A Portfolio of Study, Practice and research
submitted for the
Doctorate of Psychology (PsychD) in
Clinical Psychology.

University of Surrey

Amtul Habib Hashemi, 2002

Volume I
Acknowledgements

I would like to thank the course team and all of my clinical placement supervisors for their professional and personal input into my clinical training. In particular, I would like to extend my deep gratitude to Linda Dowdney for her support, commitment and belief in me throughout a demanding training process and for her enthusiasm and brilliant supervision of my major research.

Special thanks to Lesley Edwards for encouraging, supporting and supervising the development of my major research project as well as maintaining a huge level of enthusiasm throughout its course. I am obliged to the Royal Marsden Hospital’s Ethics Body who granted this study approval and to all of the staff at the paediatric unit who facilitated my access to the families. This study could not have happened without the willingness of the parents who were involved and I am indebted to them for sacrificing a considerable amount of their time in sharing their experiences under very difficult circumstances.

I am also grateful to Mary Dobbins for her supervision of my service related research project. I would like to take this opportunity to thank all my colleagues at Linwood Community Mental Health Team for the time that they devoted to this project and completing those questionnaires!

I have been blessed in the support and encouragement of all of my friends and especially my friends from the course with whom I shared the highs and lows of training.

Finally, I would like to thank Mohan, Naeem, Lubna, my mother and my late father for their enduring love, patience and commitment to me during this stage of my professional development.
# Table of Contents

<table>
<thead>
<tr>
<th>Contents</th>
<th>Page No.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>i</td>
</tr>
<tr>
<td>Table of Contents</td>
<td>ii</td>
</tr>
<tr>
<td>Copyright Statement</td>
<td>iv</td>
</tr>
<tr>
<td>Statement of Confidentiality</td>
<td>v</td>
</tr>
<tr>
<td>Dedication</td>
<td>vi</td>
</tr>
<tr>
<td><strong>INTRODUCTION TO THE PORTFOLIO</strong></td>
<td>1</td>
</tr>
<tr>
<td><strong>ACADEMIC DOSSIER</strong></td>
<td>2</td>
</tr>
<tr>
<td><strong>Adult Mental Health Essay:</strong></td>
<td>3</td>
</tr>
<tr>
<td>Discuss the role of cognitive behaviour therapy in the management of a psychotic disorder</td>
<td>4</td>
</tr>
<tr>
<td>Introduction</td>
<td>4</td>
</tr>
<tr>
<td>The development of cognitive behaviour therapy</td>
<td>5</td>
</tr>
<tr>
<td>Cognitive therapy for psychosis: Empirical status</td>
<td>7</td>
</tr>
<tr>
<td>Issues in cognitive therapy interventions</td>
<td>11</td>
</tr>
<tr>
<td>Challenges for future research</td>
<td>14</td>
</tr>
<tr>
<td>Conclusions</td>
<td>15</td>
</tr>
<tr>
<td>References</td>
<td>16</td>
</tr>
<tr>
<td><strong>People with Learning Disabilities Essay:</strong></td>
<td>20</td>
</tr>
<tr>
<td>What is an autistic spectrum disorder and what aetiological models have contributed to our understanding of autism? To what extent have these models guided intervention practices?</td>
<td>21</td>
</tr>
<tr>
<td>Controversies surrounding definition</td>
<td>21</td>
</tr>
<tr>
<td>Prevalence</td>
<td>23</td>
</tr>
<tr>
<td>Aetiology: Theories and models</td>
<td>24</td>
</tr>
<tr>
<td>Interventions</td>
<td>30</td>
</tr>
<tr>
<td>Conclusions</td>
<td>33</td>
</tr>
<tr>
<td>References</td>
<td>34</td>
</tr>
<tr>
<td><strong>Children, Adolescents and Families Essay:</strong></td>
<td>40</td>
</tr>
<tr>
<td>What theories have been advanced to explain childhood phobias?</td>
<td>41</td>
</tr>
<tr>
<td>Consider their strengths and limitations and the evidence base that would support their use in clinical practice.</td>
<td>41</td>
</tr>
<tr>
<td>Introduction</td>
<td>41</td>
</tr>
<tr>
<td>Definition and classification</td>
<td>42</td>
</tr>
<tr>
<td>Evaluation of the etiological theories explaining childhood phobias and the evidence supporting their use in clinical practice</td>
<td>44</td>
</tr>
<tr>
<td>Summary and conclusions</td>
<td>52</td>
</tr>
<tr>
<td>References</td>
<td>53</td>
</tr>
<tr>
<td><strong>Specialist Placement Essay:</strong></td>
<td>57</td>
</tr>
<tr>
<td>Critically evaluate the application and role of psychological interventions in the management of chronic pain.</td>
<td>58</td>
</tr>
<tr>
<td>Introduction</td>
<td>58</td>
</tr>
<tr>
<td>Definition of chronic pain and distinction from acute pain</td>
<td>58</td>
</tr>
<tr>
<td>Models of chronic pain</td>
<td>59</td>
</tr>
<tr>
<td>Psychological theories explaining chronic pain</td>
<td>62</td>
</tr>
<tr>
<td>Rationale for psychological interventions in chronic pain</td>
<td>64</td>
</tr>
<tr>
<td>Psychological therapies for chronic pain</td>
<td>66</td>
</tr>
<tr>
<td>The role of psychological therapies in the management of chronic pain</td>
<td>70</td>
</tr>
<tr>
<td>Concluding comments</td>
<td>71</td>
</tr>
<tr>
<td>References</td>
<td>73</td>
</tr>
<tr>
<td><strong>Older Adults Essay</strong></td>
<td>79</td>
</tr>
<tr>
<td>Discuss the difficulties in distinguishing depression and early stage dementia and evaluate ways in which these difficulties might be addressed.</td>
<td>80</td>
</tr>
<tr>
<td>Introduction</td>
<td>80</td>
</tr>
<tr>
<td>Inherent difficulties in distinguishing depression and early stage dementia</td>
<td>81</td>
</tr>
<tr>
<td>History taking and screening tools</td>
<td>84</td>
</tr>
<tr>
<td>Identification of the pertinent clinical features of depression and dementia</td>
<td>85</td>
</tr>
<tr>
<td>Neuro-psychological findings that identify different brain functions in depression and dementia</td>
<td>88</td>
</tr>
<tr>
<td>Identification of structural changes in the brain and use of biological markers</td>
<td>90</td>
</tr>
<tr>
<td>Summary and conclusions</td>
<td>93</td>
</tr>
<tr>
<td>References</td>
<td>94</td>
</tr>
</tbody>
</table>
# Table of Contents

## CLINICAL DOSSIER

<table>
<thead>
<tr>
<th>Placement Type</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Core Adult Mental Health Placement</td>
<td>99</td>
</tr>
<tr>
<td>Placement Details</td>
<td>99</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>99</td>
</tr>
<tr>
<td>Summary of Case Report</td>
<td>100</td>
</tr>
<tr>
<td>Core People with Learning Disabilities Placement</td>
<td>102</td>
</tr>
<tr>
<td>Placement Details</td>
<td>102</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>102</td>
</tr>
<tr>
<td>Summary of Case Report</td>
<td>103</td>
</tr>
<tr>
<td>Core Children, Adolescents and Families Placement</td>
<td>105</td>
</tr>
<tr>
<td>Placement Details</td>
<td>105</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>105</td>
</tr>
<tr>
<td>Summary of Case Report</td>
<td>106</td>
</tr>
<tr>
<td>Specialist Placement in Paediatric Oncology</td>
<td>108</td>
</tr>
<tr>
<td>Placement Details</td>
<td>108</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>108</td>
</tr>
<tr>
<td>Summary of Case Report</td>
<td>109</td>
</tr>
<tr>
<td>Core Older Adults Placement</td>
<td>111</td>
</tr>
<tr>
<td>Placement Details</td>
<td>111</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>111</td>
</tr>
<tr>
<td>Summary of Case Report</td>
<td>112</td>
</tr>
<tr>
<td>Specialist Placement in Systemic Therapy</td>
<td>114</td>
</tr>
<tr>
<td>Placement Details</td>
<td>114</td>
</tr>
<tr>
<td>Summary of Placement</td>
<td>114</td>
</tr>
</tbody>
</table>

## RESEARCH DOSSIER

<table>
<thead>
<tr>
<th>Research Project</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Related Research Project</td>
<td>116</td>
</tr>
<tr>
<td>Evaluating the impact of a multi-disciplinary team Away Day on Team Climate and membership</td>
<td>117</td>
</tr>
<tr>
<td>Abstract</td>
<td>118</td>
</tr>
<tr>
<td>Introduction</td>
<td>119</td>
</tr>
<tr>
<td>Aims and hypotheses of present study</td>
<td>120</td>
</tr>
<tr>
<td>Methodology</td>
<td>123</td>
</tr>
<tr>
<td>Results</td>
<td>129</td>
</tr>
<tr>
<td>Discussion</td>
<td>132</td>
</tr>
<tr>
<td>References</td>
<td>134</td>
</tr>
<tr>
<td>Literature Review</td>
<td>149</td>
</tr>
<tr>
<td>Childhood cancer: factors contributing to the psychological adjustment of children and parents.</td>
<td>150</td>
</tr>
<tr>
<td>Introduction</td>
<td>151</td>
</tr>
<tr>
<td>Aetiology of childhood cancers</td>
<td>151</td>
</tr>
<tr>
<td>The adjustment of the child with cancer</td>
<td>154</td>
</tr>
<tr>
<td>The adjustment of the parent</td>
<td>159</td>
</tr>
<tr>
<td>Sibling adaptation</td>
<td>160</td>
</tr>
<tr>
<td>Implications for future research</td>
<td>162</td>
</tr>
<tr>
<td>Summary and conclusions</td>
<td>163</td>
</tr>
<tr>
<td>References</td>
<td>167</td>
</tr>
<tr>
<td>Major Research Project</td>
<td>168</td>
</tr>
<tr>
<td>The experience of White and Asian parents when their child has been diagnosed with cancer: Towards a cross-cultural understanding using Interpretative Phenomenological Analysis (IPA).</td>
<td>169</td>
</tr>
<tr>
<td>Abstract</td>
<td>176</td>
</tr>
<tr>
<td>Introduction</td>
<td>184</td>
</tr>
<tr>
<td>Method</td>
<td>209</td>
</tr>
<tr>
<td>Results</td>
<td>222</td>
</tr>
<tr>
<td>Discussion</td>
<td>226</td>
</tr>
<tr>
<td>References</td>
<td>167</td>
</tr>
</tbody>
</table>
COPYRIGHT STATEMENT

No part of this portfolio may be reproduced in any form without written permission of the author. Due to the confidential nature of this portfolio this volume will be kept solely by the Department of Clinical Psychology at the University of Surrey.

© Amtul Habib Hashemi, 2002
Please note that the names of all clients and some identifying background details have been altered in all of the case reports to prevent the individuals and families from being identified.
In memory of my Dad

Syed Aziz Ullah Hashemi

(Ina-lillahi-wu-innen-illahi-rajiune)
INTRODUCTION TO THE PORTFOLIO

This portfolio contains a selection of work completed during the PsychD in Clinical Psychology. Volume I is comprised of three sections: the academic dossier, clinical dossier and research dossier. The academic dossier contains five essays covering both core and specialist topics. The clinical dossier consists of summaries of all placements undertaken and summaries of five formal clinical case reports. The research dossier includes the service-related research completed on placement in Year 1, the literature review completed in Year 2 and the major research project completed in Year 3.

Volume II contains a separate clinical dossier of work completed during the PsychD in Clinical Psychology. This volume contains five case reports covering both core and specialist topics and relevant placement documentation including placement contracts, placement evaluation forms, logbooks of clinical experience and trainee feedback of the placement. This volume will be kept within the Psychology Department of the University of Surrey due to the confidential nature of the clinical material.

The work presented in this portfolio reflects the range of client groups, presenting problems and psychological approaches covered during the course. The order in which the work was completed is retained within the portfolio to illustrate the development of clinical skills over the period of training.
ACADEMIC DOSSIER

OVERVIEW

This section contains four selected essays from the core client groups studied during the first and second years of training, and one essay on a specialist topic from the third year. These essays critically examine the theory and practice of a range of psychological approaches to various issues experienced across the life span.
Adult Mental Health Essay

DISCUSS THE ROLE OF COGNITIVE BEHAVIOUR THERAPY IN THE MANAGEMENT OF A PSYCHOTIC DISORDER.

December 1998
Year 1
1. Introduction

Almost twenty five years ago Mahoney (1974) argued that psychology was undergoing a 'cognitive revolution.' Since then, the pace of development, both with respect to research and interventions, has been such that it is now difficult to imagine the role of psychology in the understanding and treatment of disorders, such as anxiety or depression, without taking into account a cognitive approach.

Up until quite recently, schizophrenia has been one major psychiatric disorder which has remained seemingly beyond the realms of cognitive understanding, and thereby treatment. This may be because even at a conceptual level schizophrenia is both complex and controversial. What is also relevant is that although the aetiology of this syndrome remains largely unclear, biological explanations have predominated (e.g. Gottesman and Shields, 1982; Haracz, 1982) and this emphasis on a medical model led to the widely held view that schizophrenia is a disease for which little except medication can be offered. Furthermore, psychiatric classification systems define delusions as fixed, immutable and inexplicable beliefs, which are held with a strong conviction and resistant to argument (APA, 1994). The theoretical suggestion was that as such experiences could not be understood, they were more likely to be symptoms deriving from organic rather than psychological causes; and therefore, it followed that it was useless to discuss the patient's psychotic symptoms with them (Scharfetter, 1980). Although this hypothesis has not been satisfactorily clarified one way or the other, such ideas about the aetiology of psychotic symptoms in the medical literature may have initially hindered approaches using theories taken from a psychological perspective.

However, with the advent of more sophisticated multifaceted models to explain the origin and maintenance of schizophrenia, for example the Stress-Vulnerability model (Zubin and Spring, 1977), the focus for the management of this disorder has shifted from a purely medical approach towards the application of various psychotherapeutic techniques. Interventions aimed at modifying certain environmental factors, such as family climate, together with a range of behavioural approaches have been shown to be effective in changing psychotic behaviour (e.g. Leff, Kuipers, Berkowitz, Eberlein-Vreis and Sturgeon, 1982) but only in the last decade has cognitive therapy emerged as an important and feasible component in the treatment of this client group. This transferred the emphasis from therapists intervening actively and directly and highlighted the value of empowerment approaches, so that the therapist's role now was to help the client change their own behaviour (Slade and Haddock, 1996).
The aims of this review are as follows:
1. discuss the development of Cognitive Behaviour Therapy in its application to psychosis.
2. review the major studies and conclusions on the efficacy of cognitive-behaviour therapy to date.
3. consider the current issues in interventions and touch on aspects relevant to the clinician attempting to apply these techniques.
4. suggest areas for future research.

2. The development of cognitive behaviour therapy
Cognitive therapy developed from Beck’s (1967) model of depression which proposed that the behavioural and affective symptoms of the disorder are consequences of particular fundamental negative beliefs developed in childhood and beyond. These beliefs give rise to negative thoughts activated by critical events in a person’s life, and maintained by cognitive distortions. The aim of cognitive therapy is to help the client recognise and correct the cognitive distortions and beliefs, weakening the influence of these beliefs on behaviour and emotion, via verbal challenging and empirical testing. A well established form of intervention for depression, it has been considerably developed and effectively applied (together with behavioural techniques) to a wide range of affective disorders (Hawton, Salkovskis, Kirk and Clark, 1989).

The application of cognitive techniques to the modification of delusional beliefs common amongst people with a diagnosis of schizophrenia actually predates their more widespread use with non-psychotic disorders. Among the first published studies Beck (1952) reported a case in which cognitive techniques were used to modify a patient’s delusional beliefs that F.B.I. agents had him under surveillance. Treatment assisted the patient to trace the antecedents of his delusions and encouraged him to systematically test out his conclusions. At the end of the eight month intervention Beck reported that the patient had ‘reasoned’ himself out of the delusional belief.

Despite this early description, comparatively few studies for the next two decades reported on the use of a cognitive approach with psychosis, and indeed, it was ignored to such an extent that Bellack (1986) was able to describe schizophrenia as behaviour therapy’s ‘forgotten child.’ This may be a reflection of the predominant disease model for schizophrenia which emphasises a distinction between the symptoms and ‘normal’ experience. Boyle (1992) brought this to the fore-front of the debate surrounding the nature of schizophrenia by arguing that researchers and clinicians had failed to address the content of
hallucinations or delusions, assuming that they were meaningless experiences from which the individual suffered. Hence, the understanding of these symptoms has been obstructed by the lack of empirical research into the underlying psychological processes involved in the formation and maintenance of psychotic phenomena, particularly delusional beliefs. When the content of delusional ideas have been subject to examination, broad similarities between the content of beliefs widely held in the general population, for instance, beliefs in telepathy or in spiritual influences, and the delusional beliefs of psychiatric patients emerge (for review see Kingdon and Turkington, 1994).

A key tenant in the development of a cognitive approach to psychosis stemmed from this hypothesis that experiences of psychosis may derive from cognitive processes which are on a continuum with normality. In terms of providing theoretical explanations, it has been predominantly British researchers who have instigated research in this area, employing variations on information-processing models.

Helmsley (1987) proposes that the normally rapid, automatic assessment of whether sensory input is significant or not, is impaired due to the reduced influence of past regularities of personal experience. One of the most instructive aspects of this cognitive model (Helmsley, 1994) is the hypothesised chain of processes linking the abnormality to schizophrenic hallucinations and delusions. In simple terms, what is being suggested is that psychotic perceptions, such as altered feelings and thoughts, may result from a dysfunction in the normal relationship between stored experience and on-going sensations.

Frith (1992), in essence, provides a more detailed neuro-psychological model of the cognitive abnormalities underlying schizophrenia. He argues that the source of most schizophrenic type symptoms are closer to the output end of information processing sequences: a disconnection occurs between willed intentions and the self-monitoring system, so that the individual is no longer aware that perceptions, thoughts and actions are self-generated. Therefore, altered experiences may then arise as a consequence of confusion in the basic sense of whether they derive from internal sources, that is, whether they are experienced as memories or dreams, or external sources, for instance, whether they are experienced as real events in the world.

