<thead>
<tr>
<th>Correlation combinations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRS/ Apathetic-Withdrawn sub-scale</td>
<td>-.047</td>
</tr>
<tr>
<td>PRS/ Active-Disturbed sub-scale</td>
<td>-.067</td>
</tr>
<tr>
<td>PRS/ Mood Disturbance sub-scale</td>
<td>.148</td>
</tr>
<tr>
<td>PRS/ Total BMD controllability score</td>
<td>.005</td>
</tr>
</tbody>
</table>

None of the above correlations were significant at $p<.05$ or below for 1-tailed tests, indicating no significant relationship between PRS scores and perceptions of controllability.

The association between carer PRS scores and carer controllability scores was also explored using a Chi Squared test. Carers were divided into two groups a) for levels of EE; High-EE carers (carers with PRS scores equal to or more than the median; 81, $n=21$), and Low-EE carers (carers with PRS scores less than the median; $n=22$), and b) for levels of controllability; carers who perceived no controllability (carers with controllability scores of 0; $n=11$), and carers who perceived some controllability
(carers with controllability scores of greater than 0; n=32). The test revealed no significant association ($\chi^2 (1) = .068, p=.795$).

Thus, findings were not consistent with hypothesis 1.2 (Levels of carer EE would have a positive relationship with carer perceptions of care-recipients’ volitional control over their behaviour and mood disturbance).

**Carer attributions about cause of care-recipients’ behaviour and mood disturbance**

Frequency analysis revealed that the modal response for causal attributions about behaviour and mood disturbance for every one of the 31 items of the BMD, was an attribution of illness. The data were skewed in their distribution (e.g. Illness attribution scores were negatively skewed, and Personality attributions were positively skewed).

Causal attribution scores for the total BMD scale, and individual sub-scales of the BMD are shown in table 9.
Table 9: Means, standard deviations and individual ranges for carers’ causal attribution scores for the BMD scale

<table>
<thead>
<tr>
<th>Causal category/ sub-scale</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Apathetic- Withdrawn sub-scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness</td>
<td>.82</td>
<td>.25</td>
<td>0-1.0</td>
</tr>
<tr>
<td>Personality</td>
<td>.07</td>
<td>.15</td>
<td>0-0.80</td>
</tr>
<tr>
<td>Other</td>
<td>.05</td>
<td>.12</td>
<td>0-0.67</td>
</tr>
<tr>
<td>Illness/Personality</td>
<td>.07</td>
<td>.11</td>
<td>0-0.38</td>
</tr>
<tr>
<td><strong>Active-Disturbed sub-scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness</td>
<td>.87</td>
<td>.23</td>
<td>0-1.0</td>
</tr>
<tr>
<td>Personality</td>
<td>.02</td>
<td>.64</td>
<td>0-0.30</td>
</tr>
<tr>
<td>Other</td>
<td>.03</td>
<td>.05</td>
<td>0-0.20</td>
</tr>
<tr>
<td>Illness/Personality</td>
<td>.07</td>
<td>.10</td>
<td>0-0.50</td>
</tr>
<tr>
<td><strong>Mood Disturbance sub-scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness</td>
<td>.82</td>
<td>.24</td>
<td>0-1.0</td>
</tr>
<tr>
<td>Personality</td>
<td>.06</td>
<td>.13</td>
<td>0-0.60</td>
</tr>
<tr>
<td>Other</td>
<td>.03</td>
<td>.09</td>
<td>0-0.50</td>
</tr>
<tr>
<td>Illness/Personality</td>
<td>.08</td>
<td>.07</td>
<td>0-0.80</td>
</tr>
<tr>
<td><strong>Total BMD Scale</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illness</td>
<td>.86</td>
<td>.15</td>
<td>.50-1.0</td>
</tr>
<tr>
<td>Personality</td>
<td>.05</td>
<td>.08</td>
<td>0-0.33</td>
</tr>
<tr>
<td>Other</td>
<td>.03</td>
<td>.04</td>
<td>0-0.18</td>
</tr>
<tr>
<td>Illness/Personality</td>
<td>.07</td>
<td>.15</td>
<td>0-0.80</td>
</tr>
</tbody>
</table>

This table reveals that the range of individual scores for causal attributions to the Illness, Personality, Other and Illness/Personality categories on the Total BMD scale lay between 50%-100%, 0%-33%, 0%-18% and 0% -80% respectively.

Mean causal scores for attributions of behaviour and mood disturbance to the care-recipients’ illness, were higher than mean scores for attributions to any other category, regardless of the sub-scale concerned.

Thus findings were not consistent with hypothesis 1.3 (*Carers would attribute care-recipients’ apathetic/withdrawn behaviour to the care-recipients’ personality more than they would to the care-recipients’ illness*).
Relationship between carer levels of EE and carer attributions about cause of care-recipient behaviour and mood disturbance

Spearman’s Rank Order correlations were performed to assess the relationship between PRS scores and causal attribution scores. Table 10. shows the values for these correlations.

Table 10: Correlations between PRS scores and causal attribution scores for BMD sub-scales and the BMD total scale

<table>
<thead>
<tr>
<th>PRS/ sub-scale combinations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathetic-Withdrawn</td>
<td></td>
</tr>
<tr>
<td>PRS/ Illness</td>
<td>-.261*</td>
</tr>
<tr>
<td>PRS/ Personality</td>
<td>.202</td>
</tr>
<tr>
<td>PRS/ Other</td>
<td>.053</td>
</tr>
<tr>
<td>PRS/ Illness/Personality</td>
<td>.294*</td>
</tr>
<tr>
<td>Active-Disturbed</td>
<td></td>
</tr>
<tr>
<td>PRS/ Illness</td>
<td>.255*</td>
</tr>
<tr>
<td>PRS/ Personality</td>
<td>-.171</td>
</tr>
<tr>
<td>PRS/ Other</td>
<td>-.443**</td>
</tr>
<tr>
<td>PRS/ Illness/Personality</td>
<td>.283*</td>
</tr>
<tr>
<td>Mood Disturbance</td>
<td></td>
</tr>
<tr>
<td>PRS/ Illness</td>
<td>-.160</td>
</tr>
<tr>
<td>PRS/ Personality</td>
<td>.120</td>
</tr>
<tr>
<td>PRS/ Other</td>
<td>-.124</td>
</tr>
<tr>
<td>PRS/ Illness/Personality</td>
<td>.318*</td>
</tr>
<tr>
<td>Total BMD Scale</td>
<td></td>
</tr>
<tr>
<td>PRS/ Illness</td>
<td>-.317*</td>
</tr>
<tr>
<td>PRS/ Personality</td>
<td>.188</td>
</tr>
<tr>
<td>PRS/ Other</td>
<td>-.106</td>
</tr>
<tr>
<td>PRS/ Illness/Personality</td>
<td>.475**</td>
</tr>
</tbody>
</table>

**=sig. at p<0.01 (1-tailed); *=sig. at p<0.05 (1-tailed)

Taking the BMD scale as a whole, attributing behaviour and mood disturbance to illness was significantly negatively correlated with PRS scores (Total BMD Scale PRS/ Illness; r= -.317, p<0.05). In other words, carers attributing their care-recipients’ behaviour and mood disturbance to illness tended to report less critical and hostile attitudes toward them.

However, attributing behaviour and mood disturbance to personality was not significantly positively correlated with PRS scores (Total BMD Scale PRS/
Personality; r=.188). Nevertheless, attributing behaviour and mood disturbance to a combination of the care-recipient’s illness diagnosis and their personality, was significantly positively correlated with PRS scores (Total BMD Scale PRS/ Illness/Personality; r=.475, p<0.01). In other words, carers attributing their care-recipients behaviour and mood disturbance to a mixture of both illness and personality, tended to report more critical and hostile attitudes toward them.

Taking each of the sub-scales of the BMD individually, the above pattern of results also held for the Apathetic-Withdrawn sub-scale of the BMD. Although in the same direction, this relationship was statistically significant only for the Illness/Person attribution category of the Mood Disturbance sub-scale.

Results for the Active-Disturbed sub-scale were somewhat different. Attributing active-disturbed behaviours to illness was significantly correlated with PRS scores (Active-Disturbed PRS/ Illness; r=.255, p<0.05). In other words, carers attributing their care-recipients’ active-disturbed behaviour to illness tended to report more critical and hostile attitudes toward them. Attributing active-disturbed behaviour to factors other the care-recipients’ illness or personality was significantly negatively correlated with PRS scores (Active-Disturbed PRS/ Other; r=-.443, p<0.01). In other words, carers who attributed their care-recipients’ active-disturbed behaviour to factors other than illness and personality (e.g. deafness or arthritis) tended to report less critical and hostile attitudes toward them.

Therefore at a general level (BMD Total Scale), hypothesis 1.4 a. did not appear to be supported (Levels of carer EE would have a positive relationship with carer attributions of behaviour and mood disturbance to the personality of the care-recipient). However, findings were consistent with hypothesis 1.4 b. (Levels of carer EE would have a negative relationship with carer attributions of cause to the care-recipients’ illness).
Relationship between carers’ perceptions of controllability, and attributions about cause of care-recipients’ behaviour and mood disturbance

Spearman’s Rank Order correlations were calculated to assess the relationship between carers’ perceptions of controllability and attributions about cause of care-recipients’ behaviour and mood disturbance on the total BMD scale. Table 11. shows the values obtained.

Table 11: Correlations between carer causal attribution categories and the BMD total scale

<table>
<thead>
<tr>
<th>Correlation combinations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total controllability score/ Total Illness attributions</td>
<td>-0.592**</td>
</tr>
<tr>
<td>Total controllability score/ Total Personality attributions</td>
<td>0.554**</td>
</tr>
<tr>
<td>Total controllability score/ Total Other attributions</td>
<td>0.244</td>
</tr>
<tr>
<td>Total controllability score/ Total Illness/Personality attributions</td>
<td>0.334*</td>
</tr>
</tbody>
</table>

**= sig. at p<0.01 (1-tailed); *= sig. at p<0.05 (1-tailed)

These correlations reveal that carers’ perceptions of controllability were significantly negatively correlated with attributions of care-recipients’ behaviour and mood disturbance to illness (r=-0.592, p<0.01), and carers’ perception of control were significantly positively correlated with attributions of behaviour and mood disturbance to personality (r=0.554, p<0.01), and to a mixture of illness and personality (r=0.334, p<0.01). In other words, when carers attributed their care-recipients’ behaviour and mood disturbance to the dementia illness, they were more likely to perceive it to be less under their care-recipient’s control. However when they attributed it to their care-recipients’ personality, or to a mixture of both illness and personality, they were more likely to perceive it to be more under their care-recipients’ control.