Bentall (1994) also focuses on hypothesising about the immediate cognitive sources of individual schizophrenic symptoms, but differs from Frith by advancing a perspective from social psychology, rather than neuro-psychology, as an explanatory construct. Bentall's model offers the idea that emotional and social cognitive processes are also likely to play a
role in shaping the experience of voices and delusional beliefs. For example, with respect to hallucinations, he suggests that they may be maintained by errors in meta-cognitive judgement, whilst, delusions may stem from abnormal cognitive attributional sources (Bentall, 1990).

Thus it appears that a common theme to the underlying processes involved in psychotic symptoms is a difficulty in controlling and/or understanding internally generated private experiences. From a clinical perspective such core dysfunction’s occur without conscious awareness, but from a cognitive approach, the way an individual understands and gives meaning to the psychotic experience is of paramount importance as it is this meaning which will influence the development of delusional beliefs and beliefs about voices and consequently shape emotional responses and behaviour. This suggests that cognitive therapy may have the potential to modify these symptoms. It’s application, despite differences in approaches, so far has generally supported this supposition.

3. Cognitive therapy for psychosis: Empirical status

3.1 Reports of case studies

The first explicit cognitive approach to the treatment of delusions was published as a series of three controlled case studies of patients with severe paranoid delusional beliefs. The authors reported that the use of belief modification techniques resulted in a decline in belief conviction and an increase in positive areas of functioning for all three clients (Watts, Powell and Austin, 1973). With respect to specific techniques, a confrontational stance was avoided for fear that a direct approach may inadvertently reinforce the belief; instead the researchers began with beliefs which were less strongly held and sensitively questioned the evidence underlying them. The importance of adopting a non-confrontational approach with deluded patients was given further support by Milton, Patwa and Hafner (1978) who concluded that confrontation could produce ‘psychological reactance’ in some patients and result in an intensification of delusional thought. Following the success of this method the idea was incorporated into subsequent therapeutic efforts.

Hole, Rush and Beck (1979) in an attempt to understand how delusions change reported that cognitive interventions of focusing, questioning and reality testing led to a reduction in belief conviction and/or pervasiveness (percentage of time spent in thinking about or seeking goals consistent with delusional beliefs) for some but not all of the eight subjects involved. Similarly, Hartman and Cashman (1983) in a preliminary report on the use of cognitive behavioural techniques with three clients concluded that cognitive therapy showed promise in
diminishing delusions and their associated anxiety, particularly when the delusions were based on social attribution and self-labelling operations.

Chadwick and Birchwood (1994) have provided evidence that the beliefs that individuals hold about their voices, and not simply the fact or the content, have an impact on their behavioural and affective responses to them. For example, a voice threatening death would be viewed as more dangerous if it was believed to come from an omnipotent force. They propose a cognitive formulation of voices, suggesting that weakening the beliefs that people hold about them may reduce the associated distress and problem behaviours. By applying a cognitive treatment approach to hallucinations a reduction in strength of belief was found for the three clients, together with an increase in social activity and improvements in mood (Chadwick and Birchwood, 1995).

3.2 More sophisticated designs

In a more systematic evaluation of verbal challenge and reality testing in the modification of the delusional beliefs of six clients, Chadwick and Lowe (1990) incorporated a multiple baseline design and a longer term follow-up of six months. The intervention consisted of identifying the nature of the delusions and sensitively helping the individual to question the evidence underlying the belief and developing behavioural experiments designed to test out the reality of this evidence. They suggested that the technique of hypothetical contradiction (Brett-Jones, Garety and Helmsley, 1987) in which the client is asked to consider how, if at all, a hypothetical but contradictory occurrence would alter a belief, should be adopted as the first step towards more direct verbal challenging. Results were encouraging, with all but one client demonstrating a reduction in belief conviction and associated distress, and two of the six clients actually rejecting their delusion. Moreover, verbal challenges alone proved effective in reducing the degree of belief conviction in several clients, while for others this only occurred after reality testing. The authors report that improvement was maintained at 6 month follow up.

One of the original, albeit non-randomised, small scale controlled trials of the impact of cognitive behaviour therapy, using patients with a diagnosis of chronic schizophrenia or schizoaffective disorder who presented with delusions or hallucinations which were drug resistant, was reported by Garety, Kuipers, Fowler, Chamberlain and Dunn (1994). The first thirteen patients who were referred for therapy became the experimental group, and patients subsequently referred (N=7) were put on a waiting list and this comprised the control group. Therapeutic techniques included cognitive-behavioural coping strategies, psycho-education,
goal setting and modification of delusional beliefs and dysfunctional assumptions. At baseline most of the patients in the study had delusional beliefs, but at the end of the six month treatment programme the authors report that the patients in the experimental group were significantly less likely to be convinced of their delusions than those in the control group, and with respect to more negative symptoms, they were significantly less depressed than the control group. Although such results appear to advocate the efficacy of cognitive behaviour therapy, this study does have methodological problems. These include the fact that patients were not randomly allocated into groups, that the control group had more patients with hallucinatory symptoms and the small size of the research sample may have negatively affected the power of the study, thereby, limiting the validity of the findings.

These earlier indications of the efficacy of cognitive behaviour therapy inevitably resulted in the publications of larger, controlled trials, utilising more sophisticated methodologies. The main objective of a study by Drury, Birchwood, Cochrane and MacMillan (1996) was on the dissolution of positive symptoms in acute psychosis via the application of individual and group cognitive therapy. To control for the confounding effects of attention alone, the non-treatment group received matched hours of therapist input in the form of structured activities and informal support, and all patients were monitored over nine months. Both treatment and control groups demonstrated a decline in positive symptoms but the cognitive therapy group showed significantly fewer positive symptoms and significantly better outcome with respect to the presence or absence of core delusional beliefs. These are optimistic findings; however, Johnson (1996) points out a number of difficulties. Briefly, these are: that this was essentially an open study, where neither assessors nor patients were blind to the treatment strategies being offered, and thus was potentially subject to bias, that the success of this therapy was contingent on a small sub-group of patients and it is not known whether the absolute morbidity of the two groups was the same prior to random allocation of treatment or control group.

The London-East Anglia trial (Kuipers, Garety, Fowler, Dunn, Bebbington, Freeman and Hadley, 1997) is a three centre study and draws on the earlier work of Garety et al (1994). The criteria for this randomised control trial was that patients should have at least one positive psychotic symptom that was distressing, medication resistant and was enduring of at least the past six months. Therapeutic techniques were as those described in the Garety (1994) study. At 9 months post treatment the cognitive-behavioural group showed a significant change from baseline and a 25% reduction on the Brief Psychiatric Rating Scale (BPRS, Overall and Gorham, 1962). Moreover, 50% of the treatment group were treatment responders compared
to 31% of the control group. At follow-up 9 months later 65% of the treatment group showed reliable clinical change on the BPRS compared to 17% of the control group; there were also significant reductions in self-reported measures of distress associated with delusions and reductions in the reported frequency of hallucinations. Follow-up at 18 months, with 78% of the original participants, indicated that the improvement in symptoms in the cognitive-behavioural therapy group was maintained compared to the control group and that, the former, demonstrated a 29% reduction in symptomology (on the BPRS) compared to a 2% reduction in the latter group. There were also significant reductions in the treatment group with respect to changes in delusional distress and hallucination frequency, but not with respect to conviction of delusional beliefs, pre-occupation with delusions or distress or intensity of hallucinations. The authors also report that drop-out rates for therapy were low and satisfaction was high and that this suggested that clients with psychosis welcomed this type of intervention. Methodological short comings of this trial are similar to the Drury et al (1996) study, in that, (a) it could not be assured that assessors remained blind to the treatment condition, (b) the problems associated with selecting a viable control condition, (c) patients in the treatment condition did not necessarily receive the same numbers of sessions, a reflection of compliance, but therefore, level of attention becomes a confounding variable. An economic evaluation of Kuipers et al’s (1998) study demonstrated that the extra costs of cognitive behaviour therapy can be offset by reduced utilisation of other services, such as health and social care. This is an important implication, particularly in the context of a cash starved NHS.

Similar effects to the London-East Anglia trial have been reported in a recent study by Tarrier, Yusupoff, Kinney, MacCarthy, Gledhill, Haddock and Morris (1998). The study’s design constitutes the most sophisticated methodology yet with patients of chronic schizophrenia both randomly allocated and stratified according to severity of symptoms and sex to three conditions: cognitive behaviour therapy and routine care, supportive counselling and routine care and routine care alone. The cognitive behaviour therapy involved training in coping strategies and problem solving. Significant improvements were found in severity and number of positive symptoms in those treated with cognitive behaviour therapy and it was this group that was also significantly more likely to show an improvement of 50% or more in their symptoms. Conversely, the routine care group experienced more exacerbation’s and days in hospital.

Finally, the most up to date study yet presented at conference (Kingdon, 1997) offers more support that the use of cognitive behaviour therapy can offer clinical benefits. Kingdon
compared cognitive behaviour therapy with befriending, essentially, a clinically sophisticated control procedure, which involves the same therapists engaging with patients but not using cognitive methods. There was no significant difference between the two groups at the end of 9 months therapy, but at follow-up the improvements in the cognitive behaviour group had been maintained, but those in the befriending group had referred back to baseline.

In summary, what these three most recent randomised, controlled trials, as well as the stream of case studies have effectively demonstrated is the clinical benefit of cognitive behaviour therapy over alternative therapies. More generally they provide sound support for the use of cognitive-behavioural therapies with people who present with distressing delusions and voices.

4. Issues in cognitive therapy interventions

The effectiveness of the cognitive therapy approach, as in any form of psychotherapy, is contingent on the ability of the patient to engage in a therapeutic alliance and for the therapist to be able to foster this. In a recent paper Fowler, Garety and Kuipers (1998a) advocate that the therapeutic relationship should also be of such quality that the client feels understood and involved, although they do qualify this by conceding that this is indeed challenging with people who present with florid, positive symptoms. Hence, an overview of assessment and cognitive therapy principles will be presented as an adjunct to the research studies discussed above.

Co-operation and collaboration between client and therapist is implicit in cognitive therapy, and due to some of the severe difficulties experienced by some clients, most therapists would converge on the opinion that particular emphasis needs to be placed on the development of this relationship (for example, Perris, 1989). The therapist needs to adopt a flexible approach in terms of frequency and length of sessions and also needs to be sensitive to changes in the client’s mental state and interpretations, starting work from the client’s perspective (Fowler et al, 1998b). Time spent developing trust, particularly with paranoid patients, or for those whose beliefs have a strong emotional and cognitive hold over them, can be important in the development of rapport. This is particularly pertinent given the long established fact that an increase in social stimulation offered by therapeutic endeavours can, in fact, trigger relapse in patients with psychosis (Wing 1983).

In one sense effective cognitive therapy could consist of assembling a new model of events with the patient. This may be done by focusing on developing the patient’s understanding of
their beliefs and then placing these beliefs in the circumstance of their individual histories and vulnerabilities (Fowler et al, 1998b). This, in itself, relies on a sound cognitive behavioural assessment procedure that deals with two aspects: firstly, taking a complete history of the client to identify vulnerability factors, events that triggered the psychosis and any previous psychiatric history. Doing this can often clarify the evidence supporting the belief and the context in which it emerged. Secondly, it is also equally as important to appraise current experiences and delusional ideas in detail and from the client’s perspective. Pulling together the various threads, for instance, life history, emotional upheaval, and the themes of the delusions, it is then necessary for the therapist to share and discuss their psychological formulation with the patient.

The context in which therapy takes place is also an important issue. Kingdon and Turkington (1991) stress the importance of including the family or carers in the intervention. As discussed earlier symptoms such as delusions and hallucinations closely resemble beliefs in supernatural phenomena such as poltergeists, astrology and magical forces. Although such beliefs are scientifically disputable, they are nevertheless also held by many members of most societies in the world (Eysenck, 1986). Kingdon and Turkington (1991) have used a ‘normalising rationale’ in which both client and family were educated about schizophrenia on the basis of a stress-vulnerability model. The authors report that this was useful in engendering a working therapeutic relationship allowing the client to see him/herself, not as incurably mad, but as an individual who has developed symptoms in response to specific stressor’s at particular points in his/her life. Therefore, one of the ultimate aims was to facilitate de-stigmatisation in both the clients and their families. Use of social skills training, befriender’s (Kingdon, Turkington and Collis, 1989), day care and support groups was made to allow patients to discuss and defuse their over-valued ideas, delusions and hallucinations. The authors perceptions were that families frequently catastrophised as often as the patients themselves developing fears, of violence, unpredictability and violence. Indeed, the importance of the family environment both in the exacerbation of psychotic symptoms (Vaughn and Leff, 1976) and in recovery (Barrowclough and Tarrier, 1992) has been well documented, which also suggests that the clinician needs to try and ensure a safe and favourable environment from which to conduct therapy. Educating the family and involving them in the process may enhance progress, although this may be complicated by the poor economic and social situations in which many people with a diagnosis of schizophrenia live.

The use of cognitive behavioural coping mechanisms can equip the client with an adaptive way to manage the occurrence of their psychotic experience. If there is a pattern to the
patient’s beliefs or hallucinations, the new ways in which they might act or think to reduce the frequency of distress may be a point for discussion. They are then encouraged to test out a number of different strategies, in the form of behavioural experiments, until a useful coping strategy is developed. Research has examined whether patient’s own attempts to cope with or control their symptoms are effective: Falloon and Talbot (1981) report that people using fewer but more consistently applied coping strategies felt that they were more effective; in contrast, Tarrier (1987) found that people using multiple strategies report more favourable coping efficacy. Examples of specific coping strategies include thinking of rationale alternatives to paranoid ideation or learning to distract attention from hallucinations (Fowler and Morley, 1989; Tarrier, 1992) and can be used in association with a range of behavioural exercises, such as, relaxation or training in distraction. Methods to facilitate coping are often used in the early stages of therapy to offer pragmatic help with distressing symptoms and may well be reviewed over the course of therapy.

As discussed earlier, the examination of the thinking and reasoning styles associated with hallucinations and delusions assumes that ‘normal’ thinking processes are distorted or biased (Bentall, 1994). Such biases may be maintained by experiences that stem from other sources and have important implications for the nature of interventions. There is now a growing consensus on cognitive-behavioural approaches to modifying strongly held beliefs. Assisting the client to understand that they may be misinterpreting events and coming to judgements that aren’t based in reality is a central feature of therapy; an example may be working with the client to identify and monitor specific delusional interpretations, or distressing appraisals of voices, in an atmosphere of ‘collaborative empiricism,’ and then asking them to seek an alternative explanation of events (Chadwick and Lowe, 1990).

Some patients may hold dysfunctional evaluations about the Self which imply worthlessness or uselessness. This may be indicative of long-term unresolved difficulties, which may be inter-twined with the processes maintaining delusional beliefs and voices. Addressing such negative self evaluations is implicit, and Fowler et al (1998a) have outlined some of the stages in therapy to deal with them: clarifying the nature of the negative self evaluations, working with the patient to review and re-evaluate such evaluations with respect to their life history, helping patients to understand the long standing pattern of their thinking and encouraging them to reappraise past adversity. Kuipers (1996) adds that the process of sensitive questioning and discussion may help the client to realise the implications of dysfunctional assumptions and thereby develop a more appropriate and adaptive general view of themselves.
Successful therapy with people with a psychotic disorder requires commitment and persistence and changes do not often occur quickly. Coupled with this is that therapy with such clients can be challenging and the therapist may not immediately understand how the client’s delusional beliefs or voices make sense. Non-engagement may well become an issue if cognitive behaviour therapy moves at too fast a pace. The methods described above can be effective if they are applied once a sound therapeutic relationship, based on collaboration, has been established between client and therapist (Fowler et al, 1998b).

5. Challenges for future research

Although it appears fairly clear now that cognitive-behavioural treatments are effective in a range of patient problems, including, alleviating symptoms, improving skills that are transferable and utilising family support systems, there are still areas requiring scrutiny.

Existent research appears to strongly support early intervention (Birchwood, MacMillan and Smith (1992). If beliefs regarding psychotic symptoms are an important maintaining factor, then intervention to manage these beliefs at an early stage in their development may have more of an impact than an intervention delivered after they have been established for many years, because the individual would have less time to incorporate their dysfunctional beliefs into their lives. Drury (1994) reports that psychological treatments can be effective for patients who have recently become ill, and moreover, can substantially reduce the time they spend in hospital. The long-term benefit of this to patients is not clear, but it may be that a shorter hospital admission reduces the likelihood of institutionalisation and the loss of family contact or social networks. It may also reduce service costs, as the preliminary work by Kuipers et al (1998) suggests. Such intricacies need to be more formally investigated.

The nature of the relationship between these new psychological treatments and pharmacological treatments also needs to be considered, alongside thinking about the impact cognitive-behavioural treatments might have without the use of neuroleptic medication. The latter is particularly important for patients who are not able to tolerate neuroleptic medication due to side-effects and for patients who refuse to comply with a medical approach to their illness. Kissling (1992) reports that up to 75% of patients with first episode schizophrenia show poor compliance with medication and so it would be important to assess whether cognitive approaches can play an important part in facilitating the up-take of medication.

Due to the diversity of schizophrenic symptoms, it may be important to determine whether particular types of patients or particular types of symptoms respond differently to specific
types of treatment. Research is needed to further elucidate the elements of therapy which have the most impact on particular symptoms and which patients respond optimally to.

Wykes, Tarrier and Lewis (1998) suggest a number of gaps in the research literature that they feel need to be addressed. These include the following: comprehensive descriptions of therapies to identify the similarities and differences between treatments, elucidating the treatment elements, so that we are clearer about which actually affect change and which are peripherals, making explicit the standardised and relevant outcome measures, identifying the relative cost-effectiveness of different treatments when delivered by experts and setting up randomised, controlled trials looking at the long term benefits of psychological treatment across individuals and settings.

6. Conclusions
Major developments have taken place in the understanding and treatment of psychotic disorders, from a cognitive-behavioural perspective, particularly over the last ten years. Overall, this has resulted in the successful amelioration of psychotic symptoms and their associated disabilities, conveying optimism for the future of services for individuals experiencing psychosis. This needs to be balanced with the fact that, nevertheless, cognitive-behavioural approaches and their evaluation are as yet in a state of flux and there is still progress to be made. However, positive results have emerged and are still being generated from controlled studies and no doubt these will be supplemented and consolidated by future work. The long-term outlook appears promising especially when patients are managed from their first episode and in an in-direct way this could help to decrease stigma. Such positive efforts are timely given that for so long, the only treatment option available for people with distressing psychotic symptoms was medication with it's potentially damaging side-effects.
7. References


People with Learning Disabilities Essay

WHAT IS AN AUTISTIC SPECTRUM DISORDER (ASD) AND WHAT AETIOLOGICAL MODELS HAVE CONTRIBUTED TO OUR UNDERSTANDING OF AUTISM?