Thus findings were consistent with hypotheses 1.5 a and 1.5 b. (Carer attributions of behaviour and mood disturbance to the personality of the care-recipient would have a positive relationship with carer perceptions of volitional control on the part of the
care-recipient, and carer attributions to the care-recipients’ illness would have a negative relationship with carer perceptions of volitional control).

Part two:

Relationships between carer knowledge and carer levels of EE, carer attributions of cause and perceptions of controllability, and carer levels of depression and anxiety (Hypotheses 2.1-2.4).

Carers’ level of knowledge about dementia

Total Dementia Knowledge Questionnaire scores (DKQ) were fairly normally distributed (see appendix 14 for Z scores obtained for skewness and kurtosis)

Table 12. shows carers’ mean scores for the DKQ and its sub-scales.

<table>
<thead>
<tr>
<th>DKQ Scales/ sub-scales</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>DKQ Rudimentary Knowledge</td>
<td>2.91</td>
<td>.29</td>
<td>2-3</td>
</tr>
<tr>
<td>DKQ Epidemiological Knowledge</td>
<td>.77</td>
<td>.78</td>
<td>0-2</td>
</tr>
<tr>
<td>DKQ Aetiological Knowledge</td>
<td>1.77</td>
<td>1.02</td>
<td>0-5</td>
</tr>
<tr>
<td>DKQ Clinical Symptoms Knowledge</td>
<td>5.19</td>
<td>1.64</td>
<td>2-8</td>
</tr>
<tr>
<td>DKQ total score</td>
<td>10.67</td>
<td>2.57</td>
<td>4-15</td>
</tr>
</tbody>
</table>

The mean DKQ total score in this sample of carers was 10.67, and the individual scores ranged from 4-15 (higher scores reflect more knowledge).

Relationship between carer levels of EE and carer levels of knowledge scores

To assess the relationship between carer PRS scores and carer DKQ total scores, Spearman’s Rank Order correlation was calculated. The correlation was not significant ($r = -.053$, $p = .367$; 1-tailed).

259
Thus hypothesis 2.1 did not appear to be supported (*Carer levels of knowledge would have a negative relationship with carer levels of EE*).

**Relationship between carer levels of knowledge and carer perceptions of controllability, and attributions of cause about care-recipients’ behaviour and mood disturbance**

a) **Relationship between carer knowledge scores and carer controllability scores**

The relationships between carer knowledge scores and carer controllability scores were explored using Spearman’s Rank Order correlations. Table 13. reveals the values obtained.

**Table 13: Correlations between carer knowledge scores and carer controllability scores on the BMD scale**

<table>
<thead>
<tr>
<th>Correlations between DKQ total scores and carer controllability scores within the BMD and its sub-scales</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>DKQ total score/ Apathetic- Withdrawn sub-scale</td>
<td>-.103</td>
</tr>
<tr>
<td>DKQ total score/ Active-Disturbed sub-scale</td>
<td>-.086</td>
</tr>
<tr>
<td>DKQ total score/ Mood Disturbance sub-scale</td>
<td>-.121</td>
</tr>
<tr>
<td>DKQ total score/ BMD total scale score</td>
<td>-.034</td>
</tr>
</tbody>
</table>

None of the above correlations were significant at the p<0.05 level (1-tailed test).

Thus hypothesis 2.2 did not appear to be supported (*Carer levels of knowledge would have a negative relationship with carer perceptions of care-recipients’ behaviour and mood disturbance being under volitional control*).
b) Relationship between carer knowledge scores and carer causal attribution scores for care-recipients’ behaviour and mood disturbance

The relationship between carer knowledge scores and carer causal attribution scores for care-recipients’ behaviour and mood disturbance was assessed using Spearman’s Rank Order correlations. Table 14. shows the values obtained.

<table>
<thead>
<tr>
<th>Correlations</th>
<th>r values</th>
<th>Correlations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>DKQ tot. score/ Illness</td>
<td>.030</td>
<td>DKQ tot. score/ Illness</td>
<td>-.360**</td>
</tr>
<tr>
<td>DKQ tot. score/ Personality</td>
<td>-.302*</td>
<td>DKQ tot. score/ Personality</td>
<td>-.008</td>
</tr>
<tr>
<td>DKQ tot. score/ Other</td>
<td>-.104</td>
<td>DKQ tot. score/ Other</td>
<td>.150</td>
</tr>
<tr>
<td>DKQ tot. score/ Illness/Personality</td>
<td>.229</td>
<td>DKQ tot. score/ Illness/Personality</td>
<td>.377**</td>
</tr>
</tbody>
</table>

**= sig. at p<0.01 (1-tailed); *= sig. at p< 0.05 (1-tailed)

The results revealed that only correlations between knowledge and causal attributions of behaviour and mood disturbance to the care-recipients’ personality were consistently in the expected direction. This suggested that carers who had lower knowledge scores also tended to attribute their care-recipient’s behaviour and mood disturbance to personality, regardless of the type of behaviour. However, this association was only significant for Apathetic-Withdrawn behaviour (DKQ tot. score/ Personality; r= -.302, p<0.05) and for the total BMD Scale (DKQ tot. score/ Personality; r= -.288, p<0.05).
Correlations between knowledge and causal attributions of behaviour and mood disturbance to the care-recipients’ illness were consistently not in the expected direction, with the exception of Apathetic-Withdrawn behaviour. In other words, rather than higher levels of knowledge being associated with a higher proportion of causal attributions to illness as predicted, higher levels of knowledge were in fact associated with lower proportions of causal attributions to the illness. This association only reached significance on the Active-Disturbed sub-scale (DKQ tot. score/ Illness; \( r = -0.360 \), \( p<0.01 \)).

The remaining significant results revealed positive relationships between knowledge, and causal attributions of illness/personality (Active-Disturbed DKQ tot. score/ Illness/ Personality; \( r = 0.377 \), \( p<0.01 \); and Total BMD Scale DKQ tot. score/ Illness/ Personality; \( r = 0.267 \), \( p<0.05 \)).

Thus findings were consistent with hypothesis 2.3 (Carer levels of knowledge would have a negative relationship with carer attributions of care-recipients’ behaviour and mood disturbance to the personality with regards to apathetic-withdrawn behaviour).

**Carers’ levels of depression and anxiety as measured by the Hospital Anxiety and Depression Scale (HADS)**

Carers’ total HADS scores, HADS anxiety sub-scale scores and HADS depression sub-scale scores were normally distributed (see appendix 14 for Z scores obtained for skewness and kurtosis).

Table 15. shows the means, standard deviations and individual score ranges for the HADS and its sub-scales.

<table>
<thead>
<tr>
<th>Sub-scale</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual score range</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS Anxiety</td>
<td>7.58</td>
<td>4.22</td>
<td>0-20</td>
</tr>
<tr>
<td>HADS Depression</td>
<td>5.72</td>
<td>3.60</td>
<td>0-16</td>
</tr>
<tr>
<td>HADS Total</td>
<td>13.30</td>
<td>7.10</td>
<td>0-35</td>
</tr>
</tbody>
</table>
This table reveals that the mean scores for the anxiety and depression sub-scales combined together (HADS Total) was 13.3 (s.d. = 7.10). For the anxiety and depression sub-scales, the mean scores were 7.58 (s.d. = 4.22) and 5.72 (s.d. = 3.60) respectively.

A closer look at the scores revealed that 8 carers obtained scores equal to or greater than 11 on the anxiety sub-scale, and 3 carers obtained scores equal to or greater than 11 on the depression sub-scale (indicating clinically significant symptoms).

**Relationship between carer levels of knowledge and carer levels of depression and anxiety**

Spearman’s Rank Order correlations were calculated to assess the relationship between carers’ HADS scores and carers’ levels of knowledge (DKQ total scores). Table 16. shows the values obtained.

<table>
<thead>
<tr>
<th>Correlations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>DKQ tot. score/ HADS Anxiety sub-scale</td>
<td>.164</td>
</tr>
<tr>
<td>DKQ tot. score/ HADS Depression sub-scale</td>
<td>.083</td>
</tr>
<tr>
<td>DKQ tot. score/ HADS total score</td>
<td>.152</td>
</tr>
</tbody>
</table>

None of the above correlations reached significance for 1-tailed tests.

Therefore hypotheses 2.4 a. and 2.4 b. did not appear to be supported (a. *Carer levels of knowledge would have a negative relationship with carer levels of depression, and* b. *a positive relationship with carer levels of anxiety*).
Part three:

Relationships between carer levels of EE and care-recipients’ level of behaviour and mood disturbance, carer levels of depression and anxiety, and carer perceptions of pre-morbid relationship (Hypotheses 3.1-3.3).

Care-recipients’ behaviour and mood disturbance as measured by the BMD scale

Total scores for the BMD scale and its sub-scales were fairly normally distributed (see appendix 14 for Z scores obtained for skewness and kurtosis).

Table 17. reveals care-recipients’ mean scores, standard deviations and individual score ranges on the BMD scale.

<table>
<thead>
<tr>
<th>BMD Sub-scales</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apathetic-Withdrawn</td>
<td>22.56</td>
<td>8.19</td>
<td>3-40</td>
</tr>
<tr>
<td>Active-Disturbed</td>
<td>19.58</td>
<td>8.88</td>
<td>0-38</td>
</tr>
<tr>
<td>Mood Disturbance</td>
<td>9.19</td>
<td>5.00</td>
<td>0-21</td>
</tr>
<tr>
<td>Total BMD Scale</td>
<td>47.63</td>
<td>15.27</td>
<td>5-75</td>
</tr>
</tbody>
</table>

As can be seen from the table, individual score ranges and standard deviations are fairly large.
Relationship between carer levels of EE and care-recipients’ behaviour and mood disturbance as measured by the BMD scale

To assess the relationship between PRS scores and the BMD scale scores, Spearman’s Rank Order correlations were calculated. Table 18 reveals the values obtained.

**Table 18: Correlations between carers’ PRS scores and care-recipients’ BMD scale scores**

<table>
<thead>
<tr>
<th>Correlations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRS/ BMD Apathetic-Withdrawn</td>
<td>.004</td>
</tr>
<tr>
<td>PRS/ BMD Active-Disturbed</td>
<td>.040</td>
</tr>
<tr>
<td>PRS/BMD Mood Disturbance</td>
<td>.520**</td>
</tr>
<tr>
<td>PRS/ Total BMD</td>
<td>.147</td>
</tr>
</tbody>
</table>

**= sig. at p<0.01 (2-tailed)

The correlations showed that PRS scores were significantly positively correlated with scores of the BMD Mood Disturbance sub-scale. In other words, carers who reported their care-recipient to be exhibiting more mood disturbance tended to report more critical and hostile attitudes toward them.

Thus hypothesis 3.1 (null hypothesis) did not appear to be upheld (*Carer levels of EE would not have a relationship with levels of behaviour and mood disturbance*).

Relationship between carer levels of EE and carer levels of depression and anxiety

To assess the relationship between carers’ PRS scores and carers’ HADS scores, Spearman’s Rank Order correlations were calculated. Table 19 shows the values obtained.

**Table 19: Correlations between carers’ PRS scores and carers’ HADS scores**

<table>
<thead>
<tr>
<th>Correlations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRS/ HADS Anxiety sub-scale</td>
<td>.116</td>
</tr>
<tr>
<td>PRS/ HADS Depression sub-scale</td>
<td>-.030</td>
</tr>
<tr>
<td>PRS/ HADS total score</td>
<td>.110</td>
</tr>
</tbody>
</table>

None of the above values were significant at the p<0.05 level (1-tailed test), indicating that no statistically significant relationship existed between emotional attitudes of...
criticism and hostility, and experiencing symptoms of anxiety and depression in this sample.

To explore the existence of an association between anxiety and EE levels in carers who could be classed as clinically anxious (n=8; due to a cut-off score of 11 on the Anxiety sub-scale), a Fisher’s Exact Test was performed. Carers were categorised as anxious (n=8) or not anxious (n=35), and as High-EE (PRS score equal to or more than 81) or Low-EE (PRS score less than 81). There was no significant association (p=.105; 1-tailed). The number of carers who could be classed as clinically depressed on the basis of a score of 11 or more (n=3), was not high enough to do a Fisher’s Exact or Chi Squared Test.

Hypothesis 3.2 did not appear to be supported (Carer levels of EE would have a positive relationship with carer levels of depression and anxiety).

**Carer and care-recipient’s pre-morbid relationship**

A composite pre-morbid relationship score was calculated by adding the three pre-morbid relationship items together for each carer. The composite scores were negatively skewed in their distribution (see appendix 14 for Z scores obtained for skewness and kurtosis).

Table 20. reveals the means, standard deviations and individual score range for each item separately, and finally the composite score.

<table>
<thead>
<tr>
<th>Pre-morbid relationship item</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Closeness</td>
<td>4.35</td>
<td>1.00</td>
<td>1-5</td>
</tr>
<tr>
<td>Positivity</td>
<td>4.12</td>
<td>1.10</td>
<td>1-5</td>
</tr>
<tr>
<td>Conflict</td>
<td>4.09</td>
<td>1.00</td>
<td>2-5</td>
</tr>
<tr>
<td>Composite score</td>
<td>12.53</td>
<td>2.42</td>
<td>7-15</td>
</tr>
</tbody>
</table>

High score on conflict item = low levels of conflict.

The mean scores ranging between 4.09 and 4.35 reveal that generally, carers perceived their pre-morbid relationship with their care-recipient to be quite close, quite positive and with very little conflict.
Relationship between carer levels of EE and carer perceptions of pre-morbid relationship

The relationship between carer levels of EE and carer perceptions of pre-morbid relationship was explored using Spearman’s Rank Order correlation. Only the composite score was used in the analysis. PRS scores and the composite pre-morbid relationship scores were significantly negatively correlated ($r = -0.582, p<0.01; 1$-tailed). Thus carers who perceived their pre-morbid relationship to be of a poorer quality tended to report more critical and hostile attitudes toward their care-recipient.

Therefore findings were consistent with hypothesis 3.3 (*Carers’ levels of EE would have a negative relationship with carer perceptions of the pre-morbid relationship*).

Additional unplanned analyses (Spearman’s rank order correlations) were conducted to explore the relationships between carer perceptions of the pre-morbid relationship and carer perceptions of control and attributions about cause of behaviour and mood disturbance. Table 21. reveals the values obtained.
### Table 21: Correlations between composite pre-morbid relationship scores and controllability and causal attribution scores

<table>
<thead>
<tr>
<th>Correlation combinations</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre-morbid relationship/ Controllability score for total BMD Scale</td>
<td>-.323*</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Controllability score for Apathetic-Withdrawn sub-scale</td>
<td>-.248</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Controllability score for Active-Disturbed sub-scale</td>
<td>-.296</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Controllability score for Mood Disturbance sub-scale</td>
<td>-.280</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Total causal attribution score to illness</td>
<td>.356*</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Total causal attribution score to personality</td>
<td>-.201</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Total causal attribution score to other</td>
<td>-.026</td>
</tr>
<tr>
<td>Pre-morbid relationship/ Total causal attribution score to illness/person</td>
<td>-.407*</td>
</tr>
</tbody>
</table>

*=significant at p<0.05(2-tailed)

This table shows that results for correlations between pre-morbid relationship scores and controllability scores followed a trend. Carer perceptions of better pre-morbid relationship were associated with perceptions of care-recipients having less control over their behaviour. However only the correlation between relationship scores and controllability scores on the total BMD scale was significant (r= -.323, p<0.05).

Additionally, perceptions of pre-morbid relationship were significantly positively correlated with attributions of care-recipient behaviour and mood disturbance to their illness (r= .356, p<0.05), and significantly negatively correlated with attributions to a mixture of their illness and personality(r= -.407, p<0.05).
A caveat to the interpretation of the results

The current study's measure of carer perceptions of control and attributions of cause, which was modelled upon the design of the attributions measure used in studies by Harrison and Dadds (1992) and Harrison et al. (1998), presented a challenge to the process of statistical analysis.

In the current study (as with the studies mentioned above) carers were asked to rate their perceptions of controllability of care-recipients' behaviour and mood disturbance and then attribute it to cause, only if they had indicated any presence of the behaviour and mood disturbance on a measure (the BMD Scale in this study). Therefore carers naturally varied in the number of BMD items on which they reported the presence of behaviour and mood disturbance, and then made an attribution. As a consequence, every item of the BMD contained a certain percentage of missing data with regards to carers recording attributions about cause and perceptions of control. (A table detailing missing data for each item of the attributions measure can be viewed in appendix 15).

The presence of varying amounts of missing data has implications for a) the validity of the measure of attributions in collecting information about behaviour and mood disturbance which is representative of this group of carers' perceptions of their care-recipients' dementia related difficulties, and b) for the calculation of the level of carers' perceived controllability and perceptions of carer attributions to their illness, personality, illness/personality or to something else (other).

As an illustration of the implications of point b), consider the following scenario:-

Carer one indicates that their care-recipient exhibits behaviour and mood disturbance reflected in 20 items out of 31 on the BMD scale. Thus they make 20 indications of their perceptions of control and attributions about cause to illness, personality, illness/personality or other.

Carer two indicates that their care-recipient exhibits behaviour and mood disturbance reflected in 10 items out of 31 on the BMD scale. Thus they make 10 indications of their perceptions of control and attributions about cause to illness, personality, illness/personality or other.
Following procedures detailed by Harrison and Dadds (1992), Harrison et al. (1998), (and those followed in the current study for section one of the results), controllability scores would be calculated by adding each individual controllability score (1-5) together and dividing it by the total of the number of items answered (n=20 for carer one, and n=10 for carer two). Causal attribution scores would be calculated by ascertaining the percentage of attributions to each causal category (illness, personality, illness/personality or other).

Consider that carer one attributed 18 items out of 20 to illness, and the remaining two items to personality, they would have causal attribution scores of 90% (0.9) to illness, and 10% (0.1) to personality. If carer two attributed all 10 items out of 10 to illness, they would have a causal attribution score of 100% (1.0) to illness, and 0% to personality (0.0). It then becomes clear that carer two would be seen to be attributing behaviour and mood disturbance to illness to a higher degree than carer one.

Although this is technically true, at face value one would question whether this is a true reflection, bearing in mind carer one has a wider range of behaviours to make an attribution about and so is more likely to find one or two behaviours which could be attributed to something other than illness. Therefore there was some concern over the reliability of calculations of causal attributions in particular within this study.

Harrison and Dadds (1992) attempted to address this problem by excluding from their analyses items reflecting symptoms that occurred in less than 30% of the patients in their sample. In their subsequent study (Harrison et al., 1998) they addressed the problem by including in the analysis only items which had occurred in more than 60% of the patients. However, although this would improve the reliability to a certain degree, there would still be some mis-representation of the total causal attribution scores, and thus in subsequent statistical analyses.

Therefore, in order to corroborate findings with regards to main hypotheses including perceptions of controllability and attributions of cause achieved in section one of the results, further analysis was conducted and presented in section two. For the purposes of further analysis, three items from the BMD were selected on the basis of the following criteria:-

270
1. Less than 30% missing data.

2. Face validity that any degree of the behaviour and mood disturbance might be perceived as a ‘problem behaviour’ against the backdrop of additional dementia-related difficulties.

3. One item from each of the three BMD sub-scales.

The three selected BMD items were as follows:

1. ITEM 3: Sits around doing nothing (Apathetic-Withdrawn sub-scale).

2. ITEM 16: Appears restless and agitated (Active-Disturbed sub-scale).

3. ITEM 27: Goes on and on about certain things (Mood Disturbance sub-scale).

Statistical analyses on the above three items included no missing data as only carers who responded were included. Thus the sample sizes for analyses conducted on perceptions of controllability on items 3, 16 and 27, were n=35, n=36 and n=32 respectively.

For analyses conducted on causal attributions, only carers answering all three of the items in combination were included (n=24), because the items needed to be added together in order to ensure variability in individual scores for subsequent analyses.
SECTION TWO:

Further analyses to corroborate findings with regard to carer perceptions of controllability and causal attributions of behaviour and mood disturbance

Carer attributions of controllability for behaviour and mood disturbance on items 3, 16 and 27 only.

Frequency analysis revealed that the modal response for perceptions of controllability of behaviour and mood disturbance for each one of the three items was ‘0’ – ‘Not at all controllable’.

Table 22. shows carers’ mean controllability scores, individual score ranges and standard deviations for items 3, 16 and 27.

<table>
<thead>
<tr>
<th>Item number and sub-scale</th>
<th>Mean</th>
<th>Standard deviation</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 3 (Apathetic- Withdrawn)</td>
<td>.91</td>
<td>1.34</td>
<td>0-4</td>
</tr>
<tr>
<td>Item 16 (Active Disturbed)</td>
<td>.19</td>
<td>.62</td>
<td>0-3</td>
</tr>
<tr>
<td>Item 27 (Mood Disturbance)</td>
<td>.44</td>
<td>.91</td>
<td>0-4</td>
</tr>
</tbody>
</table>

This table reveals that the range of individual scores lay between ‘0’- ‘Not at all controllable and ‘4’- ‘Controllable most of the time’ Although the mean scores for each item lay between ‘0’ – ‘Not at all controllable’ and ‘1’- ‘Slightly controllable’. The behaviour from the Apathetic- Withdrawn sub-scale (item 3) was perceived by carers to be the most controllable (mean controllability score = .91). Item 16 from the Active-Disturbed sub-scale was perceived to be the least controllable. These findings were similar to findings in section one, part one of the results.