TO WHAT EXTENT HAVE THESE MODELS GUIDED INTERVENTION PRACTICES?

June 1999
Year 1
1. Controversies surrounding definition

The scientific literature on the spectrum of autistic disorders has grown significantly, even though, it is a relatively uncommon condition (Towbin, 1997). Indeed, there is now relatively consistent criteria for diagnosis of Autistic Spectrum Disorders (ASD) both in DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1993). The Autistic Spectrum may be considered to be part of a set of pervasive developmental disorders carrying effects for the individual that are frequently life-long (Wing, 1997) and which include syndromes such as autism, Asperger's syndrome, Rett syndrome (Hagberg, 1993) and childhood disintegrative disorders (Volkmar, 1992). One particular hypothesis is that the various clinical pictures of autism and related disorders depend upon a continuum of impairments ranging from the most profoundly physically and mentally disabled person, who has social impairment as one of a multitude of problems, to the most able, highly intelligent person with social impairment in it's subtlest form as their only disability (Wing, 1991).

Certainly it is useful to look at the historical evolution of the concept of autism to understand some of the controversies implicit in the literature regarding definitions. The condition was first described by Kanner (1943); his original use of the term 'autistic' was the same as Bleuler’s who used it to refer to the active withdrawal into fantasy demonstrated by schizophrenic patients (Bleuler, 1911). However, Kanner’s observations had actually described a failure to develop relationships and a lack of imagination. The confusion in the use of the term ‘autism’ thus suggested a link with adult schizophrenia and was further compounded by psychiatrists using childhood schizophrenia, autism and child psychosis as interchangeable diagnoses (Laufer and Gair, 1969). However, during the 1970’s it became apparent to researchers that it was necessary to differentiate between severe mental disorders arising during infancy and the psychoses arising in adolescence (Rutter, 1985). In 1980, DSM-III (American Psychiatric Association) used the term pervasive developmental disorders to emphasise the developmental aspects or characteristics of abnormalities which are present from early in life as opposed to mental illness which occurs in later life in individuals who had previously functioned either normally or near normally. More specifically, the adjective pervasive addresses the fact that there may be widespread distortions in communication, socialisation and thought processes which differentiate autism from specific developmental disorders of speech or language (Cantwell and Baker, 1985).

Kanner considered only two features to be necessary and sufficient for a diagnosis of Autism: ‘maintenance of sameness’ in children’s repetitive routines and extreme aloneness, with onset within the first two years. Moreover, Kanner also asserted that autistic children all had
normal cognitive potential, primarily, because they have a tendency to have a normal physical appearance. This is now known to be inaccurate; in fact, Rutter (1979) reports that over three quarters of autistic children also have a learning disability.

Soon after Kanner’s publication on autism, Asperger independently published a description of ‘autistic psychopathy,’ whereby, he discussed a less deviant group of children who were interested in social relationships but lacked the ability to understand and use the rules of social behaviour. Moreover, they were higher functioning in that they had the ability to complete school and hold jobs, they all developed speech before school age and typically had large vocabularies, but they had odd behaviours and an autistic-like resistance to change. Asperger suggested that his description of the syndrome was a distinct disorder or a mild form of autism (Blake, 1988) and with the concept of a spectrum disorder, Asperger’s syndrome is now attracting greater attention as a variant of the autistic disorder (Frith, 1991a). When other workers became interested in Asperger’s work, some took the position that the two syndromes were different in nature (Van Krevelen, 1971) (even though, in clinical practice the evidence suggested that distinguishing features could not be neatly divided), while others considered Asperger’s syndrome to be biologically linked to Kanner’s autism (Kay and Kolvin, 1987).

Partly in order to clarify the issue of whether there is a close relationship between Kanner’s and Asperger’s syndromes, and also, to tackle issues of diagnostic criteria, researchers in the MRC Social Psychiatry unit, conducted an epidemiological study of children resident in one geographical area, Camberwell, in South East London (Wing and Gould, 1979). The aim was to look at the full range of clinical phenomena in the children to examine whether the syndromes named in the literature could be identified and separated both from each other and from other childhood disorders. They included in the study any child with autistic features, as well as all children who were severely mentally handicapped. The results led them to suggest that the core deficit in autism is social in nature, so that, whereas, a child with a learning disability could be social relative to their mental age, an autistic child, irrespective of intellectual ability, would have observable social impairments. Social impairment was always associated with impairment of two-way social communication and impairment of imaginative activities; these three aspects are referred to by Wing and Gould (1979) as a ‘triad’ of impairments.

Both ICD-10 (WHO, 1993) and DSM-IV (American Psychiatric Association, 1994) concentrate on four main diagnostic criteria for autism, originally formalised by Rutter (1984), which are primarily based on behaviour. The first is that the disorder must manifest itself
before 30 months of age. The second criterion is concerned with the various aspects of deviance in the development of social relationships taking into account the child’s mental age. This inevitably means that diagnostic assessment must include a systematic cognitive evaluation (Rutter, 1984). The third criterion comprises abnormalities in communication with delayed or deviant language communication, and finally, the fourth set of diagnostic criterion concerns restrictive, repetitive and stereotyped patterns of behaviour, which links into one of Kanner’s (1943) original observations of the ‘insistence of sameness.’ Both DSM-IV and ICD-10 have also introduced Asperger’s syndrome as a diagnostic category, stipulating that cases must show social impairments and restricted interests, as for autism, but should not show significant delay in language or cognitive skills. In reality the latter is problematic, because as the diagnosis of Asperger’s syndrome is often given in late childhood or even adulthood, clinicians find it difficult to establish whether or not early language developed within normal limits.

2. Prevalence

Prevalence figures of ASD has been contingent on the definitions of autism that have been utilised. Kanner’s type of autism is rare: 2 per 10,000 in the child population (Wing, 1981). Lotter’s (1966) epidemiological study produced a prevalence figure of between 4 and 5 per 10,000, for a group of 35 children who demonstrated a persistent lack of affective contact and an obsessive desire for sameness. When Lotter divided this group into those who showed the features to a marked degree, he was able to distinguish a ‘nuclear’ group whose prevalence was 2 per 10,000, and it has been argued that these nuclear cases were clear examples of autism as originally described by Kanner (Frith, 1989). Wing and Gould’s (1979) Camberwell study discussed the relationship of autism with other disorders of social impairment and cited a prevalence of 2 per 10,000 for children with Kanner’s autism, expanding to 22.5 per 10,000 using broader definitions.

Autism is 3-4 times more likely to occur in males than in females and this ratio becomes more extreme with higher levels of ability (Gillberg and Coleman, 1992).

The only epidemiological study which has used DSM-IV or ICD-10 criteria for estimating the prevalence of Asperger’s syndrome (Ehlers and Gillberg, 1993) cited figures of between 36 and 71 per 10,000 in school age children, with a sex ratio of boys to girls estimated to increase to 8:1 (Happe and Frith, 1996).
3. Aetiology: theories and models

Precisely because of the variation in the types and degrees of behaviours apparent in the autistic spectrum, more than one causal model has been advocated. The stance of the early psycho-social theories was that autism had a purely environmental aetiology. Psychoanalysts (for example, Bettelheim, 1967) placed the blame for the disorder on rejection by the parent, usually the mother, and this conception had an influence on treatment: if the problem was with the family, then treatment ought to be directed towards changing parental behaviour or by providing surrogate parenting. Such views were challenged by a number of epidemiological points, for example, the higher incidence of autism in boys, the fact that there were very few families in which more than one child had autism and the evidence that very few children with autism had a history of deprivation (Rutter and Bartak, 1973).

The aetiologies of autism have been elusive, and because the core deficit associated with autism is unknown there is no satisfactory animal model (Fisher, Van Dyke, Sears, Matzen, Lin-Dyken and McBrien, 1999). Rutter and Schopler (1987) argue that there must be aetiological heterogeneity within the clinical picture of autism, pointing out that diseases as diverse as congenital rubella (Chess, Fernandez and Korn, 1978, tuberous sclerosis (Lotter, 1974), encephalopathy (Wing and Gould, 1979) and neurofibromatosis (Gillberg and Forsell, 1984) have all been implicated in the origins of autism. However, this very heterogeneity presents another problem for the design of well controlled clinical studies. For the purposes of this paper, the main approaches to theory development will be discussed as a precursor to considering if there is any one model which can explain the cause of autism.

3.1 Genetic theories

Several studies have found a genetic basis for autism and research also suggests that genetic factors may be involved in all of the spectrum disorders (Bailey, Le Couteur, Gottesman, 1995; Bolton, MacDonald and Pickles, 1994). The empirical evidence of male excess, of twin studies which demonstrate that there is a significant concordance between monozygotic and dizygotic twins and close associations with other genetic disorders also support a theory of genetic causation (Folstein and Rutter, 1977).

Although no single gene has been identified that would account for the phenotype of all autistic people, certain genetic abnormalities and disorders have been found to be particularly prevalent in individuals with autism. The greater prevalence of autism among the male population had suggested X-linked influences, and it was once thought that fragile X markers, identified by a mutation on the X chromosome, were strongly associated with autism (Gillberg
and Wahlstrom, 1985). However, more recent research indicates Fragile X appears to account for only 2-3% of autism (Bailey, Phillips and Rutter, 1996).

A high rate of autistic-like behaviours has been reported in other disorders linked to genetic abnormalities, such as Prader-Willis syndrome (Gillberg and Wahlstrom, 1985) and individuals with Williams syndrome, which is associated with an abnormality in chromosome 7, are also at risk for autistic disorder (Bailey, Phillips and Rutter, 1996).

Family studies have also contributed to understanding in this area. The most extensive standardised family genetic study compared the families of autistic individuals with those of Down’s syndrome individuals (Bolton, MacDonald, Pickles, Rios, Goode, Crowson, Bailey and Rutter, 1994). They found the rate of autism in siblings to be 3% (that is, an increased relative risk for siblings compared to the general population), a further 2% had an ‘atypical syndrome of autism,’ and a further 4% had a combination of cognitive and social abnormalities. Moreover, when isolated cognitive and social impairments were included, the rate of the disorder in the siblings was just over 14%.

There is now much evidence in support of genetic associations and the correlation between autism and some single gene conditions, although weak, implies that autistic spectrum disorders are likely to have multiple interacting genes. If autism is indeed genetically heterogeneous, then Bailey, Phillips and Rutter (1996) argue that one possible way of clarifying this issue may be the use of genomic searches of affected siblings.

3.2 Neuro-anatomical research

Neuroanatomic studies are also difficult to interpret due to diagnostic difficulties. Essentially they are based on the premise that a dysfunction in the nervous system causes the autistic individual to behave in a deviant manner.

Findings of the increased incidence of epilepsy and abnormal electroencephalograms (EEG’s) in autistic children provided initial evidence for an organic basis to autism (Ornitz, 1978). Approximately 40% of people with autism are affected by epilepsy (Gillberg and Steffenberg, 1987) and EEG abnormalities are found in over 50% of individuals (Bailey et al, 1996). The pattern of epilepsy in autistic individuals suggests that such electrophysiological abnormalities are an integral part of the clinical manifestation of autism and not simply the co-occurrence of two different disorders (Lord and Rutter, 1994).
Brain abnormalities in autism have been scrutinised both via imaging and autopsy studies. The data have been limited by the small number of brains studied, but research has tended to indicate that there are no gross anatomical abnormalities specific to autism (for example, Bailey, 1993).

Peculiarities in the limbic system and cerebellum have been reported (Bauman and Kemper, 1994), including, increased cell packing, reduced cell size and reduced connections in many parts of the limbic system. Additional abnormalities were found in the cerebellum with lower Purkinje cell counts apparent. The authors speculate that this may be suggestive of an underdeveloped stage as it resembles an early stage of normal brain maturation.

While initially promising, findings from structural MRI's have also had equivocal results. Enlargement of the fluid spaces in the Central Nervous System in some individuals with autism has been reported (Courchesne, 1991); however these findings have not consistently been replicated by other researchers (for example, Garber, Ritvo, Chiu, Griswold, Kashanian and Freeman, 1989).

Brain-behaviour links are not well understood for affective and social behaviour and although extensive work has been carried out over the last two decades the results have not made a great impact on the nature of the biological basis of this disorder.

3.3 Neuro-chemistry research
This is another area where potentially informative data was anticipated, but again findings have been limited (Bailey, 1993). Researchers have investigated the relationship of the neurotransmitter dopamine to autism, as the latter is implicated in mood regulation, memory and repetitive behaviours. A link between excessive dopamine activity in the basal ganglia and stereotyped behaviour has been demonstrated in animal studies (Ridley, 1994). Depressed dopamine levels have been reported in a group of autistic children when compared to learning disabled, non-autistic controls (Martineau, Barthelem, Jouve, Muh, Lelord, 1992). Moreover, these levels appeared to fall with age suggesting a maturational defect of the dopamine systems in people with autism. Although these results appear encouraging dopamiergic medications have not shown consistent benefit in the treatment of autism (Fisher et al, 1999).

Interest in the role of serotonin in autism originated in the 1960’s, when elevated serotonin levels were found in individuals with autism (Schain and Freedman, 1961). There is now
fresh research both in molecular-genetic and clinical studies which have successfully used selective serotonin re-uptake inhibitor in the treatment of stereotyped behaviours in some children with autism (Cook and Leventhal, 1996). Opioids have also been suggested as possible factors, but interpretation of many of these studies is hindered by methodological constraints (Cook, 1990).

3.4 Cognitive theories
Presently there are three broad, but critical cognitive approaches to autism: theories of impaired social cognition, theories of impaired executive functions and theories of weak central coherence.

3.4.1 Social impairment theory
This is essentially the idea that autism is a disorder of social insight and social skill (Happe and Frith, 1996). Core areas of early social interaction which have been suggested to be innately disturbed in the autistic child are: a lack of inter-personal relatedness (Hobson, 1993), a lack of joint attention (Mundy, Sigman and Kasari, 1993) and a lack of early imitation (Meltzoff and Gopnick, 1993).

As autism is currently defined at a behavioural level on the basis of impairments in socialisation, communication and imagination, that is the triad (Wing and Gould, 1979), psychological accounts have sought to explain these co-occurring symptoms in terms of underlying cognitive features. The most influential of these has been the 'theory of mind' deficit account: this is the hypothesis that people with autism are unable to represent the mental states (or mentalising) of themselves and others, in order to understand and predict behaviour with respect to these states (Baron-Cohen, Leslie and Frith, 1985). The authors argued for this deficit on the basis of failure on a simple false belief task: 80% of their sample of autistic children were unable to predict where a person would look for an object moved in his/hers absence. The child with autism would answer on the basis of the real state of affairs without taking into account the character's mistaken belief about the object's location. This has been taken as evidence for an autism-specific deficit in the process of 'mentalising.'

Frith, Happe and Siddons (1994) argue that the notion of such a 'mentalising' deficit explains the triad of impairments at a behavioural level, but it is also able to make 'fine cuts' in the smooth continuum of behaviours. Thus, it is able to make sense of the particular pattern of impairments in socialisation, particularly with respect to engaging in sensitive social reciprocity. It can also account for the communication difficulties in terms, for example, of
the inability to display the intention to communicate verbal and non-verbal information (Happe, 1993). With respect to impairment in imagination, this was shown in Wing and Gould's (1979) study by the absence of pretend play in the socially impaired group. Leslie (1987) has argued that pretence is an example of mentalising ability, as it depends on the ability to distinguish between a real state of affairs and a pretended state.

However, the theory of mind perspective is subject to limitations. It does not address the reasons for the varying degrees of severity of symptoms in autism. More crucially for the theory is that not all people with autism fail first-order belief tasks (Happe, 1995a), but perhaps the main limitation of the mentalising hypothesis is that there are other non-social features of autism which are not explained by this approach, for example, the obsessive desire for sameness and the restricted repertoire of interests (Happe, 1995b).

3.4.2 Executive function deficits
The above limitations in theory of mind accounts, plus the diagnostic criteria which requires autism to include restrictive, stereotyped and repetitive patterns of behaviour has generated interest in deficits of executive function (for example, Ozonoff, Pennington and Rogers, 1991). These include abilities such as planning, impulse control and working memory, whose normal functioning is believed to be contingent on intact frontal lobes (Ridley, 1994). Executive function theory draws on the link between brain and behaviour, as established from neuropsychological studies, and tests of executive function (for instance, Wisconsin Card Sorting Test and Tower of Hanoi) applied to autistic individuals have demonstrated substantial impairments (Pennington and Ozonoff, 1996). On the basis of this Ozonoff et al (1991) have suggested that executive function deficits are a primary causal factor in autism.

However, problems in executive functions cannot explain all aspects of the non-social impairments in autism, and more pertinently, cannot explain the intact skills. For example, Duncan (1995) argues that block design is considered a good test of 'fluid' intelligence, but this in turn relies on executive function abilities. Although this theory is favourable (Frith, 1991a), the specificity and power of this theory as a causal account of autism has to be established through systematic comparisons with other non-autistic groups who show impairments in executive function (Bishop, 1993).
3.4.3 Theory of Weak Central Coherence

Central coherence takes a different perspective in that it focuses on the performances that are successful. The theory proposes that underlying the performance peaks on IQ tests is a cognitive style which has a bias towards segmental rather than holistic processing (Frith and Happe, 1994). The idea that people with autism make relatively less use of context and pay preferential attention to parts, rather than wholes, has been demonstrated experimentally by Shah and Frith (1993). The authors presented the Block Design tests but the designs were pre-segmented. This significantly improved the performance of the normal or learning disabled control groups by removing the autistic groups advantage: it was as if the latter already saw the design in terms of it's constituent blocks. Having reviewed the evidence Frith and Happe (1994) argue that weak coherence may be an additional and independent feature of autism, and separate to the theory of mind deficits. Happe and Frith (1996) suggest an interesting possibility that since this concept has benefits as well as deficits, it could be genetically transmitted, and finding of superior block design and less coherent narratives in relatives of some autistic individuals provide evidence for this idea (Smalley and Asarnow, 1990).

4. Linking the theories

An early, but influential model of autism (Damasio and Maurer, 1978) was based on analogy at the behavioural level. Therefore, failure to develop normal relationships, ritualistic and compulsive behaviours, stereotyped movements and abnormal attention appeared to be related to acquired damage (both in human and animal studies) to the frontal lobe and related structures of the limbic system. The authors also speculated on the major role of dopamine in this system.