A Friedman Two Way Analysis of Variance test detected borderline significant differences between the mean perceptions of controllability scores of the three items ($\chi^2 = 5.879, p<.053$).
Relationship between carer levels of EE and carer perceptions of controllability scores

Spearman’s Rank Order correlations were performed to assess the relationship between carer PRS scores, and carer controllability scores.

Table 23. shows the values for correlations between PRS scores and controllability scores for items 3, 16 and 27.

Table 23: Correlations between PRS scores and controllability scores for items 3, 16 and 27

<table>
<thead>
<tr>
<th>Correlation combination</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRS/ Item 3 (Apathetic-Withdrawn sub-scale)</td>
<td>.127</td>
</tr>
<tr>
<td>PRS/ Item 16 (Active-Disturbed sub-scale)</td>
<td>.026</td>
</tr>
<tr>
<td>PRS/ Item 27 (Mood Disturbance sub-scale)</td>
<td>.064</td>
</tr>
</tbody>
</table>

None of the above correlations were significant at p<0.05 or below for 1-tailed tests. As found in section one, part one, there was no significant relationship between PRS scores and perceptions of controllability scores.

The association between carer PRS scores and carer controllability scores was also explored using a Fisher’s Exact test. Carers were divided into two groups for each item; a) for levels of EE; High-EE carers (carers with PRS scores equal to or more than the median), and Low-EE carers (carers with PRS scores less than the median), and b) for levels of controllability; carers who perceived no controllability (carers with controllability scores of 0), and carers who perceived some controllability (carers with controllability scores of greater than 0). Table 24. reveals the values obtained for each of the three items.

Table 24: Fisher’s Exact results for high/low PRS score split and none/some perceived controllability score split on items 3, 16 and 27

<table>
<thead>
<tr>
<th>Item numbers</th>
<th>Fisher’s Exact</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 3 (Apathetic-Withdrawn sub-scale)</td>
<td>P=.409</td>
</tr>
<tr>
<td>Item 16 (Active-Disturbed sub-scale)</td>
<td>P=.541</td>
</tr>
<tr>
<td>Item 27 (Mood Disturbance sub-scale)</td>
<td>P=.256</td>
</tr>
</tbody>
</table>

The table reveals no significant associations for 1-tailed tests.
Carer attributions about cause of care-recipients’ behaviour and mood disturbance

Frequency analysis revealed that the modal response for causal attributions about behaviour and mood disturbance for each one of the three items was an attribution of illness.

Mean causal attribution scores, individual score ranges and standard deviations for all three items in combination are shown in table 25.

Table 25: Means, standard deviations and individual ranges of carers’ causal attribution scores for all three items in combination

<table>
<thead>
<tr>
<th>Causal attributions category</th>
<th>Mean</th>
<th>Standard deviations</th>
<th>Individual range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attributions to illness</td>
<td>.83</td>
<td>.22</td>
<td>.33-1.0</td>
</tr>
<tr>
<td>Attributions to personality</td>
<td>.01</td>
<td>.07</td>
<td>0-.33</td>
</tr>
<tr>
<td>Attributions to other</td>
<td>.04</td>
<td>.11</td>
<td>0-.33</td>
</tr>
<tr>
<td>Attributions to illness/personality</td>
<td>.11</td>
<td>.19</td>
<td>0-.67</td>
</tr>
</tbody>
</table>

Mean scores for attributions of behaviour and mood disturbance to the care-recipients’ illness were higher than mean scores for the attributions to any other category. This pattern is similar to the one detected in section one, part one.

Relationship between carer levels of EE and carer attributions about cause of care-recipients’ behaviour and mood disturbance

A Spearman’s Rank Order correlation was performed to assess the relationship between PRS scores and attributions of cause to illness only, as this attribution category held sufficiently variable scores. There was no significant relationship (r=.121, p=.29; 1-tailed).

The association was also assessed using a Chi Squared test. Carers were divided into two groups for; a) for levels of EE; High-EE carers and Low-EE carers, and b) for attributions of cause; carers who made attributions to illness only, and carers who
made attributions to causes other than illness. Again, the association was not significant ($\chi^2 (1) = 0.00, p=1.00$). This finding was different from the one obtained in section one, part one, whereby attributions to illness on the total BMD Scale were significantly negatively correlated with PRS scores.

**Relationship between carer levels of knowledge and carer perceptions of control, and attributions of cause about care-recipients’ behaviour and mood disturbance**

a) **Relationship between carer knowledge and carer controllability**

The relationship between carer knowledge scores and carer controllability scores were explored using Spearman’s Rank Order correlations. Table 26. reveals the values obtained.

<table>
<thead>
<tr>
<th>Correlations between DKQ total scores and carer controllability scores</th>
<th>r values</th>
</tr>
</thead>
<tbody>
<tr>
<td>DKQ/ Item 3 (Apathetic-Withdrawn subscale)</td>
<td>-.229</td>
</tr>
<tr>
<td>DKQ/ Item 16 (Active-Disturbed subscale)</td>
<td>.242</td>
</tr>
<tr>
<td>DKQ/ Item 27 (Mood Disturbance subscale)</td>
<td>.112</td>
</tr>
</tbody>
</table>

As in section one, part one, none of the above values were significant at $p<0.05$ for 1-tailed tests.

b) **Relationship between carer knowledge scores and carer causal attribution scores for care-recipients’ behaviour and mood disturbance**

The relationship between carer knowledge scores and attributions to illness scores for care-recipients’ behaviour and mood disturbance was assessed using a Spearman’s Rank Order correlation. There was no significant relationship ($r = -.269, P=.102$; 1-tailed).
A Fisher’s Exact test was conducted comparing; a) carers with higher levels of knowledge (DKQ total score equal to or more than the median) and lower levels of knowledge (DKQ total score of less than the median), and b) carers making attributions to illness only, and carers making attributions to causes other than illness. There was no significant association (p= .582, 1-tailed). This result was similar to the finding in section one, part two (no significant association between knowledge and illness attributions on the total BMD scale).

To summarise, further analyses revealed similar findings to those recorded in section one, with one exception (no significant relationship between carer levels of Expressed Emotion as measured by the PRS, and carer attributions to illness).
Discussion

Findings obtained in this study will be discussed under headings which parallel the structure of objectives and hypotheses set out earlier. The study’s limitations will then be acknowledged, and their potential impact on the interpretations of the findings will be discussed. Finally, the clinical implications of the findings will be considered and suggestions for future research will be proposed.

Assessment of the generalisability of Hooley’s attributional model

The primary objective was to consider the usefulness of Hooley’s attributional model in understanding levels of Expressed Emotion in carers of people with dementia. As highlighted in the introduction, it was considered that appropriating explanatory models from one domain of condition to another may pose challenges as a result of the qualitative differences between the conditions of schizophrenia and dementia. This consideration seemed pertinent. At a general level, carers tended to perceive their care-recipients’ behaviour and mood disturbance to be uncontrollable, and to be caused by their illness. This suggests that at face value, the attributional model is of limited use in understanding levels of EE in carers of people with dementia, perhaps because dementia is more readily understood to have an organic basis in comparison to the possibly less publicly understood condition of schizophrenia.

However, exploration of specific hypotheses did generate some interesting significant results, which to some extent reflect previous findings among relatives of people with schizophrenia. Although there was no significant relationship between carer attitudes of criticism and hostility toward their care-recipient, and perceptions of controllability about their behaviour and mood disturbance, carers did seem to perceive their care-recipients to have the ability to control their apathetic-withdrawn behaviour to a greater extent than other types of behaviour. Thus behaviour such as sitting around doing nothing, not showing an interest in others, not keeping themselves busy and not understanding what was said to them, was seen by carers to be more controllable by their care-recipients.

This finding was significant, and reached borderline significance (p<.053) when comparing only three items in the re-analysis (section two). The finding reflects one
obtained by Brewin et al. (1991) who found that negative symptoms reflecting apathy or self-neglect were perceived by carers of people with schizophrenia to be more controllable. It is possible, as suggested, that more disturbed behaviour (such as wandering, appearing restless and agitated, getting lost in the house, and getting mixed up about where one is) is more readily perceived as not being linked to pre-morbid personality, and thus being less under care-recipients' control.

In contrast to this finding, carers did not attribute care-recipients' apathetic-withdrawn behaviour to personality more than to illness. Causal attributions of care-recipients' behaviour and mood disturbance to illness were the most popular attributions made, regardless of the behaviour type. This finding contrasts with Harrison and Dadds' (1992) finding that negative symptoms were perceived by relatives of people with schizophrenia to be part of the patient's personality, more than positive symptoms. This finding may again highlight the qualitative differences in perceptions about the origin of dementia, as compared with the origin of schizophrenia.

Although significant relationships were not noted between carer levels of EE and perceptions of controllability, there did appear to be significant relationships with regard to causal attributions in section one of the results. Taking all behaviour and mood disturbances into account, carers who attributed their care-recipients' behaviour and mood disturbance to illness, tended to report less critical and hostile attitudes toward them, whereas when they attributed the behaviour and mood disturbance to a mixture of illness and personality, they tended to report more critical and hostile attitudes. This is partially reflective of findings by Barrowclough et al. (1994) and Brewin et al. (1991) who reported that critical relatives of people with schizophrenia were more likely to attribute their care-recipients' unusual behaviour to personality characteristics than to genuine illness.

It should be noted however that the finding with regards to illness attributions only was not supported by re-analysis on three items in section two of the results, and the finding with regards to illness/ personality attributions could not be re-analysed. Furthermore, results obtained for active-disturbed behaviour were in the opposite direction and in conflict with expectations. It may be that such behaviour evokes different attributional mechanisms in carers. Alternatively, the difference between the scores may be explained by the larger proportion of missing data in the Active-
Disturbed sub-scale. However, if the latter were true, items on the Mood Disturbance sub-scale would also be affected as this sub-scale also had larger amounts of missing data than the Active-Withdrawn sub-scale.

Whilst remaining cautious about results with regard to causal attributions because of reasons explained in the caveat earlier, it may be possible to conclude that perceptions of controllability and attributions about cause were correctly considered separately for this population of carers, as in Harrison and Dadds (1992) because there was a difference in their relationships with EE. Having said this however, at a general level the logical hypothesis of a relationship between carers’ perceptions of controllability and their causal attributions seemed to exist within this study. Carer attributions of behaviour and mood disturbance to the personality of the care-recipient had a significant positive relationship with carer perceptions of controllability on the part of the care-recipient, and carer attributions to the care-recipient’s illness did have a negative relationship with carer perceptions of volitional control.

In summary, this study suggests that Hooley’s attributional model has only a limited ability to provide explanation for levels of high EE in carers of people with dementia, because carers generally attribute their care-recipients’ behaviour and mood disturbance to illness, and perceive it to be uncontrollable. However, it is worth noting that apathetic-withdrawn behaviour appears to be perceived as more controllable than any other behaviour. Additionally, carers who report more critical and hostile attitudes toward their care-recipient may be attributing their behaviour to a mixture of both their illness and their personality, rather than simply to their illness. This final finding should be regarded with caution as it could not be tested in the re-analysis of three behavioural items only.

**Exploration of relationships between carer levels of knowledge and other variables**

The overall level of knowledge in this sample of carers was comparable to that observed in the study of knowledge among carers of people with dementia by Graham et al. (1997a). The mean score lay half way between scores generated by carers in contact with mental health care professionals and carers attending an Alzheimer’s support group.
It was hypothesised that carers who knew more about the clinical symptoms of dementia, and also about epidemiological, aetiological and rudimentary facts pertaining to dementia would also report feeling less critical and hostile toward their care-recipient. However, this hypothesis was not supported and thus did not replicate findings by Harrison and Dadds (1992) and Harrison et al. (1998). The knowledge questionnaires used in these two studies required the carer to know similar facts about schizophrenia to those requested from the Dementia Knowledge Questionnaire used in the current study. Therefore either the relationship was too weak and was a true reflection of knowledge being an unimportant variable within the process of explaining EE in this population of carers, compared with other variables left unexplored, or methodological issues such as sample size and choice of EE measure (to be discussed at a later point) were responsible for the lack of significance obtained.

Certainly within the current study carer knowledge failed to be significantly related to any other variables with the exception of causal attributions. Carers' understanding of the dementia illness was not significantly related to their experience of depressive or anxiety symptoms (although there was a negative correlation). This finding contrasts with findings by Graham et al. (1997b) who used a measure specifically designed for older adults. It is possible that the HADS was not sensitive enough to detect small differences in symptomology of older adults, however mean scores obtained by the HADS are higher than those obtained by older adults in the general population (Spinhoven et al., 1997). Thus it is unlikely that the measure was not sensitive enough. A lack of significant association between carer levels of knowledge and their perceptions about controllability of care-recipients' behaviour and mood disturbance, lends support to the speculations that the levels of knowledge in this sample was not as important a variable as anticipated.

The only significant relationship in the expected direction between carer levels of knowledge and another variable was between knowledge and causal attributions of care-recipients' behavioural disturbance to their personality. Thus carers with less knowledge about the dementia illness tended to attribute behaviour and mood disturbance at a general level, and more specifically at the level of apathetic-withdrawn behaviour, to their care-recipients' personality. This finding mirrors Harrison and Dadds' (1992) finding whereby relatives with lower levels of knowledge
about schizophrenia attributed significantly higher proportions of negative symptoms to care-recipients' personality than to illness.

However this finding should be regarded with caution as it was not appropriate to re-analyse the relationship in section two of the results, due to the lack of variability of distribution within the data pertaining to causal attributions other than illness. Also, additional significant findings were not in the expected direction within the Active-Disturbed sub-scale (e.g. more knowledge being associated with lower proportions of behaviour being attributed to illness). It is possible that the large number of individual correlations with regard to causal attributions and knowledge (n=16) gave rise to significant results by chance. More likely however is the possibility that there may be something different about behaviour reflected in the Active-Disturbed sub-scale which means that carer attributions do not conform to the usual mechanisms, especially as the deviation from the expected also happened with regard to the relationship between causal attributions and EE.

In summary, the importance of carer levels of knowledge in this sample was not as pertinent as anticipated, although carers with lower levels of knowledge did tend to attribute higher proportions of their care-recipients' behaviour and mood disturbance (particularly their apathetic-withdrawn behaviour) to their personality. This finding however should be viewed with caution due to an inability to test the association in section two of the results.

Assessment of relationships between carer EE and other variables formerly studied in carers of people with dementia

The mean carer EE level (81.5) as measured by the Patient Rejection Scale within this sample was high, relative to Whittick's finding (1992; mean score = 68, minimum-maximum range =47-99). This is probably because in the current study the maximum scores were higher, as there were two cases with scores of 123 and 126. It was decided not to exclude these cases as they did not create an abnormal distribution. Also Whittick (1992) only included twenty carers in her sample, thus the variation in scores obtained may have been reduced as a result. The mean score in the current study was also higher than that obtained by McReadie and Robinson (1988) in their
sample of 58 carers of people with schizophrenia. It is possible that the demands upon carers of people with dementia (physical and emotional) are greater as a result of their increased dependency, and because of the knowledge that their care-recipient will continue to deteriorate. Thus they may feel more negative emotion toward their care-recipient and the caring situation as a whole. Completion of the Patient Rejection Scale within this study may have provided an opportunity to channel previously unvented frustration, and thus their scores may have been inflated.

The severity and frequency of behaviour and mood disturbance in this sample of care-recipients was only very slightly less (approximately two points per sub-scale) than that observed in the original standardisation sample of the BMD Scale which involved care-recipients living in the community and attending day hospitals (Greene et al., 1982). Thus this sample of care-recipients appeared to be representative of the population in question. Despite earlier studies among carers of people with dementia consistently failing to find an association between carers’ attitudes of criticism and hostility and the severity or type of behavioural disturbance/ cognitive impairment, EE levels were found to be significantly positively correlated with carers’ perceptions of the frequency and severity of their care-recipients’ mood disturbance in this sample. In other words, carers who reported their care-recipients to be exhibiting more mood disturbance (e.g. mood changing for no apparent reason, becoming angry and threatening, appearing unhappy and depressed, and going on and on about certain things) also reported more critical and hostile attitudes toward them.

This was an unexpected finding and it contradicts in particular, the lack of relationship observed by Bledin et al. (1990) who also used the BMD Scale. However they measured carer EE by using the brief version of the Camberwell Family Interview, and so findings cannot be directly compared. Additionally, total BMD Scale scores from the Bledin et al. study were higher (by 12 points). Therefore perhaps mood disturbance is only perceived as particularly troublesome against the backdrop of less disturbed behaviour in general. At a common sense level, it may be more likely that carers feel more critical and hostile about care-recipients’ mood disturbance because they perceive it as more personal or attacking of them. It may be especially difficult to adjust to negative emotions which may not have been present within the pre-morbid
relationship (as the scores pertaining to perception of the pre-morbid relationships in this sample might suggest).

As stated earlier, mean scores obtained on the HADS in this sample were higher than those obtained by older adults in the general population (Spinhoven et al., 1997). Eight carers (18.6%) were likely to be suffering from clinical anxiety, and three carers (6.9%) from clinical depression, using the cut-off score of eleven suggested by Milne (1992). This suggests that carers of people with dementia may be a vulnerable subgroup of the general population who require specific monitoring by health care professionals. There was however no significant relationship between carer levels of EE and their reported experience of depression and anxiety symptomology. This finding is not in keeping with findings in the literature which consistently support significant relationships between the two variables (e.g. Bledin et al., 1990; Gilhooly and Whittick, 1989; Vitaliano et al., 1989; Wagner et al., 1997; and Whittick, 1992).

None of the previous studies used the HADS to measure symptoms. It was unlikely that the HADS was insensitive to measuring symptomology in this sample as the scores were higher than obtained from the general population. The Patient Rejection Scale used to measure EE has proved sensitive enough to detect a relationship between depression and EE in a previous study (Whittick, 1992). Therefore it is unclear why results within the current study failed to replicate a rather robust finding within the literature. The explanation may lie within the methodology used, whereby participants’ scores are averaged and compared to each other so that clinically significant associations between EE and symptoms are sometimes not detected. This however did not prevent significant findings being detected within the earlier studies.

Finally, carers who perceived the pre-morbid relationship with their care-recipient to be of a poorer quality tended to report more critical and hostile attitudes toward them, than carers who perceived their pre-morbid relationships to be of a better quality. This finding reflects a number of findings in the literature (Fearon et al., 1998; Gilhooly and Whittick, 1989; and Whittick, 1992) and therefore requires more research. It could potentially be an important factor in explaining EE levels among carers of people with dementia.
The unplanned analyses exploring carers’ attributions and perceptions of control in relation to perceptions of the pre-morbid relationship suggested that this might be so. Carers who perceived their pre-morbid relationship to be of a poorer quality (potentially less positive feeling, less closeness and more conflict) tended to perceive their care-recipients to have more control over their behaviour at a general level, and tended to attribute greater proportions of the behaviour to a mixture of illness/personality. On the other hand, carers with perceptions of a better pre-morbid relationship with their care-recipient tended to attribute a greater proportion of the behaviour to illness. However the results with regard to causal attributions should again be viewed with caution due to reasons explained in the caveat earlier. Additionally, the unstandardised measure tapping perceptions of pre-morbid relationship was very simplistic and not systematic.

To summarise, explorations into the relationship between carer EE and other variables proved to be useful. They highlighted a new finding which suggested that carers who reported their care-recipients to be exhibiting more mood disturbance, also tended to report feeling more critical and hostile toward them, compared with carers who reported lower levels of mood disturbance. The significant relationship between carer EE and their perceptions of pre-morbid relationship also lent support to a fairly consistent finding in the literature, and so emphasised the need for further exploration into the variable.

**Limitations of the study**

A number of aspects within this study’s methodology pose limitations to the interpretation of the results. It should be noted that this was an exploratory study seeking mainly to assess the generalisability of an explanatory model from one domain to another. Thus the procedures and measures employed should be regarded as constituting a pilot study on which to make further improvements.
Limitations of measures

The main concern with regards to the measures employed was that the Behaviour and Mood Disturbance Scale with its sections added in order to record carer perceptions of controllability and causal attributions, made responses difficult to analyse with a high degree of reliability. Despite modelling the measure upon one used by Harrison and Dadds (1992) and Harrison et al. (1998), it requires much improvement if it is to be used in future studies. Primarily the problem resides in the presence of missing data due to carers answering variable numbers and combinations of items within the BMD Scale, allowing them to make attributions about a variable number of behaviours. Calculating proportions of causal attributions on a variable number of items then becomes problematic. The corrective procedures followed by Harrison and Dadds (1992) and Harrison et al. (1998) were not sufficient to enable entirely reliable calculations and thus it is likely that their results may be slightly misleading.

Re-analyses were undertaken in section two of the results in order to produce more reliable calculations of causal attributions. However, the analyses served only to corroborate some of the findings in section one of the results, and used only three items from the BMD Scale. An entirely reliable calculation of proportions of causal attributions could only be achieved if carers answered every item on a measure. This requires a highly valid measure of symptomology for use by carers of people with dementia, and such a measure was not evident in the literature. Even with such a measure, it is unlikely that all carers would indicate presence of symptomotology on every item.