Although Damasio and Maurer's model appeared to provide a coherent account of a range of autistic features, much of the evidence was circumstantial. Moreover, Bishop (1993) makes the point that the frontal lobes and limbic system are involved in so many different aspects of behaviour that almost any pattern of symptoms could be explained in terms of a dysfunction in this system. Furthermore, they placed little emphasis on the impairments of social behaviour, and indeed they regarded most of the symptoms of social impairment as secondary to the other deficits of autism.

The evidence for genetic, neuro-psychological, neuro-anatomical and cognitive theories suggests a multi-factorial basis to autism. Frith (1991b) conceptualises this in terms a 'causal chain,' which has discrete links. Any one biological cause, such as faulty genes, chromosome
abnormalities, viral agents, metabolic disorders and immune intolerance has the potential to disturb neural development. Consequently, lasting harm may be done to the development of specific brain systems, concerned with higher mental processes, which results in the ‘arrest of a critical system at a critical point in time.’ Frith hypothesises that it is only then that autism will occur. What the ‘critical system’ actually encompasses is not at all understood, and it is probable that whatever it is that underlies the normal development of social and communication abilities is highly protected, but, nevertheless, the likelihood of this particular damage increases with the extent of general damage. Moreover, in the causal chain model for autism there is provision for multiple causes and for multiple levels of impairment; each possible cause could affect the critical system involved in autism, irrespective of whether it affects other systems as well. Hence, a common pathway notion of aetiology may be involved, and this common pathway may be susceptible to damage by a number of different agents.

Frith (1989) is clear in pointing out the inherent difficulties in locating pathology and linking it to developmental arrest at a critical point in time. The existence of multiple deficits at the cognitive level is also a key issue and may help in the elucidation of why autism can exist in many different forms ranging from mild to severe. Ultimately, it has the potential to inform matters with respect to diagnosis, management, education and intervention.

5. Interventions

Because research into the causes and expression of autism has been slow and erratic, this has clearly influenced the progress of applied research which has sought to identify and evaluate treatment approaches. As a consequence of the recognition that the autistic spectrum is fundamentally different to psychosis, methods of treatment have undergone radical change in the last three decades, with individual psychotherapy being usurped in favour of behavioural and educational methods as constituting the approach of first choice (DeMeyer, Hingtgen and Jackson, 1981).

In the absence of a thorough understanding of the causes of autism attempts at medical treatment have tended to be haphazard (Tsai, 1992). However, pharmacological interventions may be useful to control certain behaviours. For instance, the major tranquilisers or neuroleptics may reduce agitation, tension and hyperactivity (Corbett, 1976). Halperidol is a dopaminergic blocking agent and has been reported to improve co-ordination, self-care, affect and exploratory behaviour (Engelhardt, Polizos, Waizer and Hoffman, 1973. Stimulants, sedatives, opiates and ‘mega-vitamin’ therapy have all been popular forms of treatment, but
drug therapy as a whole comprises only one component of a total treatment plan for individuals with autism.

The basic goal of education and therapy for children with autism is to re-shape the specific developmental processes found to be disturbed. Rutter (1985b) has formalised this in terms of four general aims:

1. fostering social and communicative development,
2. enhancing learning and problem solving,
3. decreasing behaviours that interfere with learning and access to opportunities for normal experiences, and
4. helping families to cope with autism.

The following discussion provides an account of the main types of intervention and how they have developed from theories of aetiology.

5.1 Behavioural interventions

This is based on learning theory and the formal principles of classical and operant conditioning; it has been shown to be helpful in increasing adaptive behaviours and for controlling maladaptive behaviours (Lovaas, Berberich, Perloff and Shaeffer, 1966; Risley, 1968). Strong arguments have been made that positive principles of learning, and a better understanding of organising the environment to make it more meaningful and predictable to autistic individuals, reduces the need for behaviour programmes aimed at negative behaviours (Lord and Rutter, 1994). Moreover, LaVigna and Donnellan (1986) present the case that the majority of aberrant behaviours can be reduced by effective non-aversive procedures.

An extensive range of behaviours have been the targets of behaviour modification. For instance, social impairment is a critical deficit in those with autism and behavioural treatments have attempted direct training of socially appropriate behaviours using positive reinforcement techniques (Matson, Benavidez, Compton, Paclawskyj and Baglio, 1996). Speech and language deficits have also been addressed using behavioural approaches using both positive and combined (that is, positive and aversive) procedures (Lovaas, 1981). Target behaviours have also included daily living skills and academic skills and functional analysis has been investigated as a determinant for effective treatment (Matson et al, 1996).

McEachin, Smith and Lovaas (1993) have reported that unusually intensive behavioural treatment beginning at a very young age can lead to major gains for most children. Intensity can be considered on several levels, including duration of treatment, the number of
environments in which the interventions take place and the educational validity of the interventions provided. Lovaas (1987) reports that substantially more positive outcomes were observed for children receiving at least 40 hours per week treatment compared to those who received less than 10 hours per week treatment. Both these findings have yet to be replicated and there are methodological concerns and uncertainty about the completeness of recovery but they have generated a number of investigations in early intervention (Schopler, 1989).

5.2 Education

Although there may be no miracle 'cures' for autism, it is clear that the provision of appropriately structured educational programmes is an important aspect of successful treatment (Rutter and Bartak, 1973). There is evidence to show that the most effective educational programmes are those that begin early, that is, before the age of 4 (Rogers, 1996) and with access to appropriate educational services fewer children need to be placed in long stay institutions (Schopler and Olley, 1982). Early studies reported that for higher functioning autistic children there was a positive correlation between time spent in the classroom working on an academic subject and consequent improvements in that subject (Bartak and Rutter, 1973).

Educational programmes tend to take into consideration the individual needs of the autistic child. This approach is important because these children do not learn by modelling their peers and either withdraw or 'act out' when not given appropriate attention (Wolf-Schien, 1994). Jordan and Powell (1996) have incorporated aspects of the aetiology of autism to propose a 'specialist curriculum' for pupils with autism. They argue that the content of educational interventions ought to have a number of features: a pupil-centred approach rather than subject-centred so as to enhance social interaction, priority should be given to communication and inter-personal areas, functional and life skills should be addressed from the start, and the provision of training in imitation and observational skills with access to normally developing peers.

The TEACHH programme (Schopler, Mesibov and Hearsey, 1995), originally developed from a psycho-linguistic approach, stresses the importance of a structured environmental organisation and the use of clear visual information; in individuals with autism the latter is easier to process than verbal information. The authors also argue for the need to develop individually based learning programmes which take place both in the classroom and at home.
5.3 Special Therapies

Apart from the two major theory driven approaches to intervention discussed above, there are many individual therapies available, particularly aimed for young children which have little or no empirical basis.

‘Holding’ therapy (Welch, 1988) involves ‘intrusive interaction’ between parent and child. Theories as to why holding therapy appears effective with some children vary from the restoration of a ‘maternal bond,’ to stimulation of the cerebellum and changes in brain chemical levels caused by the child’s struggle to be released.

Gentle teaching has been advocated as a totally non-aversive therapy emphasising bonding between the teacher and student (McGee, Menolascin, Hobbs and Menousek (1987). McGee et al contend that this approach is particularly suitable for individuals with aggressive behaviour, or who self harm, as the process allows them to move from a state of ‘emotional distancing to one of meaningful human engagement.’

Facilitated Communication is an example of an approach which was prominent in the early 1990’s (Biklen, 1990). The technique was alleged to demonstrate that individuals with autism were actually of superior intellect and was claimed to lead to ‘Communication unbound.’ Controlled investigations have consistently indicated that responses are almost invariably under the control of the facilitator rather than the client (Bebko, Perry and Bryson, 1996).

6. Conclusions

An understanding of the autistic spectrum is dependent both on a careful description of the features specific to it and a recognition of the deficits that are associated with but not necessarily central to the disorder. There is significant knowledge about the prevalence and course of autism, the methods of assessment and clear details with respect to the social and cognitive deficits. As a relatively rare disorder, the involvement and interest of agencies such as scientific journals, multi-disciplinary research teams and national organisations facilitates the dissemination of information on diagnosis, potential aetiologies and the evaluation of interventions. A multi-factorial and multi-disciplinary approach to foster a more complete understanding of the aetiology of the spectrum disorders at a clinical, genetic, neuro-psychological and neuro-biological level remains a research and clinical challenge. This would ultimately provide clues for improved interventions and perhaps an improved quality of life.
7. References


Children, Adolescents and Family Essay

WHAT THEORIES HAVE BEEN ADVANCED TO EXPLAIN CHILDHOOD PHOBIAS?

CONSIDER THEIR STRENGTHS AND LIMITATIONS AND THE EVIDENCE BASE THAT WOULD SUPPORT THEIR USE IN CLINICAL PRACTICE.

December 1999
Year 2
1. Introduction

Fears are common in children of all ages, and indeed, it is well established that there are both qualitative and quantitative changes in fear patterns that are symptomatic of normal development (King, Hamilton and Ollendick, 1988). Moreover, Carr (1999) argues that fear is a natural and evolutionary response to a stimulus posing a threat to the safety or security of any individual, and that an individual can be affected in a number of ways. At a cognitive level the individual may perceive the situation as threatening, at an affective level the individual may experience feelings of unease or apprehension, at a physiological level the individual will experience automatic arousal to prepare him/her for fight or flight and at a behavioural level the danger may either be addressed or avoided.

Typical childhood fears change over the course of development reflecting increasing cognitive and social competencies (Ollendick, King and Yule, 1994). In early infancy loss of support or loud noises are the principle sources of fear indicative of the fact that sensory abilities are primary in the infant’s adaptation of their immediate environment. During late infancy with the development of object constancy, concern about separation from the attachment figure becomes apparent, and as a consequence, concern of strangers emerges. Pre-operational thinking and the capacity to imagine (although not the ability to distinguish fantasy from reality) result in the fear of the dark and supernatural beings for toddlers between the ages of 2 and 4 years. By the time the child is 5 years olds and up to 7 years, the principle sources of fear are natural disasters, injury and fears of the world based on a media portrayal, indicating that the capacity to think in concrete logical terms is beginning to develop. With the development of self esteem in middle childhood (8-11 years) fears become concentrated on the school context, particularly with respect to academic and sports performance. Finally, with the onset of adolescence (12-18 years) the capacity for abstract thought emerges via formal operational thought processes and this facilitates the individual’s ability to anticipate future dangers. Also in this stage, esteem is more derived from peer relationships so fears about peer rejection is particularly pertinent at this stage.

Most childhood fears do not become problematic in the clinical sense (Ollendick, King and Yule, 1994). However, children can and do demonstrate fears that are maladaptive, enduring and are the source of distress both for the child and for their carers. This is a very general definition of anxiety (Carr, 1999). With generalised anxiety, the eliciting stimuli are less defined and many aspects of the environment are interpreted as potentially threatening, even when there appears to be no apparent grounds for the anticipation of danger. In contrast, specific phobias are irrational and persistent fears of certain objects, animals or situations.
In considering the difference between fears and phobias Miller, Barrett and Hampe (1974) make the following points about phobias:
(a) that they are out of proportion to the demands of the situation,
(b) that they cannot be rationalised,
(c) that they are beyond voluntary control,
(d) that they can result in increased avoidance of the feared situation,
(e) that they persist over time,
(f) that they are maladaptive, and
(g) that they are not age or stage specific.

In recognition of their seriousness and stability, phobias are included in the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (American Psychiatric Association, 1994) and in the International Classification of Mental and Behavioural Disorders (ICD-10) (World Health Organisation, 1992).

The aims of this essay is to briefly discuss the criteria for childhood phobia with respect to its classification and then to evaluate the theories that have been postulated to elucidate the etiology of childhood phobias. The evidence supporting the interventions based on these theories will be considered before drawing some final conclusions.

2. Definition and classification

Both DSM-IV and ICD-10 include phobias under the general axis of a disorder where anxiety is a major feature. Both systems also distinguish between generalised anxiety disorder where many possible stimuli may evoke an anxiety response and specific phobias that are elicited by a particular type of stimuli. Furthermore, phobic anxiety disorders are sub-divided into specific phobias, agoraphobia and social phobia. The first type of phobia requires a very narrow range of stimuli with an ensuing relatively discrete effect on the individual’s adjustment. A broader class of stimuli are involved in the latter two types of phobic anxiety disorders and the impact on the person’s adaptation may be more impaired or pervasive (Carr, 1999). Moreover, DSM-IV sub-divides specific phobias into those associated with animals, injury (including blood and injections), features of the natural environment (for example, heights) and particular situations, such as flying.

The criteria specified in the early definitions of phobia (Marks, 1969 and Miller et al (1974) and discussed above, have on the whole, been adopted by DSM-IV and ICD-10. Moreover, DSM-IV also concedes that children may well not be able to identify their fears as excessive or unreasonable. Thus, phobias in young children may be expressed in ‘childhood’ ways,
such as crying, tantrums, freezing or clinging (King and Ollendick, 1997). In addition, the ‘intensity’ of the fear has been fine tuned by both classification systems so that fear is typically severe enough to lead to interference in functioning, such as in the child’s academic, social or family participation. The ‘three systems model’ originally proposed by Lang (1968) conceptualised typical response patterns of childhood phobias in terms of three components: cognitive, physiological and overt behavioural. This ties in with the diagnostic criteria stipulated by DSM-IV and ICD-10 and King, Hamilton and Ollendick (1988) have provided evidence of a variety of responses that may occur in the phobic child with respect to this tripartite model. Self-deprecatory thoughts and thoughts of being afraid are examples of a cognitive response, increased heart rate and changes in respiration are examples of a physiological response and a rigid posture, avoidance or thumb-sucking may be examples of overt behavioural responses.

DSM-IV requires that other anxiety conditions must be eliminated before reaching a diagnosis of specific phobia, so that they are not mis-diagnosed as agoraphobia or obsessive compulsive disorder. Furthermore, children who demonstrate school refusal behaviour can often be labelled as having school phobia (Silverman and Rabian, 1994). However, it is now acknowledged that school refusal should not be considered to be a unitary syndrome, but rather one that is heterogeneous and multi-causal with children refusing school for a variety of reasons (Atkinson, Quarrington and Cyr, 1985).

Studies on the prevalence of childhood phobic disorders suggest that on a comparative basis specific phobias occur relatively frequently compared to social phobia or agoraphobia, but that all childhood phobias are relatively stable across intervals varying from 2-5 years (Costello and Angold, 1995). There is also evidence that they are more prevalent among girls than boys (Anderson, Williams, McGee and Silva, 1987).
3. Evaluation of the etiological theories explaining childhood phobias and the evidence supporting their use in clinical practice

A number of theories have been considered in the literature pertaining to the etiology of childhood phobia, generating controversy as well as empirical evidence. They can be crudely classified into those focusing on biological variables such as the role of genetics and neurotransmitters and those emphasising the importance of psychological theories, including psycho-analytic theory, learning theory, cognitive-behavioural theory and family systems hypotheses. Although there is evidence in the literature for both the roles of genetics and neurologically based deficits only the psychological theories will be presented here.

3.1. Psychoanalytic theories

The early etiological theories of anxiety primarily consisted of the work of Freud (1926) and were central to Freud’s ideas about neurotic symptomatology. According to classical psychoanalytic theory, defence mechanisms keep unacceptable impulses and feelings, such as anger or sexual impulses, from entering consciousness. These unacceptable feelings and the accompanying moral anxiety become transformed into neurotic anxiety and are eventually expressed as an anxiety disorder. Therefore, in psychoanalytic terms the child with a phobia is actually afraid of giving way to the temptation to express deeply rooted, forbidden impulses. Therefore, the avoidance element of a phobia essentially shields the child from a situation in which repressed aggressive or erotic impulses might be aroused. Furthermore, displacing the anxiety on to some associated object deflects the temptation. This substitute object symbolises the original object about which the unacceptable impulses were, but is a more socially acceptable target. Freud’s case example was ‘Little Hans’, in which the boy’s taboo fears were castration anxiety and fear of the father and this was displaced onto horses (Freud, 1909).

The status of this kind of etiological theory is highly controversial as psychoanalytical observations stem from a very different epistemology to other what are considered more scientist-practitioner approaches (Herbert, 1994). Treatment is typically conducted within an individual non-directive play therapy format with young children and within individual psychodynamic psychotherapy with adolescents. The aim of treatment is to interpret the defence, the hidden feelings which are being repressed and the associated neurotic anxiety (Malan, 1979).

According to Carr (1999) there is no evidence to support the idea that all anxiety disorders represent displacement of anxiety associated with psycho-sexual developmental conflicts.
Fonagy and Moran (1990) acknowledge that there are many reasons why child psychoanalysis has not been subject to systematic evaluation, including the fact that treatment tends to be intensive, averaging five times weekly and relatively long term. Nevertheless, Bernstein, Rapaport and Leonard (1997) argue that for many children with anxiety disorders, therapy that focuses on underlying fears is often an appropriate component of treatment and two studies in particular indicate that child psychotherapy is at least as good as systematic de-sensitisation. Henicke and Ramsee-Klee (1986) and Target and Fonagy (1994) using children diagnosed with anxiety disorder both report that intensive psychotherapy, that is, more than one session per week, for at least 6 months, were significantly more likely to show an improvement in adaptation than those receiving fewer sessions. Moreover, Target and Fonagy (1994) suggest that predictors of improvement were greater frequency of sessions, longer periods of treatment, phobic symptomatology and younger age.

3.2. Behavioural theories

For decades researchers have sought to explain the etiology of specific phobias in terms of classical aversive conditioning models (Watson and Raynor, 1920). The basic tenet of this is the assumption that phobias have traumatic origins. Typically, the fear of what was once a neutral stimulus, that is, a 'conditioned stimulus,' can be traced back to the occurrence of this stimulus with a highly aversive incident, that is an 'unconditioned stimulus.' This basic phenomenon of aversive classical conditioning, that fear can be conditioned to a conditioned stimulus by pairing it with an aversive unconditioned stimulus has been demonstrated empirically. Indeed, in Watson and Raynor's (1920 notorious 'Little Albert' study, the researchers used conditioning methods to convert the subject's affinity for white rats into phobic anxiety. Almost half a century later, Campbell, Sanderson and Leverty (1964) essentially repeated this dubious ethically study by having subjects listen to a tone, that is, the conditioned stimulus, followed by an injection which caused temporary respiratory paralysis (the unconditioned stimulus). After just a single conditioning trial and even with the elapse of some time following the presentation of the conditioned stimulus, participants reacted with overt autonomic responses, that is, conditioned responses, to isolated presentations of the same tone. Aversive classical conditioning also built in two other concepts. Stimulus generalisation explains how other stimuli similar to the original conditioned stimulus can also elicit a fear response. Extinction clarifies how the intensity of the fear can become diluted or even extinguish if the conditioned stimulus is repeatedly presented without consequent trauma.
However, although experimental studies have illustrated that conditioning can occur, in theory, to produce phobic anxiety, and even for it to be treated, there is little direct evidence to suggest that this is the primary source of childhood phobias. Researchers have identified several, specific shortcomings of this theoretical approach. For instance, it is not always the case at the point of assessment that individuals reveal any traumatic incident (unconditioned stimulus) to have taken place (Menzies and Clarke, 1995). There is also evidence that people do not necessarily acquire conditioned fears in what are clearly aversive confrontations (Milne, 1977). Moreover, the conditioning approach fails to explain why specific fears are non-randomly distributed (Seligman, 1971). Neither does it account for the fact that extinction does not always occur in the natural environment when the conditioned stimulus is repeatedly confronted without being followed by an aversive event (King, Hamilton and Ollendick, 1994).

The conditioning theory of children's phobias, in contrast, is more sophisticated. It evolved from aversive classical conditioning to a two factor conditioning theory (Eysenck and Rachman, 1965) into the development of a model that recognises that phobias can have non-traumatic origins. One of the most influential explanations with respect to basic behavioural formulations is that of Rachman's (1977) pathways to phobia acquisition theory. Rachman proposed that there are three major, often overlapping, pathways to the acquisition of phobias that are particularly relevant to children. The first is via direct conditioning, the second is through modelling (that is, vicarious exposure) and the third pathway is through the acquisition of information or due to instruction.

The modelling pathway assumes that phobic fears can be acquired by watching others reacting in a fearful way to a stimulus. There is evidence for this assumption: Ollendick and King (1991) using a community sample of school aged children reported that for ten highly prevalent fears, such as snakes or getting burnt, the causal factors that were thought most influential by a majority of respondents were modelling and instructions. More significantly, only a minority of the children attributed their phobic anxieties to direct conditioning. In a survey using a clinical sample, a majority of parents endorsed modelling to be the most significant in the origins of their children's phobia (King, Clowes-Hollins and Hollendick, 1997). With respect to negative information it is assumed that information of certain stimuli provided by significant others, whether they be parents or peers, or by the media, may give rise to a fear of those stimuli. There is some evidence that information on dental procedures is more pertinent than modelling so far as the development of dental phobias are concerned (Emmelkamp, 1982). Furthermore, Muris, Steerneman, Merckelbach and Meesters (1996)
have shown that fears reported by children are a function of the extent to which mothers express their own fears in the presence of their children. This suggests that both the modelling and information pathways may operate in familial situations.

Other studies do not present such a clear-cut picture. Menzies and Clarke (1993) conducted a study simultaneously examining the influence of all three of Rachman’s pathways in water phobic children. A majority of parents believed that their child’s water phobia had been present since their first contact with water and that none of the three pathways appeared to fit with the onset of their child’s phobia. King and Ollendick (1997) argue that this type of finding implies that there may be many etiological factors inherent in childhood phobias. Interestingly, Rachman (1997) originally proposed that there might be a systematic connection between the etiology of phobia, symptom profiles and treatment. Accordingly, phobias based on a direct conditioning pathway would have clear behavioural and physiological symptoms and could be appropriately subjected to behaviourally based interventions such as systematic de-sensitisation or exposure therapy. However, phobias acquired through variables such as modelling and information exchange, would be more characterised by cognitive symptoms and, therefore, the success of their extinction would be more applicable via cognitive techniques, such as cognitive re-structuring. Partly because research participants may themselves attribute their phobia to more than one pathway and perhaps also because this may be too simple an account, the empirical status of Rachman’s proposals have yet to be verified (Merckelbach et al, 1996). Moreover, much of the research that has tested Rachman’s (1977) model is methodologically limited as it has almost always been limited by the use of retrospective reports and also as many of these studies have used non-clinical samples.

Incubation theory is another complex model offering a view on the etiology of phobias (Eysench, 1979). The theory essentially uses the principle of a positive feedback loop, where the subjective perception of fear reinforces the fear of the phobic stimulus. Eysench’s main premise is that anxiety can develop through just one trial of classical conditioning and this is at a sub-conscious level. The main point is that the neutral stimulus (the conditioned stimulus) is one for which the person is already biologically primed to develop an extinction-resistant fear to. This conditioned stimulus is paired with a strongly feared object (the unconditioned stimulus) which results in the inevitable anxiety (unconditioned response). Subsequent exposure to the conditioned stimulus leads to mild anxiety and repeated brief exposures to the conditioned stimulus results in an increase in fear through a process Eysench refers to as incubation. The brief exposure itself leads to anxiety (conditioned response),
which is effectively, paired with the feared object, and on the next brief exposure even more fear is experienced.

Operant conditioning, with the particular use of positive reinforcement, has also been argued as playing some role in the development of children's phobias (Miller, Barrett and Hampe, 1974) and could also be compatible with the indirect pathways of phobia acquisition proposed by Rachman (1977). According to Miller et al (1974) the premise of operant theory is that phobic behaviour in children may be established on a gradual basis via inadvertent or deliberate reinforcing on the part of significant others. Thus, behaviour which is rewarded will tend to recur whilst behaviour that is not rewarded will eventually extinguish. The theory assumes that children engaging in avoidance behaviours, as well as secondary behaviours such as temper tantrums, are positively and systematically reinforced. Typical reinforcers would be social rewards, given by significant care-givers, and attention, be it positive or negative. Moreover, parents teach children to be afraid by selectively attending to and rewarding fearful and avoidant behaviours. A consequence of this is that children learn that parents respond even to the smallest of their fears with frequent attention, so that the more fear and avoidance that they display, the more attention they will potentially receive by significant others. The longer-term outcome of this is that children fail to develop more adaptive responses to aversive stimuli.

Although there is controversy surrounding all of the above theories encapsulating some element of the conditioning process, research evidence does appear to suggest that techniques such as systematic de-sensitisation and flooding, particularly when used in vivo are effective methods for treating specific phobias in children. In both these paradigms phobias are viewed as classically conditioned responses that can be unlearned through counter-conditioning procedures (Wolpe, 1958). There have been four controlled group outcome studies examining the efficacy of systematic de-sensitisation. One study reported systematic de-sensitisation to be a superior intervention to two other active treatments (Kondas, 1967). Mann and Rosenthal's (1969) study demonstrated that systematic de-sensitisation was better than no treatment and worked equally as well as modelling. The results of Barabasz's (1973) research indicated that children who underwent a systematic de-sensitisation programme demonstrated significantly reduced anxiety. Miller, Barrett, Hampe and Noble (1972) reported that essentially systematic de-sensitisation and psychotherapy were equally as effective in reducing phobic behaviours compared to no treatment. Having recently reviewed empirically supported treatments for children with phobias Ollendick and King (1998) argue that systematic de-sensitisation is likely to be an effective intervention for children with a specific
phobia even though it appeared to be inconsistent with the reported clinical experience of many therapists.

Modelling draws on vicarious conditioning principles as referred to above, and is based on observational learning to overcome children's phobias. Ollendick and King (1998) reported this to be a probably efficacious technique, reviewing nine studies which have demonstrated its effectiveness over systematic de-sensitisation and no treatment (for example, Lewis, 1974 and Murphy and Bootzin, 1973).

The usefulness of operant conditioning as a theory has also been tested in research and clinical settings (King, Hamilton and Ollendick, 1988). According to King et al (1988) contingency management procedures try to change phobic behaviour by manipulating its consequences. The model demands a functional analysis of the positive and negative reinforcing stimuli that trigger and maintain the phobic behaviour rather than trying to reduce the anxiety per se. The authors argue that the functional analysis should then inform the contingency management procedure to be used. Examples of some commonly used techniques are shaping, positive reinforcement and extinction (Morris and Ktratochwill, 1983). Both controlled and uncontrolled studies have examined the efficacy of operant conditioning, for example, Glassock and MacLean (1990) and Leitenberg and Callahan (1973). The treatment used in the latter study consisted of practice of exposure to the fear, feedback and reinforcement. Leitenberg and Callahan (1973) demonstrated that the children in the treatment group were able to tolerate their fear for longer periods of time compare to those children who were in the control group.

However, in many of the studies testing the utility of the operant conditioning methods, the findings have been confounded by the simultaneous use of other types of strategies, such as systematic de-sensitisation, for instance, Obler and Terwilliger (1970). Thus, King and Ollendick (1997) conclude that the evidence for the efficacy of operant based mechanisms, although suggestive, is less convincing than those based on classical conditioning theories.

3.3. Cognitive and Cognitive-Behavioural theories
Cognitive mechanisms have been subject to much research (McNally, 1995) albeit not specifically with children. The general consensus is that cognitive dysfunction in specific phobias appear to be associated to certain information processes and semantic domains rather than overall deficits in memory or motor function. Merckelbach et al (1996) argue that phobic clients tend to demonstrate evidence of deficits in attention and making judgements and that
the attentional and judgmental biases accompanying phobias are bound to specific fear relevant stimuli.

Beck, Emery and Greenberg (1985) offer a more substantial account of how anxiety problems may develop and be best treated. They argue that anxiety disorders are a result of threatening life events triggering threat orientated cognitive schemas which were formed during a stressful and threatening experience in childhood. Within these schemas are dysfunctional assumptions about the world containing many threats. Cognitive distortions such as minimising safety-related events and maximising threat-related negative events are also implicit.

Cognitive behavioural interventions aim to alter the dysfunctional thoughts, perceptions and beliefs held by children with a phobia primarily through the use of cognitive restructuring. The underlying hypothesis is that dysfunctional behaviour is a consequence of maladaptive cognitions and that cognitive changes will produce behaviour changes. However, in recognition of the complex interaction of cognitive and environmental factors, both cognitive and behavioural principles are often used in conjunction at treatment. There is some empirical support for cognitive-behavioural interventions with studies employing sophisticated multiple baseline designs across participants. In a clinical outcome trial, Graziano and Mooney (1980) showed that children with severe night time fears significantly improved following participation in a group comprising of self-instruction, verbal coping skills and parental reinforcement compared to those children who were in control group. Moreover, this improvement in night-time fears was maintained at 6 months and 12 months follow-ups. In an uncontrolled case report, Matthey (1988) reported successful application of cognitive behavioural treatment with a girl who had a phobia of thunderstorms. Treatment involved self-statements, reinforcement, peer modelling and exposure to video recordings of storms. Outcome ratings from parents and teachers indicated a decrease in fear behaviour and this was maintained over a 12 months follow-up period. King and Ollendick (1997) argue that although more controlled and prospective studies are still required, the available research findings are suggestive of the efficacy of cognitive behavioural strategies. Furthermore, they make the point that successful outcome of such types of interventions is bound to be dependent on factors such as the age and cognitive abilities of the child and therapy moving at a pace that the child is confident with so that their anxiety is not inadvertently exacerbated.
3.4. Theories of Family systems

A clear, unified theory about the role of the family and the socialisation process in the etiology of phobic anxiety is still not yet complete. However, social learning theory (Bandura, 1986) and advocates of family therapy are now beginning to offer a strong psychosocial emphasis to the consideration of the etiology and treatment of children with anxiety problems (Estrada and Pinsof, 1995).

Rather than focusing primarily on the child, the social context of children, that is, the family has come under scrutiny. Learning is seen to occur within a social nexus where events are mediated by family members, within attachment and social systems and not just as a direct result of an incident. In essence, this hypothesis suggests that children not only respond to stimuli but also interpret them. A systemic model of explaining the development of childhood phobias takes the position that children probably develop anxiety problems when they are socialised in families where primary caregivers elicit, model and reinforce anxiety related beliefs and behaviours. There is some evidence for this notion in that epidemiological research indicates that parents of phobic children are significantly more likely to have anxiety problems themselves (Silverman, Cerny and Nelles, 1988). McFarlane (1987) argues that family belief systems, which perpetuate anxiety, may involve a view of world where ambiguous situations are interpreted as threatening or dangerous; therefore avoidant responses are commonly used. By observing significant family members expressing these beliefs and accordingly engaging in family interactions based on these beliefs, children come to internalise them and develop a personal danger saturated belief system. Moreover, the significant people in the child’s milieu may all inadvertently maintain the child’s maladaptive beliefs and avoidance behaviour by generally supporting the child’s fears, taking on board the child's catastrophic view of the situation and excusing or condoning the avoidance behaviour as a justifiable coping strategy. If the primary care-giver themselves have an anxiety or any type of phobic sensitivity, then this may mean that the child does not get the appropriate opportunity to develop the skills required to address and overcome feared situations.

Therefore, increasingly, therapists from differing traditions have started to integrate their approaches into comprehensive programmes targeting the child, the family and even the school (Kazdin, 1991). Ginsburg, Silverman and Kurtines (1995) have also hypothesised that family orientated behavioural intervention may prove to be more effective than child focused behavioural strategies in the treatment of childhood phobia. Support for this approach comes from an early study by Windheuser (1977). Windheuser not only used techniques from conditioning, operant and cognitive behavioural theories as a treatment regime, he also
required the mothers of the phobic children to receive treatment of their own phobic anxieties and to adopt a coping role model for the benefit of their child. The results demonstrated that this approach was more effective than standard behavioural treatment or no treatment at all; moreover, treatment gains were maintained at 3 months follow-up. Estrada and Pinsof (1995) have reviewed other more recent studies. They assert that although there are methodological limitations in much of this body of research, nevertheless, there is tentative support for the efficacy of approaches that involve parents in the treatment of their child’s fears, for example, Giebenhain and O’Dell (1984) and McManamy and Kratz (1989).

4. Summary and conclusions

Fear is a natural response to threatening stimuli, whereas phobias are irrational and persistent fears in the absence of any apparent danger. In a significant minority of children phobic anxiety interferes with normal functioning and can become chronic. Specific phobias form a heterogeneous class of disorders that are characterised by etiological diversity. Psychoanalytic, behavioural, cognitive-behavioural and family systems formulations of phobic anxieties have been developed to account for the development of phobias, and the research and clinical accounts ensuing from these theories illustrate the complex, multidimensional nature of this disorder incorporating genetic, constitutional and environmental factors.

A variety of behavioural, cognitive-behavioural and family orientated interventions have been demonstrated to be more effective in the treatment of childhood phobias than waiting list control conditions, and indeed, some specific techniques appear to be more superior than others. Multi-component exposure based treatment programmes seem to be more effective precisely because they appropriately address the diversity of factors that are probably involved in the development and maintenance of phobic reactions. However, due to the overall limitations of the both the theoretical and clinical literature, it is difficult to draw general conclusions about which constitutes the ‘best method’ for treating phobic anxiety in children.
4. References


Specialist Placement

CRITICALLY EVALUATE THE APPLICATION AND ROLE OF PSYCHOLOGICAL INTERVENTIONS IN THE MANAGEMENT OF CHRONIC PAIN.

June 2000
Year 2
1. Introduction

Chronic pain affects over 10% of the world’s population (Magni, Caldieron, Rigatti-Luchini and Merskey, 1990) and in a British survey 11% of respondents reported chronic pain (Rigge, 1990). As such it presents a significant challenge. For patients and their carers, additional stressors that accompany the pain symptoms, for example, the loss of career and social activities, financial constraints, social isolation and limited mobility can cause considerable hardship (Turk, 1996). Moreover, demands placed on limited health service resources, the overall costs of medical treatment, as well as the cost in economic terms due to lost working hours, litigation and welfare benefits has increased research into effective interventions.

2. Definition of chronic pain and distinction from acute pain

Pain has been conceptualised as an ‘unpleasant sensory and emotional experience, associated with actual or potential tissue damage’ (International Association for the Study of Pain [IASP], 1979). This definition incorporates the multi-dimensional aspects of the phenomenon, including sensory, affective, motivational, environmental and cognitive components (Melzack and Wall, 1982). Moreover, it implies that the experience of pain involves not only nociceptive events but also a complex of psychological association.

Chronic pain can be distinguished from acute pain in terms of the latter’s positive response to medical intervention. When a patient’s pain becomes unresponsive to any single modality of treatment or if it endures beyond the normal healing time and in the absence of on-going pathology, it is viewed as chronic pain (Jacobson and Mariano, 2001). A variety of conditions may be the source of chronic pain, for instance, low back pain, rheumatoid arthritis and migraine. It specifically excludes persistent pain that is associated with a malignancy as that often has a direct relationship with tissue pathology (Jacobson and Mariano, 2001). Predominantly in chronic pain diagnostic tests fail to identify clear pathology (Flor and Turk, 1984), drugs only provide limited relief and can produce adverse side effects (Bonica, 1977) and invasive treatments can prove unhelpful and carry a risk of further deteriorating matters (Flor and Turk, 1984). Thus, chronic pain disability is now viewed as a complex and interactive psycho-physiological behaviour pattern that cannot be broken down into distinct, independent psychological and physical components (Gatchel and Turk, 1999).

Psychological research and intervention have arguably contributed more to the study of chronic pain and its management than to any other medical speciality. However, in reality, its position alongside bio-medical interventions has, up until quite recently, remained ambiguous (Williams and Erskine, 1995). This is no doubt at least partly due to the complexity in the
conceptualisation of chronic pain. This has resulted in the growth of inter-disciplinary research programmes in the United States, and in the last five years there has been a rapid expansion of these programmes in the U.K. (for example, Williams, Nicholas, Richardson, Pither, Justins, Chamberlain, Hardin, Ralphs, Jones, Dieudonne, Hodgson, Ridout, Shannon, 1993). When the early programmes were subjected to evaluation, beneficial, although equivocal, results were reported (Deardoff, Rubin and Scott, 1991). More recently, Morley, Eccleston and Williams (1999), in a systematic review of randomized controlled trials of cognitive-behaviour therapy and behaviour therapy for chronic pain in adults, report finding good evidence for the use of psychological treatments.