Other criticisms of the measure include the issue of eliciting attributions instead of evaluating spontaneous ones, the use of the word ‘illness’ in requesting carers to make causal attributions, the lack of standardisation procedures applied, and the use of the frequency rating ‘rarely’ as a cut-off for inclusion of a behaviour disturbance on which to make attributions. The difficulties inherent in variable response rates on the measure make the case for studying spontaneous attributions stronger. Frequency counts or global ratings of spontaneous attributions as used for analysis by Brewin et al. (1991) and Weisman et al. (1993), may give rise to a more accurate reflection of
carers’ attributions. It is also possible that the category ‘illness’ would have been better changed to ‘disorder’ or ‘condition’ so that carers who perhaps had not explicitly considered their care-recipients to be suffering from an illness per se, were not prompted to think in such a way and then be influenced in subsequent attributional responses.

The measurement of attributions in this study was not subject to an assessment of test-retest reliability. It was considered unethical to request carers to record their attributions again within a short time frame due to their stressful life situations and limited time available. Additionally, if a longer time had been allowed to lapse, carers’ attributions may have altered due to knowledge obtained by attending support groups for example. If the measure were to be used in subsequent studies it would be necessary to obtain reliability data. Finally, it may have been more appropriate to request that carers only made an attribution about their care-recipients’ behaviour if they had indicated that it occurred ‘sometimes’ or more often. Within this study, behaviours were perceived as problematic and necessitating an attribution even if they were present only rarely. Requesting carers to make an attribution about a behaviour which occurs only rarely may encourage less reliable attributions on less valid ‘problem’ behaviours.

The measurement of EE in this study was not carried out with the use of the traditional Camberwell Family Interview or Five Minute Speech Sample. However its self-report format was very appropriate, being easy to administer and quick to complete. It was clearly sensitive enough to indicate high levels of EE. One draw back however was the lack of cut-off score with which to separate High-EE carers from Low-EE carers. Treating it as a continuous variable necessitated correlational analyses. Although the median score was used to separate carers with higher scores from those with lower scores in order to conduct Chi Squared tests, this cut-off score was a statistically logical one rather than an empirically validated one. Further investigation into the use of the measure with carers of people with dementia to increase its clinical application would be beneficial.
Finally, with regards to measures used in this study, all were subjective and based upon carers’ perceptions of the variables in question. Thus carer self-reports may have been influenced by temporary states of mind, or be distorted by memory of events in the week prior to data collection. Collection of data from additional more informal carers (e.g. day centre staff) with regards to care-recipients’ behavioural disturbance was not deemed to be useful as it was the information on behaviour at home that was relevant to the questions in this study.

Other methodological issues

Due to the exploratory nature of the study, Bonferroni’s adjustment was not made. Therefore some of the significant findings (particularly those at p<.05) may have been obtained by chance rather than being a reflection of reliable relationships within the phenomena. In order to draw firmer conclusions it would be necessary to replicate this study with a larger sample size and perhaps with Bonferroni’s adjustment. Additionally, multivariate analyses were not conducted in order to explore the relative influences of certain variables on findings, or to make predictions. This was not necessary as all hypotheses were adequately explored with bivariate analyses. Also the use of non-parametric correlational tests would have rendered subsequent parametric multivariate analyses quite unreliable. It would be important to consider multivariate exploration in future studies as Harrison et al. (1998) had done in building upon the study carried out by Harrison and Dadds (1992).

Although the sample size in this study was sufficient to detect significant differences, larger numbers would be preferable in future studies in order to obtain more representative samples. Unfortunately due to the limited time available to conduct the research, it was not possible to continue recruiting carers for data collection. This time limit also necessitated ease of access to participants and thus only carers in contact with mental health services or the Alzheimer’s Disease Society were approached to take part in the study. Therefore the sample may be somewhat biased because it is likely that these carers may have been struggling in their caring role more than those who were not yet in contact with services. Furthermore, approximately 40% of carers did not respond to letters of invitation. Those who did may be
qualitatively different from those who chose not to (e.g. under less stress at the time) thus results may be biased accordingly.

Finally, this study did not explore wider contextual factors that might be directly or indirectly influencing carers’ perceptions and attributions about their care-recipients’ behaviour and mood disturbance (for example factors such as chronic physical illness in the carer, or financial difficulties experienced in the face of the caring situation). Measurement of these variables and explorations into their relative influence or predictive power within levels of Expressed Emotion would be desirable.

Clinical implications

Some of the significant findings and patterns observed within the results section gave rise to suggestions for clinical practice within services providing for people with dementia and their carers. Despite concerns about the reliability of the measure of carers’ perceptions of control and their causal attributions, the use of the measure in providing a rough indication of how carers perceive and explain their care-recipients’ behaviour and mood disturbance may be appropriate in the process of assessment. It may provide a broad picture of whether carers are processing behaviour in such a way as to create unrealistic expectations about their care-recipient, and thus make them more vulnerable to negative emotional attitudes toward them. Equally, the quickly administered Patient Rejection Scale may be useful in screening for extremely high levels of EE as part of the process of risk assessment within the caring situation.

Although the reliability of the measure of carers’ causal attributions and perceptions of control is to be questioned, some of the findings were in keeping with previous findings and expectations in the literature. To a certain extent it may be that providing carers with information that encourages them to attribute more of their care-recipients’ behaviour and mood disturbance to illness, may then be associated with decreases in feelings of criticism and hostility toward them. Additionally, emphasising the fact that apathetic-withdrawn behaviour is often associated with dementia, may help carers to understand that their care-recipients may not have as much control over it as they believe.
Due to the finding that carers who report more critical and hostile attitudes are also reporting more mood disturbance among their care-recipients, it may be useful to screen for high levels of mood disturbance in care-recipients living at home with a carer. Such carers may benefit from additional support from health care professionals in the form of advice in dealing with, for example aggressive behaviour, or from less direct contact with their care-recipient (more attendance at a day centre or increased respite).

Finally, obtaining information about a carers’ perceptions of the quality of the pre-morbid relationship with their care-recipient during a routine assessment of needs could be useful in highlighting carers who may be more at risk of more negative attitudes. This form of risk assessment may create an opening for dialogue between the professional and carer so that the carer’s newly acquired caring role can be understood within the context of their pre-morbid relationship.

**Suggestions for future research**

The process of carrying out this study gave rise to a small number of suggestions for future research. It would be helpful to investigate further the measurement of elicited attributions about cause and perceptions of controllability in order to improve the validity and reliability of the measure used in the current study. This might necessitate the development of a new measure based upon behavioural items that all carers answer. This seems essential if the measure is to be used again among carers of people with dementia. Furthermore, it would be advantageous to establish an empirically validated and clinically relevant cut-off score for High- and Low-EE carers on the Patient Rejection Scale for use in clinical work.

Due to the unexpected results obtained with regards to active-disturbed behaviour and the corresponding causal attributions and perceptions of control, it may be helpful to understand more about why these scores deviated from the expected. This could provide valuable information for professionals working with carers who live with care-recipients exhibiting such behaviour. There may be qualitative differences in the
attributional process carers experience in the face of these behaviours. Additionally, it would be interesting to explore why carers perceive apathetic-withdrawn behaviour to be more controllable than other types of behaviour with the use of qualitative methods. Within this sample of carers it did not appear to be the fact that they attributed such behaviour to personality more than other behaviour. Obtaining this information may guide professionals in understanding what type of information is beneficial to impart to carers.

The finding that carers who perceived their pre-morbid relationship to be of a poorer quality tended report more critical and hostile attitudes, to perceive their care-recipients to be able to control their behaviour more and attributed a greater proportion of their behaviour to a mixture of personality and illness than carers with perceptions of better quality pre-morbid relationship, requires further investigation. The context of a poor pre-morbid relationship may be of importance when considering EE and its attributional explanation. Research concentrating specifically on these variables and employing analyses which establish each variable’s relative influence on significant relationships might be the logical next step in research.

Finally, the results obtained in this study do not imply direction of causality. It would be useful to compare changes in carer Expressed Emotion and attributions, before and after intervention designed to modify specific attributions in carers of people with dementia, in order to establish whether Expressed Emotion levels reduce as a result (as in Brewin’s study with carers of people with schizophrenia; 1994).

Overall, this study provided a basis from which to develop further research into explanatory models of Expressed Emotion in carers of people with dementia. It is hoped that the limitations and suggestions for research discussed within this section would be helpful to take into consideration during this process.
References


Appendices
Our Ref: EC104/98

9 December 1998

Ms Zena Dowling
32D Copenhagen Gardens
Chiswick
LONDON
W4 5NN

Dear Ms Dowling

EXPRESSED EMOTION AMONG CARERS OF PEOPLE WITH DEMENTIA:
KNOWLEDGE AND ATTRIBUTIONS ABOUT CAUSE AND CONTROLLABILITY
OF SYMPTOMS

I am pleased to inform you that, at its meeting on 8 December 1998, the Ethics Committee ratified Chairman’s Action and approved the above study.

2. The Committee’s decision is based on its review of the following documents:

(i) The research protocol enclosed with your letter to me dated 23 October 1998.

(ii) The amended version of appendices 1 and 2 to the protocol and the addition of appendix 12 enclosed with your letter to me dated 23 November 1998.

(iii) Your letter to me dated 23 November 1998 providing assurances to the Committee in response to the points it raised.

(iv) The South West Surrey LREC application form which you signed on 26 October 1998.

3. CONDITIONS OF APPROVAL

The Committee’s approval is subject to the following conditions:

Modifications to the Protocol

(i) No deviations from or changes of the protocol should be initiated without prior written approval of the Committee. Approval of the Committee is not required for protocol changes of an administrative nature.
Reports

(ii) The Committee should be provided with a copy of the report on the outcome of the study or a copy of any published document.

Time Limit on Committee’s Approval

(iii) If the start of the project is delayed by more than one year from the date of approval the protocol should be re-submitted to the Committee for further review.

4. I enclose a copy of the Application Form, which I have signed confirming the Committee’s approval.

Yours sincerely

DR J W WRIGHT
Chairman
Dear Sir/Madam,

I am writing to let you know of a study being carried out in your area. The study involves people who care for a relative or spouse with dementia at home.

I have attached an information sheet to this letter which tells you about the study. I would be very grateful if you could read the attached information and think about whether you might be interested in participating in the study.

If after reading the information you feel you would be happy for me to contact you by telephone in the near future to discuss the study, I would be most grateful if you could return the slip at the bottom of the sheet in the pre-paid envelope provided as soon as possible.