3. Models of chronic pain

A number of models have been posited to explain the chronic pain phenomena. Jacobson and Mariano (2001) argue that they can essentially be categorised as either restrictive or comprehensive. Restrictive models, (for example, the biomedical model) tend to ignore plausible facets of pain or the potential interactions among them whereas comprehensive models, namely the bio-psychosocial model take into account multiple facets and their reciprocal relationship (Jacobson and Mariano, 2001). The two models will be discussed and examined in relation to chronic pain and a third model, the bio-behavioural model will be introduced that aims to promote a more integrated and systemic understanding of chronic pain.

3.1. The Biomedical model

The earliest attempts to conceptualise pain can be traced back to the 17th century philosopher Descartes and depended upon dualistic notions of body and mind. The evolution and development of medical science resulted in the biomedical model (for example, Sternbach, 1968) establishing itself as the primary theoretical explanation and treatment of chronic pain. Underlying this model is the assumption that pain results from a disease state, which can be identified via objective tests of physical damage and impairment (Turk, 1996). A linear relationship is assumed between the level of pain experienced and the degree of damage or stimulation. Therefore, the aim of medical interventions is to ‘correct the organic dysfunction or pathology,’ and thus remove the pain (Turk, 1996). Jacobson and Mariano (2001) argue that people with chronic pain often adhere to this model as it supports and reinforces their belief that they have a real, physical disease underlying their pain symptoms.
However, the biomedical model does not seem to be appropriate for understanding chronic pain and it is not strongly supported by the clinical evidence. It has difficulty accounting for the following frequently made clinical observations:

1. Patients having the same level of underlying disease activity often report very different levels of pain (Taylor and Curran, 1985).
2. Pain can be present even when there is no clear evidence of tissue damage (Compas, Haaga, Keefe, Leitenberg and Williams, 1998).
3. Pain may persist long after a reasonable time for healing has passed.
4. Individuals may experience variable levels of pain, even though, there is no perceptible underlying change in tissue damage (Compas, Haaga, Keefe, Leitenberg and Williams, 1998).

This suggests the influence of other mediating factors in the relationship between pathology and the subjective pain experience.

3.2. The Bio-psychosocial model

Difficulties with the biomedical model describing pain in solely physiological terms led to the formulation of a more sophisticated bio-psychosocial model. This model recognises the importance of biological factors but also emphasises the significant influences that psychological factors (for example, anxiety, depression, coping strategies and perceived control over pain) as well as social factors (that is, family and environment) can have on the pain experience. Indeed the IASP definition of chronic pain acknowledges both the subjective nature of the pain experience as well as the non-linear relationship which can exist between tissue pathology and pain severity (Skevington, 1995). It is also noteworthy that the IASP have recommended that chronic pain management should ideally involve both medically trained and psychologically trained health professionals (Fields, 1991).

An important issue with respect to the bio-psychosocial framework is the conceptual difference between 'disease' and 'illness,' and it appears to parallel the shift from the biomedical model to the bio-psychosocial model. Diefenbach and Leventhal (1996) argue that disease is characterised by 'a set of signs and symptoms' on the basis of which a diagnosis can be made. Illness, however, relates to the social definition of illness as well as the psychological dimension and does not require all the signs and symptoms of a specified disease to be present (Kleinmann, 1988).

One of the most influential bio-psychosocial theories is the Gate Control Theory of Pain (Melzack and Wall, 1965, 1989). It is significant in two respects: it describes the mechanisms
of the transmission and modulation of nociceptive signals and it recognises pain as a psycho-
physiological phenomenon resulting from the interaction between physiological and 
psychological events.

The Gate Control theory postulates spinal 'gates' in the spinal cord that determine which of 
the competing impulses (pain, heat or touch) is transmitted at any particular moment. 
Successful transmission through the gate is affected not only by the intensity of the 
stimulation and competing local stimuli, but also by descending fibres from the higher central 
nervous system from. In addition, the theory allows for the possibility that pain stimulation 
and transmission might occur in patterns of sensations. Thus the Gate Control Theory has 
incorporated biological (for example, tissue damage or temperature) and psychological (mood, 
self-esteem or locus of control) factors in the experience of chronic pain.

Williams and Erskine (1995) argue that the gate remains a model rather than an identifiable 
mechanism but that its strength lies in its integration of sensory-affective processes. It has 
received support from empirical research (McQuay, Carroll and Moore, 1988) and although it 
has its limitations, Melzack and Wall's work has facilitated a theory driven role for 
psychological factors in the experience of chronic pain (Main and Spanswick, 2000).

3.3. The bio-behavioural model
One limitation of the Gate Control Theory is that it does not address in detail the nature of the 
psychological factors implied in the perception of chronic pain. Flor, Birbaumer, and Turk 
(1990) have presented a bio-behavioural model that outlines the pre-conditions for chronic 
pain including the predisposing factors, precipitating stimuli, precipitating responses and 
maintaining processes.

Flor at al (1990) argue that the first component of this model may be a physical predisposition 
where there is a reduced threshold for nociceptive activation. This may be related to genetic 
variables, previous trauma or social learning experiences and results in a physiological 
response stereotypy of the specific body system. Ultimately, persistent aversive external or 
internal stimuli (pain related or other stressors) coupled with aversive emotional stimuli (for 
example, familial conflicts or pressures related to employment) activate the sympathetic 
nervous system and muscular processes as unconditioned and conditioned stimuli and 
motivate avoidance responses.
The important role played by cognitive processing and behavioural factors is highlighted and related to the experience of pain: for example, increased perception of, preoccupation with and over-interpretation of physical symptoms. Furthermore, the nature of the coping response may determine the course of the chronic pain. Other subsequent maladaptive physiological responding, such as increased and persistent sympathetic system arousal may induce or exacerbate pain episodes. Flor at al (1990) also suggested the roles played by social and operant learning of pain behaviours in ultimately contributing to physical and/or psychological disability. A recent review by Vlaeyen and Linton (2000) discusses research on the fear-avoidance theory. This argues that chronic pain is exacerbated due to the avoidance of activities based on fear. The fear-avoidance theory seems to lend itself to the psychological aspect of the bio-behavioural model by demonstrating how the formation of conditioned responses to the fear of activity can contribute to the chronicity of pain.

There is evidence for specific details of the bio-behavioural model. For instance, it has been shown that psychological processes in the form of learned pain memories can directly influence the physiological processing of pain (Birbaumer, Flor, Lutzenberger and Elbert, 1995). Interventions that can change beliefs about pain, coping styles, perceived control over the pain and decreased catastrophising have been found to be associated with decreases in pain severity ratings and functional disability (Jensen, Turner, Romano and Karoly, 1991). However, future research will need to refine and validate the theoretical and clinical utility of this complex model.

4. Psychological theories explaining chronic pain
A broad range of theories has been applied to the treatment of chronic pain including psychoanalytic (for example, Engel, 1959), behavioural (Fordyce, 1976), cognitive-behavioural (Turk and Rudy, 1986) and social theories (Roy, 1989). Despite their differences almost all psychological interventions involve a re-conceptualisation of the pain and it's associated problems, and indeed, this is considered to be an essential element if the client is to understand the ethos of their treatment and accept the approach. However, it has been the behavioural and cognitive theories that have been the most influential in the development of psychological interventions for chronic pain. Correspondingly, it is these theories and their corresponding therapies that have been the most widely evaluated and thus will be discussed in detail.
4.1. Operant conditioning mechanisms

Relatively shortly after the publication of Melzack and Wall's Gate Control Theory (1965), Bandura (1969) began to use his theory of observational learning and modelling as a basis for explaining the development of pain behaviours where underlying pathology appeared to provide an insufficient explanation for excessive pain behaviours.

Following from this, Fordyce (1976) argued that it was the behavioural manifestations of pain rather than pain per se that was central, and thus formulated the role of operant factors and contingency management techniques in the development of chronic pain. Using the operant model, Fordyce (1976) suggested that pain is inferred from overt pain behaviours such as non-language sounds (for example moaning), body posture and gestures (for example, grimacing), lack of daily activity/functional limitations and verbal complaints. These overt behaviours may be in turn be being shaped by external consequences, that is, operant conditioning. The behaviours are frequently reinforced by social rewards such as attention, support from significant others and relief from responsibilities. Thus the pain behaviour that might originally have been elicited by organic factors may come to occur solely in response to reinforcing environmental events. Moreover, it has been suggested that in accordance with operant conditioning and the process of extinction, if no reinforcement occurs then the frequency of the behaviour will decrease (Ott, 1992).

Although operant factors clearly play a role in the maintenance of disability, exclusive reliance on this model to explain chronic pain has been subject to criticism particularly as it fails to consider the emotional and social aspects of pain (Turk and Flor, 1987).

4.2. Respondent (classical) conditioning

Factors contributing to chronicity that have previously been conceptualised in terms of operant learning may also be initiated and maintained by respondent learning (Phillips, 1987). Thus from a classical conditioning perspective, the patient with chronic pain may have learned to associate increases in pain with all types of stimuli that were originally associated with nociceptive stimulation (that is, stimulus generalisation has occurred). As a consequence, patients display maladaptive responses to many stimuli and reduce the frequency of many activities. As the pain symptoms persist more situations elicit anticipatory pain, anxiety and depression because of the low rate of reinforcement obtained when behaviour is greatly reduced (Letham, Slade, Troup & Bentley, 1983). Ultimately with chronic pain, either the anticipation of suffering or prevention of suffering may be sufficient for the long-term maintenance of avoidance behaviours.
4.3. Cognitive-behavioural theories

Cognitive-Behavioural Therapy (CBT) is a broader approach and views pain as the result of a complex interaction of patho-physiology, cognition, affect and behaviour (Shipton, 1993). It utilises and incorporates behavioural principles but places greater emphasis on training the client to monitor and deal with unhelpful beliefs and cognitions about pain. People with pain often have negative expectations about their ability to control certain motor skills without pain (Turk and Flor, 1999). Moreover, pain patients tend to believe that they have limited ability to exert any control over their pain. Such negative appraisals about the situation and personal efficacy may reinforce the experience of demoralisation, inactivity and overreaction to nociceptive stimulation (Brown and Nicassio, 1987).

Both empirical and clinical studies have identified links between a number of cognitive factors, for instance, catastrophising, helplessness, maladaptive coping styles, maladaptive beliefs about pain and control and the subjective experience of chronic pain. Moreover, it is also likely that these factors are related in complex and reciprocal ways (Polatin, Kinney, Gatchel, Lillo and Mayer, 1993) and therefore assessment of idiosyncratic beliefs and coping repertoires become critical for optimal treatment planning.

5. Rationale for psychological interventions in chronic pain

Medical and surgical interventions are often relatively ineffective for many clients with chronic pain (Webb, 1982). The emergence of research supporting the value of psychological interventions (for example, Pither and Nicholas, 1991 and Morley et al, 1999) has resulted in the expansion of multi-disciplinary pain management programmes in the United Kingdom. Realistically, they often represent the last treatment option for clients with chronic pain. One reason for this may be that medical practitioners and clients interpret a referral to psychology as an acceptance of the failure of medicine despite the evidence presented of the important role of psycho-social factors. In addition, there may also be an erroneous assumption that psychological intervention requires the presence of psychiatric disturbance (Pither and Nicholas, 1991). Many chronic patients too have initial difficulty accepting treatment based on a psychological premise: it may reinforce their fear that they are not believed, they may feel rejected by ‘real’ doctors and they may not be able to accept the implication of an ‘emotional’ or personal component to their physical pain symptoms.

Given the above it is perhaps unsurprising that clients may initially be reluctant to attend a psychology appointment. The challenge for the psychologist is two fold: firstly, an assessment of the client’s pain should be conducted to identify elements contributing to the
varied nature of pain experience. These would include illness or trauma history, past and current medical and drug history, history of the perceived aetiology of the pain, a description of the severity, frequency and duration of the pain, pain related behaviour and pain avoidance behaviour as well as social, employment and psychiatric history (Diamond and Coniam, 1998). Secondly, existing knowledge of factors affecting the pain response as well as knowledge about the cause(s) of the pain has to be utilised. In both cases the ultimate aim is to facilitate the planning of an individualised treatment programme and to engage the client’s confidence (Dalton and Lambe, 1995).

5.1. Context and aims of psychological intervention
Psychological interventions for chronic pain are typically employed in the context of either an inpatient or outpatient multi-disciplinary programme where psychological principles are integrated (Pither and Nicholas, 1991). The context in which the intervention takes place directs the structure, content and objectives of therapy (Appendix 1). The main aim of a pain management programme is not to relieve pain but rather to enable the person with chronic pain to improve the quality of their life, despite their enduring experience of pain. This is typically achieved through improving function, reducing distress, enhancing coping and encouraging the self-management of pain and its associated problems (Spanswick and Parker, 2000).

When psychological interventions are offered as the main treatment approach, the therapist presents a collaborative model as opposed to an expert model so that the client actively participates in their own treatment plan. The role of the therapist is to help the client to make the necessary behavioural, cognitive and emotional changes necessary to improve the management of their pain and to function optimally despite that persisting pain (Pither and Nicholas, 1991).

Interventions may be provided on an individual or group basis although there is some evidence that the latter is more widely used and that it has a number of advantages. Therapeutic factors special to groups include a sense of not being alone with the problem, a sense of altruism and the validation of their pain experiences (Yalom, 1986). This can work against the helplessness that often accompanies the experience of chronic pain. In addition, groups can give opportunities for feedback, observational learning, modelling and can ultimately reinforce positive change (Williams and Erskine, 1995). In terms of health service resources they have the potential of making multi-disciplinary work cost-effective (Main and Spanswick, 2000).
5.2. Outcome variables
Given the constraints on healthcare resources, evaluating the effectiveness of those psychological interventions derived from psychological theory is essential for monitoring the quality of care being received by clients and in enabling professionals to meet the requirements for evidence-based practice (Loeser and Turk, 2001).

A broad spectrum of outcome variables has been utilised in the evaluation of psychological interventions for chronic (Shipton, 1993). These include subjective ratings of pain, perceived levels of disability, mood, degree of cognitive distortions, coping styles, pain behaviours, activity levels, improvements in fitness measures (for example, strength, stamina) and the client's utilisation of health care resources (Williams, 1995). Given that there is very little evidence for a consistent relationship between actual disease and self-reported pain (Main and Waddell, 1991), appropriate measures to assess and monitor progress over the course of an intervention programme are crucial. This is primarily so that therapeutic goals and the identification of areas where change is intended to occur are set within a realistic and manageable framework (Kane and Kane, 1981).

6. Psychological therapies for chronic pain
6.1. Behavioural therapy
The focus of behavioural therapy is for the client to take control and responsibility for their own pain management and not for ameliorating pain (Williams et al, 1993). Moreover, contingency management can also be viewed as a method for rehabilitating chronic pain patients by increasing functional performance in daily life (Fordyce, 2001).

More specifically, the goals of operant behavioural therapy (OBT) are to identify and reinforce adaptive coping skills and physical functioning, for instance, exercising, participating in daily activities and talking about non-pain topics. In parallel, reinforcement for pain behaviours, for example, guarded movement, is reduced. Typically, although not exclusively, the operant approach is employed in inpatient settings where multi-disciplinary treatment staff has some control over reinforcement contingencies, particularly the differential reinforcement of desired goal activities and the non-reinforcement of pain behaviours. However, it is also used in outpatient contexts too, often involving spouses or immediate relatives to directly implement the programme (Pither and Nicholas, 1991).

Despite the rigour of the theory that OBT interventions for chronic pain are based on that is not to say that the efficacy of operant methods is without debate (Roberts, Sternbach and
Polich, 1993). There has been evidence that this method is effective in both increasing activity and reducing dependence on analgesics for many types of chronic pain (Large and Peters, 1991). However, of the randomised-controlled trials that have evaluated OBT there have been mixed results in terms of efficacy.

Turner, Clancy, McQuade and Cardenas (1990) compared four conditions for chronic low back pain: behavioural intervention, exercise, behavioural intervention plus exercise and a waiting list control group. Although no significant difference was found between the two behavioural intervention groups, they did demonstrate significantly greater improvement on psychosocial outcome measures than the exercise and waiting list conditions. However, by 6 and 12 months follow-up, all of the treatment groups were significantly improved from pre-treatment levels and there was no significant difference between the groups.

In a large study limited by not having a control group, Roberts et al (1993) assessed the outcome of over 350 outpatients who as part of their multi-disciplinary pain programme received physiotherapy, occupational therapy and biofeedback. Pain reduction was maintained at two-year follow-up, although there was indication of some regression towards pre-treatment levels with respect to physical functioning. As this has been reported in other studies it illustrates the importance of follow-up appointments and brief refresher courses in fostering maintenance.

6.2. Cognitive-Behavioural therapy and chronic pain
Fisher and Johnson (1998) argue that cognitive factors may play a key role in mediating the relationship between chronic pain and disability as well as having an influence on mood. Targeting cognitive factors such as coping strategies, cognitive distortions, control beliefs and self-efficacy in intervention may therefore promote improvements in various aspects of functioning. Indeed, there is evidence that changes in beliefs and coping strategies have been associated with post-programme improvements in physical functioning (Jensen, Turner, Romano and Lawler, 1994).

Turner and Romano (2001) have considered some advantages and disadvantages to the use of CBT techniques. They argue that a clear advantage is of their applicability to a broad range of pain syndromes, including chronic pain and the fact that their efficacy in group and individual treatment formats has been demonstrated. The authors argue that this makes CBT interventions appealing in the current healthcare climate, because of their relatively low long-term cost and their ability to sit with evidence-based practice. However, a disadvantage cited
is that CBT requires active client participation and the practice of techniques outside of sessions. Another consideration is that it usually requires a trained CBT therapist to conduct the intervention.

CBT for pain is an active, time-limited structured intervention usually within a pain management programme, which is implicitly designed to assist clients identify, reality test and correct unhelpful conceptualisations and dysfunctional beliefs. Essentially it involves three stages to the process of reframing, although in practice they are rarely so separate or discrete:

1. An educational phase in which clients are oriented to the bio-psychosocial model of pain and taught to recognise the connections linking cognitions, affect, physiology and behaviour. The identification of dysfunctional thoughts is also addressed.

2. A skills training phase in which training is provided in a variety of cognitive and behavioural pain coping skills. The former include cognitive re-structuring, problem solving, identifying and challenging the dysfunctional underlying beliefs and attitudes. The latter comprise relaxation training, activity pacing, pleasant activity scheduling and visual imagery techniques.

3. An application phase in which the patients learn to apply their skills in progressively more challenging pain related situations (Parker, Doomat and Booker, 2000).

Nevertheless, there is frequently considerable variation in the content and practice of CBT interventions (Turner and Romano, 2001).