If however you have already decided that you would not like to discuss the study further, please do not return the slip. Deciding not to take part will not affect the healthcare you or your relative receive in any way.

Thank you very much for your time,

Yours sincerely

Ms Zena Dowling
Psychologist in Clinical Training
This information has been prepared in order to tell you of a study (piece of research) which is currently being carried out in your area. Please read the information carefully and think about whether you might be interested in participating in the study.

**What is the study about?**

We are interested in understanding how carers feel about their relative or spouse who has been diagnosed as suffering from dementia. We are interested in positive and negative feelings, as well as mixed feelings. In particular, we would like to understand some of the reasons why carers have different feelings.

**What will happen during the study?**

If you are interested in participating in the study after asking any questions you might have, a psychologist will meet with you for about an hour. The meeting will be arranged at a time convenient for you, and without the person for whom you are caring. This is so that you can speak freely and not feel distracted.

You will be asked some questions about yourself, and will fill in some forms. The forms ask you how you are feeling in yourself, how you feel about your relative or spouse, your understanding of dementia, and about your relative’s behaviour. A minimal amount of writing is required as you will be asked to simply choose the responses which best reflect your answers.

**How is the study useful?**

This study will help us to understand what might influence carers’ feelings toward their relative or spouse. The information gained may help healthcare professionals in providing information to carers in a better way. Although you may not directly benefit from this study, we hope your answers will help other carers like you in the future.
What happens if I say "No"?

Your participation in this study is entirely voluntary and your decision will be respected whatever you decide. Yours or your relative’s care will not be affected in any way if you do not wish to take part. You can withdraw from the study at any time without giving a reason.

What about confidentiality?

All of the information you give will be strictly confidential. The information you give us will be put together with others in order to come to some conclusions. A final report will be prepared as a result, however it will contain no names and only the ‘general’ results will be stated.

Has this study been approved?

This study has been approved by the South West Surrey Local Research Ethics Committee.

The Local Research Ethics Committee has approved the above statement.

IMPORTANT

N.B. If you are interested in helping with this study please complete and tear off the slip below. Then send it in the pre-paid envelope as soon as possible. Thank you

My full name is:

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

My relative’s full name is:

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

Telephone number:

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

I have read the information sheet which explains your study and I am happy for you to contact me to discuss the study further.
SOUTH WEST SURREY HEALTH AUTHORITY

CONSENT FORM

Title of project:

Expressed Emotion, attributions and knowledge in carers of people with dementia

I have read the information sheet, and agree to take part in the above study.

Signed (Participant): ....................
Name (Print): ................................
Date: ..............................

Signed (Researcher): ......................
Name (Print): ..............................
Date: ..............................
Dear Dr X

Re: Patient and carer name and address

I am writing to inform you that the above carer has recently volunteered to take part in a study involving carers of people with dementia at home.

The study aims to explore levels of Expressed Emotion (emotional attitudes) towards the person they care for. High levels of expressed emotion (higher levels of negative emotion) have been found to be associated with adverse outcomes in both patient and carer. This study is exploring the strength of association between carers’ level of knowledge about the dementia illness and attributions about cause and controllability of symptoms, and Expressed Emotion. It is hoped that findings will guide healthcare professionals in providing information to carers in a more effective way.

Participation in the study involves a meeting of approximately one hour with a psychologist, at a time convenient for the carer. The carer simply completes a number of self report questionnaires with the aid of the psychologist.

This study has been approved by the South West Surrey Local Research Ethics Committee, and is being conducted in association with Surrey University and Surrey Hampshire Borders NHS Trust.

If you have any queries about the project please contact me at the above address.

Yours sincerely

Ms Zena Dowling
Psychologist in Clinical Training
Appendix 6
Patient Rejection Scale (PRS)

Please read the following information carefully:-

People who care for someone who is suffering from dementia often have mixed feelings about that person. We would like to know how you feel about the person you care for.

Here is a series of statements other people have made about a person with dementia that they care for. Please read each statement carefully and indicate how often you feel that way, by circling the number of the response that comes closest to the way you feel.

In the statements that follow, (x) stands for the name of the person you are caring for.

<table>
<thead>
<tr>
<th>Response categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 = Always</td>
</tr>
<tr>
<td>2 = Almost always</td>
</tr>
<tr>
<td>3 = A lot of the time</td>
</tr>
<tr>
<td>4 = Sometimes</td>
</tr>
<tr>
<td>5 = Once in a while</td>
</tr>
<tr>
<td>6 = Almost never</td>
</tr>
<tr>
<td>7 = Never</td>
</tr>
</tbody>
</table>

REMEMBER, ANSWER EACH STATEMENT ACCORDING TO HOW OFTEN YOU FEEL THAT WAY ABOUT (X). Please ask the interviewer for help if you are unsure of anything.

1. I enjoy being with (X). 1 2 3 4 5 6 7
2. It gets easier to understand (X) as time goes on. 1 2 3 4 5 6 7
3. (X) could get better if (X) would only try. 1 2 3 4 5 6 7
4. (X) is an important part of my life 1 2 3 4 5 6 7
5. I am very disappointed in (X). 1 2 3 4 5 6 7
6. I love (X) very much. 1 2 3 4 5 6 7
7. I don’t expect much from (X). 1 2 3 4 5 6 7
8. I am very proud of (X). 1 2 3 4 5 6 7
9. I am tired of having to organise my life around (X). 1 2 3 4 5 6 7
10. (X) is driving me mad. 1 2 3 4 5 6 7
11. It makes me happy to do things for (X). 1 2 3 4 5 6 7
12. I have to treat (X) like a child. 1 2 3 4 5 6 7
13. I can help (X) be more independent. 1 2 3 4 5 6 7
14. (X) is not grateful for what I do for him/her. 1 2 3 4 5 6 7
15. I get more irritated with (X) as time goes by. 1 2 3 4 5 6 7
16. (X) is pretty easy to get along with. 1 2 3 4 5 6 7
17. It would be better if (X) lived with someone else. 1 2 3 4 5 6 7
18. It is hard to tell what (X) is going to do next. 1 2 3 4 5 6 7
19. (X) acts as if he/she doesn’t care about me. 1 2 3 4 5 6 7
20. I can count on (X) for help. 1 2 3 4 5 6 7
21. If (X) leaves me alone, I leave I leave (X) alone. 1 2 3 4 5 6 7
22. I don’t care what happens to (X) anymore. 1 2 3 4 5 6 7
23. I wish I had never had any connection with (X). 1 2 3 4 5 6 7
24. (X) makes me happy. 1 2 3 4 5 6 7
September 3, 1998

Dear Ms Dowling:

You certainly have my permission to use the Patient Rejection Scale in your study of Alzheimer's patients and their families. You are quite right about the changes you have made to the items. I am sure they will have no affect on the item reliabilities but may materially affect the understanding of the content. Please let me know whether there are any other changes you intend to make and how your research proceeds when you are using the scale. I am always interested not only in the scale's utility but in the results of such FE studies. My best wishes.

Sincerely,

Dolores Kreisman, PhD
Associate Research Scientist
Appendix 8  
Dementia Knowledge Questionnaire (DKQ)

The following questions are asking you how you understand dementia as an illness. Please tick the responses you think are correct.

<table>
<thead>
<tr>
<th>Question</th>
<th>Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is dementia a disease affecting .....</td>
<td>1. The lungs?</td>
</tr>
<tr>
<td></td>
<td>2. The brain?</td>
</tr>
<tr>
<td></td>
<td>3. The heart?</td>
</tr>
<tr>
<td></td>
<td>4. Don’t know</td>
</tr>
<tr>
<td>Does dementia mostly affect people aged....</td>
<td>1. 30-40 years?</td>
</tr>
<tr>
<td></td>
<td>2. 40-60 years?</td>
</tr>
<tr>
<td></td>
<td>3. 60 years and over?</td>
</tr>
<tr>
<td></td>
<td>4. Don’t know</td>
</tr>
<tr>
<td>Is there a cure for the majority of patients with dementia?</td>
<td>1. Yes</td>
</tr>
<tr>
<td></td>
<td>2. No</td>
</tr>
<tr>
<td></td>
<td>3. Don’t know</td>
</tr>
<tr>
<td>How many types of dementia are there?</td>
<td>1. One</td>
</tr>
<tr>
<td></td>
<td>2. Two</td>
</tr>
<tr>
<td></td>
<td>3. Three or more</td>
</tr>
<tr>
<td></td>
<td>4. Don’t know</td>
</tr>
<tr>
<td>How many people out of 100 over 65 years are affected?</td>
<td>1. Less than 5</td>
</tr>
<tr>
<td></td>
<td>2. 5-20</td>
</tr>
<tr>
<td></td>
<td>3. 20-50</td>
</tr>
<tr>
<td></td>
<td>4. 50-70</td>
</tr>
<tr>
<td></td>
<td>5. 70-100</td>
</tr>
<tr>
<td></td>
<td>6. Don’t know</td>
</tr>
<tr>
<td>Which of the following could cause dementia?</td>
<td>1. Diet</td>
</tr>
<tr>
<td></td>
<td>2. Infection</td>
</tr>
<tr>
<td></td>
<td>3. Hereditary factors</td>
</tr>
<tr>
<td></td>
<td>4. Old age</td>
</tr>
<tr>
<td></td>
<td>5. Strokes</td>
</tr>
<tr>
<td></td>
<td>6. Alcohol</td>
</tr>
<tr>
<td>Which of the following is affected in a person suffering with dementia?</td>
<td>1. Eyesight</td>
</tr>
<tr>
<td></td>
<td>2. Reasoning</td>
</tr>
<tr>
<td></td>
<td>3. Personality</td>
</tr>
<tr>
<td></td>
<td>4. Memory</td>
</tr>
<tr>
<td></td>
<td>5. Mobility</td>
</tr>
<tr>
<td></td>
<td>6. Speech</td>
</tr>
<tr>
<td></td>
<td>7. Bladder / Bowel control</td>
</tr>
<tr>
<td></td>
<td>8. Life expectancy</td>
</tr>
</tbody>
</table>
Appendix 9
Behaviour and Mood Disturbance scale with added sections for carers to record perceptions of controllability and causal attributions

Overleaf is a list of some behaviour and mood difficulties. Please read each item and decide to what extent the person you care for shows these difficulties. When you have decided, please tick the response which best indicates the frequency of the person’s behaviour and mood.

It you have indicated that the person does exhibit a certain behaviour or mood to any extent (even if rarely), please indicate in the next column to what extent you believe the difficulty is controllable by that person by inserting the correct number from the key below. Then in the next column, indicate whether you believe the behaviour or mood is due to the person’s dementia illness, their personality or due to something else. You need not do this if you have indicated that the person does not exhibit a particular mood or behaviour difficulty.