Studies have consistently reported that CBT techniques are effective in the treatment of chronic pain (Tan and Leucht, 1997). Reviews of CBT for specific types of chronic pain (for example, Jensen et al, 1991) and meta-analyses (for example, Morley, Ecclestone and Williams, 1999) have supported the efficacy of CBT in improving physical function and mood, reducing pain reports and decreasing observable disability. However, Tan and Leucht (1999) also make the point, alluded to above, that no one set of CBT techniques have been found to be effective with all pain patients or with all types of chronic pain.

With respect to particular pain conditions, multi-component CBT has been reported to be an efficacious and specific treatment for rheumatoid arthritis (Compas et al, 1998). In their review of empirically supported psychological interventions Compas et al (1998) looked at five studies which compared multi-factorial CBT to both attention control and standard medical control conditions. All of the studies found significant improvements in psychological functioning following a course of CBT and the majority also reported significant reductions in pain. The latter is particularly surprising given that it was not
included in the main goals of treatment and could reflect subjective processes such as empowerment and distraction from the pain symptoms. Only one study failed to demonstrate any improvements in outcome following CBT (Kraaimaat, Brons, Geenen and Bijlsma, 1995). Its results were probably a reflection of the sample: rheumatoid arthritis patients who had extremely active disease and demonstrated progressive deterioration, with statistically significant increases in clinical measures of disease activity, over the course of the study.

The efficacy of CBT for low back pain has also been confirmed when compared to a waiting list control group, resulting in increased activity, improvements in pain and improvements in psychological functioning (Nicholas, Wilson and Goyen, 1991). Moreover, in a similarly designed study looking at chronic pain syndrome Puder (1988) reported that CBT was beneficial with respect to the afore-mentioned outcome measures and also reduced dependence on medication.

6.3. Meta-analyses of studies investigating chronic pain
There have been three major meta-analyses of CBT for chronic pain but only one used studies that had randomised-controlled designs. The first two meta-analyses (Malone and Strube, 1988); Flor, Fydrich and Turk, 1992) reported that the largest effect sizes were found for CBT in outcome measures of mood, behaviour and pain ratings rather than medication or health care use. Furthermore, Malone and Strube's data suggested that even at long-term follow-up the CBT group had maintained better levels of functioning than comparison groups. The third study (Turner, 1996) employing a randomised-controlled design suggested findings congruent to the previous studies. However, the effect for mood was not replicated in this study. Morley et al (1999) have suggested that this may be due to initially very low baseline effects of depression in the community samples.

In a recent review and meta-analysis of randomised-controlled trials of behavioural and cognitive-behavioural interventions for chronic pain in adults, Morley et al (1999) concluded that such trials provide good evidence for the effectiveness of psychological interventions. Moreover, CBT was found to have produced 'significant changes in measures of pain experience, mood/affect, cognitive coping and appraisal, pain behaviour and activity level and social role function.' However, the reviewers also noted several methodological limitations across the studies. These raised issues about statistical power, varied reliability of outcome measures, variation in the quality and quantity of treatment and lack of transparency about the form and content of the psychological techniques used.
In terms of studies that have looked at the relative efficacy of OBT compared to CBT, Turner and Clancy (1988) reported that both OBT and CBT resulted in long-term improvement in multiple aspects of chronic pain problems. The former appeared to have more immediate effects whereas the CBT group maintained a steady improvement over time. It is possible that this difference in the CBT group reflected continued practice of the skills taught during the therapy, although clearly, further research is required to explore the process by which change occurs both during and following treatment. It also merits noting that CBT clients reported greater satisfaction and rated the pain management programme as more helpful than OBT clients.

7. The role of psychological therapies in the management of chronic pain

7.1. Multi-disciplinary and inter-disciplinary programmes

As has been noted a range of psycho-social factors can significantly interact with physical pathology to modulate a patient’s self-report of chronic pain, disability and response to treatment. The complex nature of chronic pain means that such patients often reach tertiary care levels of service where intervention and rehabilitation is via either a multi-disciplinary or an inter-disciplinary team (Gatchel and Turk, 1999). Several epidemiological studies (for example, Flor, Fydrich and Turk, 1992) have compared the characteristics of people with chronic pain in the community with those treated at multi-disciplinary pain management clinics. Patients treated at the specialist centres demonstrated higher levels of emotional distress, use of the health care system, constant pain, use of opioid medication and functional impairments (Flor, Fydrich and Turk, 1992).

Gatchel and Turk (1999) distinguish between these multi- and inter-disciplinary pain management clinics arguing that the former has the involvement of several health care providers but that the latter involves a greater coordination of such services in a comprehensive programme with frequent communication between the health professionals involved. Leaving this debate aside, fundamentally both types of programmes have similar goals and structures (Appendix I), can offer both inpatient and outpatient and staff composition typically includes a medical director or physician, a clinical nurse specialist, a psychologist, a physical therapist, an occupational therapist, a social worker and a Medical-Disability case manager (Loeser and Turk, 2001).

The success of such programmes in the management of chronic pain has been documented in a number of investigations with results demonstrating significant changes in a number of outcome measures, for example, increased functional ability, improvement in mood and return
to work (Hildebrandt, Pfingsten, Saur and Jansen, 1997; Mayer, Gatchel, Mayer, Kishino, Keeley and Mooney, 1987).

7.2. The role of the psychologist
As researchers have become aware of the important role that psycho-social variables play in the rehabilitation of patients suffering from chronic pain, the role of the psychologist has become especially pertinent. Indeed a psychologist must be included in British and American pain management programmes before accreditation of the programme can be approved (Gatchell and Turk, 1999).

Gatchell (1996) has emphasised that chronic pain should be viewed as a major stressor that can have implications for a person’s mental health. Thus the pain management team needs to be aware of the individual’s psycho-social barriers that could potentially impact on a successful outcome. Hence one role of the psychologist is in detailed psychological assessment of the client including psycho-social functioning, personality characteristics, mental status, social support resources, motivational state, beliefs and attitudes and available coping resources (Loeser and Turk, 2001). Another important role is argued to be in explaining the model of the pain management programme as that of being a collaborative endeavour (Loeser, 2001). Implementing psychological techniques such as teaching patients coping skills, identifying and challenging dysfunctional thoughts, and reiterating the relationship between thoughts, feelings and behaviour is a key task, but acting as a consultant to other team members with respect to the application of psychological principles and using the scientist-practitioner philosophy to continually evaluate the programme are also important responsibilities (Loeser and Turk, 2001).

8. Concluding comments
This essay has tried to demonstrate that psychological treatments and in particular, OBT and CBT, are frequently effective in reducing the experience of chronic pain and in improving the psychological and physical functioning of those clients with persistent pain. Although other treatment options of a psychological nature are also available such as Bio-feedback and to a lesser degree hypnotherapy and psychodynamic psychotherapy, the evidence for their efficacy appears to be much more limited (Livengood, 1996).

However, there are problems with the studies that have evaluated chronic pain management. Clearly, the lack of standardisation in the content and practice of behavioural and cognitive-behavioural interventions impede the evaluation of chronic pain research and therefore its
interpretation. Neither do many studies have sound research methodologies, for instance, the use of control groups or random assignment of clients to treatment and control groups. When control groups are available, it is often difficult to know what extra interventions control group participants might have received during the course of the study (for example, medication, contact with health professionals or alternative therapies); potentially, this could confound results. The systematic assessment of pain has to be improved by the use of validated pain measures that can integrate biomedical and physiological data with behavioural and psychological information. The development of such sophisticated measures as well as measures which can elicit more subtle effects needs to be addressed (Tan and Leucht, 1997). Finally, at least as far as this discussion is concerned, the lack of component analyses in multifaceted CBT interventions has the consequence of failing to establish which aspects of the therapy were necessary or sufficient for clinical efficacy making it more difficult to identify the most effective treatment component. Tan and Leucht (1997) argue this last point has costs both in terms of time and resources.

Viewing chronic pain from a rigid biomedical standpoint is both unrealistic and unworkable. Psychological techniques such as the application of behavioural and cognitive-behavioural strategies can teach and empower clients with chronic pain to address factors that have a role in maintaining and exacerbating significant levels of distress and dysfunction as well as transferring the responsibility for the management of the illness from the health professional to the client. Moreover, the cost-effectiveness and the limited risk of complications, as compared to medical procedures, would recommend their use earlier in the client’s contact with the health service than is typically practised.
9. References


75


10. Appendix

Goals of a pain management programme (from Pither and Nicholas, 1991)

1. Increase the range and level of daily activities including reducing time spent resting and lying down.

2. Increase physical fitness in terms of: power, endurance and flexibility.

3. Improve management of pain by patient, by e.g.:
   - Reduce tendency to overdo things by improved pacing
   - Learn and utilise a relaxation technique.

4. Increase confidence in ability to function and cope.

5. Eliminate unhelpful cognitions concerning pain. Challenge such thoughts with more realistic thinking.

6. Reduce level of pain behaviours.

7. Reduce or eliminate powerful analgesics, antidepressants and tranquillisers.

8. Improve understanding of chronic pain and relevant medical conditions.

9. Improve sleep and eliminate inappropriate sedatives.

10. Eliminate unnecessary aids such as corsets, collars and crutches.

11. Return to work if appropriate.

12. Reduce long term health care utilisation.
Older Adults Essay

DISCUSS THE DIFFICULTIES IN DISTINGUISHING DEPRESSION AND EARLY STAGES OF DEMENTIA AND EVALUATE WAYS IN WHICH THESE DIFFICULTIES MIGHT BE ADDRESSED.

August 2001
Year 3
1. Introduction

Depression and dementia are the two most frequently occurring psychiatric disorders in the elderly and historically they had been considered to be mutually exclusive (Gallagher and Thomson, 1983). However, differentiating dementia from depression is now reported to be one of the most common problems in clinical practice where patients are referred to an older adult service in the NHS (Cheston and Bender, 1999). Moreover, the complexity of the issue in terms of accurately resolving whether a client is suffering from dementia, depression or indeed both has been described as 'probably the knottiest problem of differential diagnosis,' (Lezak, 1995). Arguably, the crux of the differential diagnosis problem in older adults surrounds the initial, early stages of both diseases. Crowe and Hoogenraad (2000) have pointed out that as dementia of the Alzheimer's type advances and cognitive impairment becomes more severe it can be relatively easily distinguished from depression with cognitive impairment. The challenge lies in separating them into discrete nosological categories at a time in the development of the two disorders when their symptoms can considerably overlap (Roth, Mountjoy and Amrein, 1996). The implications for appropriate and specific intervention and treatment are obvious and this has driven a huge research effort aimed at identifying potential diagnostic tools and tests, whether biological, pharmacological or psychological, that could conclusively diagnose dementia before death.

One assumption of this approach is that it presupposes that normal and abnormal processes are discrete entities rather than lying on a continuum, whereas, research into normal ageing indicates that there are unlikely to be clear distinctions between the two processes (Cheston and Bender, 1999). A specific example is that the plaques and tangles implicated in Alzheimer's disease have also been found in the brains of some older people who did not demonstrate symptomatic evidence of dementia during life (Ulrich, 1985). If one bears this in mind it becomes less surprising that the relationship between dementia and depression could be anything less than complex and research studies have often inadvertently illustrated this very point. For example, Katzman, Lasker and Bernstein (1988) suggest that between 1% and 31% of people who receive a diagnosis of progressive dementing illness may in fact be suffering from depression with associated cognitive deficits. Even in the general population primary dementia and dementia secondary to depression are reported to be mistaken for each other between 10% and 20% of the time (Des Rosiers, 1992).

This raises questions about the true prevalence rates for both dementia and depression in older adults. One study estimates that between 5% and 10% of people in the community over 65 years of age are diagnosed with dementia (Cooper, 1991) and approximately 15% diagnosed
with depression (Copeland, Dewey, Wood, Searle, Davidson and McWilliams (1987). A comprehensive review by Ballard, Bannister and Oyebode, 1996) extrapolated that given such estimates perhaps 1% of the population would have dementia and depression concurrently.

Uncertainties such as those cited above underpins the differing approaches that have been adopted in attempting to distinguish depression from the early stages of a dementia illness. This paper will attempt to address the problems researchers have encountered with respect to adequately discriminating between the two disorders and the shift that has taken place in the literature over the last two decades in terms of recognising that dementia and depression frequently co-exist. Some of the numerous methods used to distinguish the disorders will also be presented and critiqued as illustrations of the general discussion.

2. Inherent difficulties in distinguishing depression and early stage dementia

In terms of defining dementia and depression a key point is that neither term offers a unitary concept. With respect to the former the primary characteristics are described as an ‘acquired memory disorder and intellectual decline associated with changes in behaviour and personality that result in impaired psychosocial performance’ (McLoughlin and Levy, 1996). Essentially, it is a syndrome encompassing a number of disorders each defined by the disease process underlying the observed decline in function (Hasegawa, 1991); the most common type of dementia is Alzheimer's disease (Kokmen, 1993). Depression is ranked a ‘spectrum severity’ of depressive disorders and its manifestation is varied and dependent upon the combination of presenting symptoms (Kaszniaak and Christenson, 1994), although features typically include low mood, lethargy, reduced ability to concentrate and sleep and appetite changes (DSM-IV; APA, 1994).

In theory depression and dementia appear very different syndromes: one is predominantly a disorder of affect, the other of cognition. In practice, the two have a number of symptoms in common: depressed patients can report experience of difficulties with memory and cognition and patients with dementia may suffer from dysphoric mood, loss of interest in previous activities and disturbed sleep patterns (Swanwick, Rowan, Coen, O'Mahony, Lee, Lawlor, Walsh and Coakley, 1996). Moreover, as alluded to already, researchers have increasingly recognised that depression and dementia can co-exist (Teri and Wagner, 1992) and one estimate is that approximately 30% of patients diagnosed with Alzheimer's disease also reaches the criteria for clinical depression (Teri and Reifler, 1987). Thus the process of diagnosis for clinicians becomes ever more difficult: the question ‘is this depression or dementia?’ is now insufficient, one also needs to explore the possibility of whether the patient
is 'depressed and dementing.' Recent evidence that in some cases symptoms of depression may be the prodromal evolution of dementia (Touchon and Richie, 1999) merits the further question of whether a depressive illness indicates the start of a future dementia.

The gradual move from 'either/or' type questions can be sourced to the development of the term 'pseudodementia' which has been used to describe 'intellectual impairments in patients with a primarily psychiatric disorder,' (Caine, 1981) whereby the depression can imitate or mask symptoms of dementia. Use of the term implies that the cognitive function is reversible following successful intervention of the psychiatric problem. While the expression is still used, many clinicians and researchers argue that it is misleading for a number of reasons. These include the arguments that depressed patients have a genuine cognitive deficit, that the concept of dementia no longer requires irreversibility as a necessary feature and that a 'pseudodementia' diagnosis may miss an actual underlying dementia (Pitt and Yousef, 1997). When information is available the pre-morbid history of a patient may help to differentiate between cases: in dementia, there is often a pre-morbid history of declining cognitive function but in depression a patient is more likely to have a rapid and acute cognitive decline associated with changed mood.

Co-existence aside, Pitt and Yousef (1997) suggest that depression is the most common reversible cause of dementia but also refer to some research which describes residual cognitive deficits remaining following the resolution of the emotional disorder (Abas, Sahakian and Levy, 1990, cited in Pitt and Yousef, 1997). One hypothesis is that for those patients who retained impairments in their cognition, the depression was a sign of the start of a dementia that only became diagnosed as the latter progressed in its natural course. The authors argue that although this prodromal depression of dementia may respond to anti-depressant medication or electro-convulsive therapy, cognition tends to remain impaired.

Related to this research are attempts to determine whether the existence of one disorder will predispose an individual to the development of another. Some studies have demonstrated evidence that depression in later life (that is aged 65 years and over) is a precursor to subsequent dementia; Reding, Haycox and Blass (1985) reported that 57% of non-demented patients with severe depressive symptoms were diagnosed with dementia at 3-year follow-up. The reverse argument, that dementia could lead to depression has been less closely scrutinised but is no less interesting. It has been suggested that depression could occur in patients with an existing dementia because of the neuro-chemical and neuro-anatomical damage that takes place within the diseased brain (Liston, Jarvik, and Gerson, 1987) or that depression could be
a reaction to the gradually eroding skills and abilities of the dementia (Teri and Gallagher, 1991).

Given that depression and dementia are likely to co-exist, the general debate has also been extended to include the issue of the relationship between depression and the severity of cognitive impairment in dementia sufferers (Ballard et al, 1996). Research studies have speculated about the causal relationship between depression and dementia according to the degree of cognitive impairment although no clear link has yet been established. For instance, a significant association between depression and less severe cognitive impairment has been reported (Reifler, Larson and Hanley, 1982) but in contrast, Rovner, Broadhead, Spencer, Carson and Folstein (1989) have reported a relationship between depression and increased severity of cognitive impairment.

From the evidence presented the relationship between dementia and depression seems to be a conundrum: whilst appearing to share symptom similarity and even co-exist they simultaneously remain discrete entities. Clearly this is an inherently complex question but efforts at elucidation have been hampered by the quality of some research studies. For example, some studies attempting to determine causation have had major methodological limitations such as being retrospective or employing a correlational design with no way of empirically assessing whether one diagnosis was influenced by another. Prospective studies have often had a limited sample size and selection and patients have been poorly matched on demographic issues. Notwithstanding, questions such as whether dementia and depression are variants of the same disorder or whether the diagnosis of one predisposes an individual to the development of the other has led to the following avenues of research:

a) Clinical investigations of the presentation of each disorder examining factors such as the clinical course and the way it varies between the disorders,
b) Examination of the different brain function via the neuro-psychological sequelae of the disorders and
c) The study of neuro-chemical and neuro-anatomical changes that accompany the disorders.

Throughout this paper specific reference has been made to Alzheimer's disease. This is because most studies examining the issue of differential diagnosis have focused on Alzheimer’s disease as it represents the highest percentage of dementias diagnosed in Britain and North America. Indeed, UK prevalence rates are estimated to be between 50% and 60% of the 670,000 people diagnosed with dementia (Alzheimer’s Disease Society, 1997).
Alzheimer's disease is also probably the most well-known of the dementias and this may be reflected in terms of the research grants that this area generates.

3. **History taking and screening tools**

The sensitivity and breadth of the initial assessment or examination undoubtedly impacts on the accuracy of the final evaluation of the diagnosis and this may be partly why a detailed clinical interview is considered a necessary starting point (Kaszniak and Christenson, 1994). It may also lead to questions from which more refined assessments via the use of screening tools can be carried out.