<table>
<thead>
<tr>
<th>Controllability</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>0 = Not at all controllable</td>
</tr>
<tr>
<td></td>
<td>1 = Slightly</td>
</tr>
<tr>
<td></td>
<td>2 = To some extent</td>
</tr>
<tr>
<td></td>
<td>3 = Often</td>
</tr>
<tr>
<td></td>
<td>4 = Most of the time</td>
</tr>
<tr>
<td></td>
<td>5 = Completely controllable</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Cause</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I = Illness</td>
</tr>
<tr>
<td></td>
<td>P = Personality or nature</td>
</tr>
<tr>
<td></td>
<td>O = Other (please indicate what)</td>
</tr>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>---------------------</td>
<td>-------</td>
</tr>
<tr>
<td>*1. Takes part in family conversations:</td>
<td></td>
</tr>
<tr>
<td>*2. Reads newspapers, magazines, etc.:</td>
<td></td>
</tr>
<tr>
<td>3. Sits around doing nothing:</td>
<td></td>
</tr>
<tr>
<td>*4. Shows an interest in news about friends and relatives:</td>
<td></td>
</tr>
<tr>
<td>*5. Starts and maintains a sensible conversation:</td>
<td></td>
</tr>
<tr>
<td>*6. Responds sensibly when spoken to:</td>
<td></td>
</tr>
<tr>
<td>*7. Understands what is said to him/her:</td>
<td></td>
</tr>
<tr>
<td>*8. Watches and follows television:</td>
<td></td>
</tr>
<tr>
<td>*9. Keeps him/herself busy doing useful things:</td>
<td></td>
</tr>
<tr>
<td>10. Fails to recognise familiar people:</td>
<td></td>
</tr>
<tr>
<td>11. Gets mixed up about where he/she is:</td>
<td></td>
</tr>
<tr>
<td>12. Gets mixed up about the day, year etc.:</td>
<td></td>
</tr>
<tr>
<td>13. Has to be prevented from wandering outside the house:</td>
<td></td>
</tr>
<tr>
<td>14. Hoards useless things:</td>
<td></td>
</tr>
<tr>
<td>15. Talks nonsense:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Never</td>
</tr>
<tr>
<td>---</td>
<td>-------</td>
</tr>
<tr>
<td>16.</td>
<td>Appears restless and agitated:</td>
</tr>
<tr>
<td>17.</td>
<td>Gets lost in the house:</td>
</tr>
<tr>
<td>18.</td>
<td>Wanders outside the house at night:</td>
</tr>
<tr>
<td>19.</td>
<td>Wanders outside the house and gets lost:</td>
</tr>
<tr>
<td>20.</td>
<td>Endangers him/herself:</td>
</tr>
<tr>
<td>21.</td>
<td>Paces up and down wringing his/her hands:</td>
</tr>
<tr>
<td>22.</td>
<td>Wanders off the subject:</td>
</tr>
<tr>
<td>23.</td>
<td>Talks aloud to him/herself:</td>
</tr>
<tr>
<td>24.</td>
<td>Seem s lost in a world of his/her own:</td>
</tr>
<tr>
<td>25.</td>
<td>Mood changes for no apparent reason:</td>
</tr>
<tr>
<td>26.</td>
<td>Becomes irritable and easily upset:</td>
</tr>
<tr>
<td>27.</td>
<td>Goes on and on about certain things:</td>
</tr>
<tr>
<td>28.</td>
<td>Accuses people of things:</td>
</tr>
<tr>
<td>29.</td>
<td>Becomes angry and threatening:</td>
</tr>
<tr>
<td>30.</td>
<td>Appears unhappy and depressed:</td>
</tr>
<tr>
<td>31.</td>
<td>Talks all the time:</td>
</tr>
</tbody>
</table>
Appendix 10
Hospital Anxiety and Depression Scale (HADS)

The following statements describe how a person may be feeling. Please read each item and underline the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or ‘wound up’:
   - Most of the time
   - A lot of the time
   - From time to time, occasionally
   - Not at all

2. I still enjoy the things I used to enjoy:
   - Definitely as much
   - Not quite so much
   - Only a little
   - Hardly at all

3. I get a sort of frightened feeling as if something awful is about to happen:
   - Very definitely and quite badly
   - Yes, but not too badly
   - A little, but it doesn’t worry me
   - Not at all

4. I can laugh and see the funny side of things:
   - As much as I always could
   - Not quite so much now
   - Definitely not so much now
   - Not at all

5. Worrying thoughts go through my mind:
   - A great deal of the time
   - A lot of the time
   - From time to time but not too often
   - Only occasionally

6. I feel cheerful:
   - Not at all
   - Not often
   - Sometimes
   - Most of the time

7. I can sit at ease and feel relaxed:
   - Definitely
   - Usually
   - Not often
   - Not at all

8. I feel as if I am slowed down:
   - Nearly all the time
   - Very often
   - Sometimes
   - Not at all

9. I get a sort of frightened feeling like ‘butterflies’ in the stomach:
   - Not at all
   - Occasionally
   - Quite often
   - Very often

10. I have lost interest in my appearance:
    - Definitely
    - I don’t take as much care as I should
    - I may not take quite as much care
    - I take just as much care as ever
11. I feel restless as if I have to be on the move:

Very much indeed
Quite a lot
Not very much
Not at all

12. I look forward with enjoyment to things:

As much as I ever did
Rather less than I used to
Definitely less than I used to
Hardly at all

13. I get sudden feelings of panic:

Very often indeed
Quite often
Not very often
Not at all

14. I can enjoy a good book or radio or TV programme:

Often
Sometimes
Not often
Very seldom
Appendix 11
Items measuring carer perceptions of the
pre-morbid relationship with their care-recipient

1. How would you describe the relationship between yourself and X before you noticed that X had changed?

Not at all close
A little close
Somewhat close
Quite close
Very close

2. How would you describe the relationship between yourself and X before you noticed that X had changed?

Not at all positive
A little positive
Somewhat positive
Quite positive
Very positive
3. How would you describe the relationship between yourself and X before you noticed that X had changed?

- No conflict at all
- A little conflict
- Some conflict
- Quite a lot of conflict
- Very much conflict
Appendix 12
Demographic data

Demographics

Date:
Code:
Source:
Age:
Gender:
Relationship to patient:
Working (FT/PT), unemployed, retired?
Live with carer?
Have children under 18 years living in same house?
Respite arrangements/day care/home help (How often)?
Care-recipient’s diagnosis:
How many hours a week do you spend caring for X?

7-14 hours a week (approximately 1-2 hours a day) □

15-35 hours a week (approximately 2 ½ -5 hours a day) □

36+ hours a week □

How long ago did X receive a diagnosis?

0-3 months ago □

4-12 months ago □

13 months ago -3 years ago □

3-5 years ago □

5 years or more ago □
Appendix 13
Histogram of distribution of Total PRS Scores
Appendix 14:
Table showing Z scores for skewness and kurtosis

<table>
<thead>
<tr>
<th>Variable</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total PRS</td>
<td>0.87</td>
<td>0.16</td>
</tr>
<tr>
<td>Total controllability</td>
<td>3.58*</td>
<td>1.23</td>
</tr>
<tr>
<td>Total Illness attribution</td>
<td>-2.72</td>
<td>0.08</td>
</tr>
<tr>
<td>Total Personality attribution</td>
<td>5.19*</td>
<td>4.46*</td>
</tr>
<tr>
<td>Total Other attribution</td>
<td>4.68*</td>
<td>3.53*</td>
</tr>
<tr>
<td>Total Illness/Personality</td>
<td>8.69*</td>
<td>18.32*</td>
</tr>
<tr>
<td>Total DKQ</td>
<td>1.56</td>
<td>0.12</td>
</tr>
<tr>
<td>Total HADS</td>
<td>2.76</td>
<td>1.73</td>
</tr>
<tr>
<td>Total HADS Anxiety</td>
<td>2.21</td>
<td>1.02</td>
</tr>
<tr>
<td>Total HADS Depression</td>
<td>2.36</td>
<td>1.11</td>
</tr>
<tr>
<td>Total BMD</td>
<td>-2.10</td>
<td>1.44</td>
</tr>
<tr>
<td>Composite pre-morbid relationship</td>
<td>-2.57</td>
<td>-0.03</td>
</tr>
</tbody>
</table>

*= significant (above 3.29 or below -3.29)
Appendix 15
Table showing percentage of carers not making attributions about cause and control on BMD Scale items

<table>
<thead>
<tr>
<th>BMD Scale items</th>
<th>Percentage not making attributions</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>16.3%</td>
</tr>
<tr>
<td>2</td>
<td>11.6%</td>
</tr>
<tr>
<td>3</td>
<td>18.6%</td>
</tr>
<tr>
<td>4</td>
<td>25.6%</td>
</tr>
<tr>
<td>5</td>
<td>9.3%</td>
</tr>
<tr>
<td>6</td>
<td>23.3%</td>
</tr>
<tr>
<td>7</td>
<td>20.9%</td>
</tr>
<tr>
<td>8</td>
<td>7%</td>
</tr>
<tr>
<td>9</td>
<td>7%</td>
</tr>
<tr>
<td>10</td>
<td>41.9%</td>
</tr>
<tr>
<td>11</td>
<td>20.9%</td>
</tr>
<tr>
<td>12</td>
<td>7%</td>
</tr>
<tr>
<td>13</td>
<td>65%</td>
</tr>
<tr>
<td>14</td>
<td>53.5%</td>
</tr>
<tr>
<td>15</td>
<td>25.6%</td>
</tr>
<tr>
<td>16</td>
<td>16.3%</td>
</tr>
<tr>
<td>17</td>
<td>44.2%</td>
</tr>
<tr>
<td>18</td>
<td>88.3%</td>
</tr>
<tr>
<td>19</td>
<td>83.7%</td>
</tr>
<tr>
<td>20</td>
<td>67.4%</td>
</tr>
<tr>
<td>21</td>
<td>81.4%</td>
</tr>
<tr>
<td>22</td>
<td>25.6%</td>
</tr>
<tr>
<td>23</td>
<td>58.1%</td>
</tr>
<tr>
<td>24</td>
<td>44.2%</td>
</tr>
<tr>
<td>25</td>
<td>41.7%</td>
</tr>
<tr>
<td>26</td>
<td>20.9%</td>
</tr>
<tr>
<td>27</td>
<td>18.6%</td>
</tr>
<tr>
<td>28</td>
<td>39.5%</td>
</tr>
<tr>
<td>29</td>
<td>62.8%</td>
</tr>
<tr>
<td>30</td>
<td>25.6%</td>
</tr>
<tr>
<td>31</td>
<td>76.7%</td>
</tr>
</tbody>
</table>