The Mini Mental State Examination (MMSE; Folstein, Folstein and McHugh, 1975) is a validated and quick to administer tool which is typically used by clinicians when screening for dementia (Lundquist, Bernens and Olsen, 1997). However, its use is limited for a variety of reasons. Firstly, it has a strong verbal bias, therefore, individuals with significant language difficulties are likely to be penalised because it would mask true ability in memory and orientation. Secondly, individuals with a high IQ in the early stages of dementia may not be identified (Hestad, Ellertsen and Klove, 1998). Finally, the MMSE is not specific to the assessment of dementia and is relatively insensitive to subtle changes in cognition.

Two instruments have been specifically designed to assess depression in older adults: the Geriatric Depression Scale (GDS, Yesavage, Brink, Rose, Lum, Huang, Adey and Leirer, 1983) and the Schwab-Gilleard Depression Scale (SGDS; Gilleard, Wilmott and Vaddadi, 1981). Although reliability and validity for the GDS is acceptable there is concern that patients are more likely to under-report depressive symptoms than clinicians or carers (Teri and Wagner, 1992). The SGDS has been demonstrated to have good internal consistency and reliability as well as good concurrent and discriminant validity; moreover it is reported to be relatively insensitive to dementia (Richardson and Hammond, 1996).

More sophisticated measures have also been designed for the assessment of depression in dementia in older adults. One example is the Cornell Scale for Depression in Dementia (CSDD; Alexopoulos, Abrams, Young and Shamoian, 1988). It is a 19-item scale with good inter-rater reliability and internal consistency that requires a trained clinician to obtain information from both the patient and a carer. An advantage of the scale is that it has operationalised rules which enables the clinician to differentiate between factors such as the loss of interest related to dementia and the loss of interest linked to depression. However, a
problem is that the rules appear to be unclear when trying to determine which report is the more accurate: the client’s or the carer’s (Ballard et al, 1996).

More recently a scale has been developed to discriminate pseudodementia from dementia (Yousef, Ryan, Lambert, Pitt and Kellet, 1998). This will be discussed in more detail in the following section.

4. Identification of the pertinent clinical features of depression and dementia
Before weighing up whether clinical characteristics can act as a guide to differentiating depression from dementia a general point about assessment issues will be made. There are a number of elements that in combination make assessment of whether an individual is suffering from depression or dementia problematic. Psychological tests alone are not able to precisely make this distinction (Zapotoczky, 1998) and thus the use of biological markers and a range of other methods are additional and essential components to the assessment process. It has been argued that ‘neuro-psychological evaluation and cognitive testing remain the most effective differential diagnostic methods in distinguishing patho-physiological dementia from age related cognitive decline, cognitive difficulties that are depression related and other related disorders’ (APA, 1998). Despite this assertion, Bair (1998) has warned that because of the very complexity of this topic the use of an inter-disciplinary approach should be more widely adopted to facilitate research endeavours. Thus, a variety of empirically validated methods need to be drawn upon when assessing for dementia or depression, for example, comprehensive history taking, screening tools, informant interviews (from both client and caregivers), neuro-psychological and cognitive testing and biological approaches such as neuro-imaging.

Comprehensive research investigating key behavioural symptoms of patients within each disease category and whether these behavioural symptoms could differentiate one diagnostic category from another has been limited. Recently, however, an ambitious study has compared the non-cognitive behavioural changes recorded during an initial interview of patients with early Alzheimer’s Disease, Frontotemporal Dementia (FTD) and late life depression (with or without psychotic features); these four disorders are difficult to differentiate clinically. Using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN; WHO, 1992) Swartz, Miller, Lesser, Booth, Darby, Wohl and Benson (1997) were able to correctly classify over 95% patients of a total sample size of 73 according to their respective diagnostic category.
With the use of a discriminant analysis technique, the authors reported that the four disorders demonstrated different clusters of behavioural abnormalities and were significantly differentiated by these symptoms. A sub-set of fourteen SCAN items was identified that correctly classified 94.7% of the Alzheimer’s Disease group, 100% of the FTD patients, 87.5% of the patients with depression and psychotic features and 100% of the of those with depression without psychotic features. The fourteen discriminating items were delusions of persecution, altered body functions, delusions of reference, other speech abnormalities, heightened subjective function, incoherent speech, delusions about the body, non-specific auditory hallucinations, non-verbal communication, low subjective function, miscellaneous delusions, special features of depression, socially embarrassing behaviour and poverty of speech.

Moreover, although depressive symptomatology was present in all four of the diagnostic groups, certain features defined with the SCAN were more characteristic of both types of depressive illnesses than either of the dementias. For example, hopelessness accompanied by suicidal ideation and anxiety associated with panic symptoms were significantly more common in the depression groups than in the dementia groups.

In terms of the several limitations of the study, the first is that none of the investigators were blind to the patient’s diagnosis thereby raising the possibility of rater bias. The authors raise but reject the possibility that the differences in SCAN scores could be attributed to demographic factors such as age or education or cognitive variability as measured by the Mini Mental State Exam (MMSE). Another difficulty is in generalising from this kind of study where all of the participants were carefully selected to satisfy research criteria to a clinical population that might conceivably be seen in the community. Swartz et al. (1997) themselves concede that it was possible that some potential participants who were evaluated for other research studies presented with confusing clinical presentations and thus might have been excluded from the protocols precisely because their diagnoses were unclear. This would have potentially skewed the subject samples towards easier discrimination.

Swartz et al. (1997) conclude that their results suggest that non-cognitive behavioural symptoms identified from their analysis may be useful in clarifying the differential diagnosis of dementia and depression among the elderly. However, none of the fourteen discriminatory items on the SCAN were exclusive to one diagnosis and the summary provided by the authors of the main non-cognitive features observed in each group, although theoretically useful, may be limited in clinical practice because of its very crudity.
Another group of researchers has tried to differentiate the characteristic features of pseudodementia from dementia on clinical grounds using a sample of one hundred and twenty-eight people aged 65 years and over with a differential diagnosis of depressive pseudodementia (Yousef et al., 1998). A ‘pseudodementia scale’ was devised based on 44 behaviours that a literature review indicated as discriminating between organic dementia and depressive pseudodementia. During a clinical interview with the participant by a member of the research team the checklist was completed. Information was also collected on cognitive function (via the MMSE), abstract thinking and verbal fluency and the effect of depressive symptomatology on the level of cognitive functioning. The aim of the prospective study was to examine the discriminating power of the scale by reassessing each patient approximately one year on from the initial interview. A retrospective diagnosis was made by a consultant psychiatrist who had access to the patients medical notes but was blind to the contents of the original information and the diagnosis was compared to that indicated by the scores on the checklist.

Of the original forty-four items on the pseudodementia scale, 18 were identified as discriminating well between the dementia and pseudodementia groups, correctly classifying 98% of patients with dementia and 95% of patients with depression. This exploratory study suggests that a relatively accurate behavioural rating scale may have clinical utility for helping to distinguish between dementia and depression. However, the authors note the possibility for a patient initially presenting with depression to develop early dementia during the time lapse required for follow-up. This would be categorised as inaccurate classification by the scale and thus reduce its sensitivity. Yousef et al (1998) stress the need for further research using this tool to clarify its actual usefulness and generalisability.

Other indications derived from clinical experience may also assist with differential diagnosis. Time between onset of symptoms and seeking medical help is reported to be shorter in patients of depressive dementia. However, depressed patients appear to complain more frequently about cognitive loss, emphasise their disability more, are more likely to communicate a strong sense of distress and are more likely to respond with ‘don’t know answers’ on psychological tests (Wells, 1979).
5. Neuro-psychological findings that identify different brain functions in depression and dementia

Neuro-psychological assessment is considered the most sensitive way of determining the existence and nature of cognitive deficit with respect to differential diagnosis (Kasznia and Christenson, 1994); moreover, it looks set to continue to play a prominent part in the research of both disorders. In particular memory has been identified as 'one of the most investigated areas of cognitive function' (Lachner, Satzer and Engel, 1994) and as a relatively successful means of differentiating individuals with dementia and those with depression.

Specific research has indicated that depressed patients experience specific difficulty on memory tasks that require greater effort in the organisation and processing of material to be remembered (Weingartner, 1986). By contrast, patients with dementia appear to have difficulty on a much wider range of memory tasks, that is tasks that are both 'effortful' and 'automatic.' In an early study Weingarter, Cohen, Murphy, Martello and Gerdt (1981) found memory deficits in depressed patients compared to normal controls in semantic processing tasks, delayed recall, recognition memory and cued recall. By comparison, patients with dementia failed to remember even on those cognitive tasks that had low processing demands. The authors inferred from this that dementia results in an individual experiencing difficulties in accessing knowledge structures required for the effective encoding of information. Moreover, the Weingartner team considers that tasks that are typically completed automatically and require little cognitive capacity are particularly able to distinguish depressed patients from progressive dementia patients.

Following on from studies conducted by the Weingartner team, Lachner et al. (1994) conducted a study to identify a potential memory measure that could be useful in the differential diagnosis of cognitively impaired older adults. Seven common variations of verbal memory tests, five recall tasks and two recognition tasks were administered to 60 patients. Of the seven tasks, two were found to distinguish individuals with dementia from those with depression: delayed recall and recognition after long delay. Lachner et al (1994) argue that although the power of the memory tasks to discriminate the two patient groups may seem low significance levels were still achieved even though patients with mild to moderate dementia and depressed patients demonstrated similar levels of cognitive performance.

In their discussion, Lachner et al. (1994) submit that the results support higher rates of forgetting in patients with dementia. The hypothesis that dementia could be distinguished from depression by poorer performance on tasks of low cognitive demand and effort was not
supported. The recognition tasks did distinguish the patient groups better than free recall tasks but delayed recognition differentiated the groups significantly better than recognition after a short delay. Similarly, delayed recall showed more discriminative power than immediate recall tasks. The authors conclude by stating that future research should investigate memory performance within a model of cognitive processing demands so that the cognitive capacity of tasks can be examined more rigorously. Presumably this would address concerns that allocating tasks as high or low in cognitive effort has a somewhat arbitrary flavour.

In another type of memory study, Niederehe (1986) compared differences in episodic memory (that is, memory for events), semantic memory and constructive memory between patients with depression and those with dementia. The author reports that these three dependent measures could significantly differentiate the two groups of patients. Robbins, Elliott and Sahakian (1996) also tentatively confirm that deficits in episodic memory are likely to progress in individuals with Alzheimer’s disease as compared to depressed patients. However, these types of findings cannot be considered to be unequivocally partly because previous studies have assessed patients using very different paradigms and partly due to theoretical difficulties around the concept of episodic memory.

In addition, deficits in psychomotor and visuospatial skills have been implicated in preceding the onset of more complex impairments in Alzheimer’s disease (Nebes, Brady and Reynolds, 1992). One study that has assessed the extent to which neuro-psychological probes were predictive of cognitive course in patients with dementia from those with depression was by Jones, Tranel, Benton and Paulsen (1992). The authors found that patients with dementia demonstrated impairment on tests of temporal orientation, visuoconstructive skills and visual memory whereas patients with depression had intact abilities on the same tests. Another team reported contrasting findings: Hoffman, Seifritz, Krauchi, Hock, Hampel, Neugebauer and Muller-Spahn (2000) administered a brief battery of simple psychomotor and visuospatial tasks to two sets of participants with mild to moderate Alzheimer’s disease and major depression. Their results suggested that when the level of cognitive functioning was accounted for, performances on the tasks by the two groups could not be distinguished.

When psychologists are presented with a question of differential diagnosis, a logical and typical approach is to try to compare the patient’s current functioning with their previous ability level to determine what if any discrepancy there is in the scores obtained. However, few people have undergone cognitive evaluation whilst healthy so methods have been devised
to estimate previous levels of cognitive function. These tend to be either estimating pre-morbid levels of intelligence from the reading aloud of irregular words as in the NART-R (Nelson and Willison, 1991) or comparing 'hold' and 'non-hold' sub-tests in the WAIS-R (Wechsler, 1981). Discrepancy analysis has been used to analyse the current and pre-morbid performances of patients with Alzheimer's disease and those with depression (O'Carroll, Curran, Ross, Murray, Moffoot, Ebmeier and Goodwin, 1994). Although significant mean group differences were achieved, there were such large overlaps between the groups that cut-off points for adequately discriminating between the groups could not be established. The authors concluded that these methods could not be recommended for use in clinical practice.

Qualitative information provided by an individual's behaviour, as well as performance under neuro-psychological test conditions, has also been suggested as being useful in assisting in questions of differential diagnosis (Sweet, Newman and Bell, 1992). Although this may be considered to be looking at minutiaeem, it could help build a more rounded picture of the individual whose diagnosis is trying to be clarified. For example, Des Rosiers (1992) has observed that depressed individuals tend to be more cautious than individuals with Alzheimer's disease during recognition testing. Individuals with dementia have been reported to be less likely to complain about memory difficulties than those with depression but the latter are more likely to give 'I don't know' answers (Des Rosiers, 1992). Finally, depressed patients are more likely to demonstrate a greater degree of inconsistency and variability in the performance of tasks compared to patients with Alzheimer's disease (Kretschmar, Kretschmar and Stuhlmann, 1989). This latter observation opens the possibility of discriminating dementia and depression when comparing an individual performance across a range of psychological tests.

6. Identification of structural changes in the brain and use of biological markers

Biological methods employed in differential diagnosis questions are generally based on non-invasive neuro-imaging techniques and molecular neurobiology that help to distinguish a distinct biological pattern (Muller-Spahn and Hock, 1996). Table 1 shows some of the main biological approaches that have been used in the differential diagnosis of depression and dementia.
### Table 1: Biological approaches in the differential diagnosis of depression and dementia (adapted from Muller-Spahn and Hock, 1996)

<table>
<thead>
<tr>
<th>Type of biological approach</th>
<th>Specific technique</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Structural neuroimaging</strong></td>
<td>Computed tomography (CT)</td>
</tr>
<tr>
<td></td>
<td>Magnetic resonance imaging (MRI)</td>
</tr>
<tr>
<td><strong>Functional neuroimaging</strong></td>
<td>Electroencephalography (EEG)</td>
</tr>
<tr>
<td></td>
<td>Evoked potential (EP)</td>
</tr>
<tr>
<td></td>
<td>Single photon emission computed tomography (SPECT)</td>
</tr>
<tr>
<td><strong>Biochemistry</strong></td>
<td>CSF-tau</td>
</tr>
<tr>
<td></td>
<td>β-amyloid peptide</td>
</tr>
<tr>
<td></td>
<td>Platelet monoaminoxidase (MAO) activity</td>
</tr>
<tr>
<td></td>
<td>Dexamethasone-corticotropin releasing hormone (dex-CRH) test</td>
</tr>
<tr>
<td><strong>Molecular biology</strong></td>
<td>ApoE genotyping</td>
</tr>
</tbody>
</table>

Technological advances in neuroimaging have increasingly allowed more of the live and abnormal brain to be exposed. Whenever there is a question about differential diagnosis CT scans have been primarily used to exclude other causes of dementia, for instance, strokes or tumours (Denihan, Wilson Cunningham, Lowley, Coakley and Lawlor, 2000). Research has established that CT and MRI scans can show that cerebral atrophy occurs in the brains of patients with Alzheimer’s disease but it is also found in those diagnosed with depression and to some degree is a process of normal ageing (Rabins, Pearlson, Aylward, Kumar and Dowell, 1991).

Physiological changes such as enlarged ventricles have been found in the brains of people with Alzheimer’s disease and also those with major depression. This has led some researchers to argue that depression, cognitive impairment and dementia lie on a continuum with related brain abnormalities underlying each disorder (Emery and Oxman, 1997). However, this view has been challenged by a study which investigated the volume of different brain structures in patients with depression and Alzheimer’s disease using an MRI approach (Pantel, Schroder, Essig, Popp, Dech, Knopp, Schad, Eysenback, Backenstrass and Friedlinger, 1997). The authors found evidence that indicated a different pathomorphological basis for the two...
diseases and thus challenged the notion of a continuum. More interestingly, the depression group demonstrated significant differences to patients with Alzheimer's disease leading to the conclusion that assessment of cortical atrophy may facilitate a differential diagnosis.

The use of CT and MRI scans also present with practical and economic difficulties because they are relatively expensive and tend to have long waiting times for non-emergency issues. More routine use of such approaches would probably provide a great deal of information to clinicians but the cost inhibits the use in cases that lack particularly strong indicators of the need to scan. A less expensive technique is the EEG and Rosen (1997) suggests that the EEG could be useful in differentiating early stage dementia from depression because the EEG is often normal in patients with depression.

Other biological markers such as the Flash Visual Evoked Potential (FVEP) have proved to be a relatively sensitive measure of cognitive dysfunction in a study that compared people with very mild Alzheimer's disease with normal controls (Swanwick et al, 1996). Nevertheless, further measures would need to be used in conjunction with this technique to successfully distinguish patients with dementia from those with depression.

There is great interest in research based on identifying a biological marker for Alzheimer's disease and while specific genes have been identified (Baldwin, 1997) there is still no biochemical change that definitely diagnoses its presence in the early stages. Some researchers argue that although such techniques may exclude causes other than dementia or depression it is unlikely that a diagnosis would be based solely on the basis of biological techniques (Lundquist et al, 1997).
7. **Summary and conclusions**

The wide-ranging difficulties of distinguishing depression and early stage dementia in a clinical context have been discussed and evaluated. Overlaps in the behaviour and clinical neuropsychological functions of the disorder hamper easy diagnosis but the importance of finding salient and practical ways of addressing these problems has driven the research process over the last three decades. These have been discussed in the essay with particular reference to identifying pertinent clinical behaviours, neurochemical and structural changes in the brain and biological markers that could facilitate the differential diagnosis question.

The above critique of the work in this area, although selective, has strongly demonstrated the lack of consistency in the findings and therefore it is difficult to draw any definitive conclusion about 'the' method of assessment. A promising avenue of future research, both in terms of its ability to discriminate between depressed patients and those with dementia and because of its ease of administration seems to be the 'pseudodementia scale developed by Yousef et al. (1998).

It may be that there is no one test that can clarify differential diagnosis of dementia from depression. McLoughlin and Levy (1996) seem to support this view by arguing for the importance of a comprehensive assessment process to include a thorough history from the patient and carer, a detailed mental state examination, a physical examination with special attention to the central nervous system, laboratory investigations, EEG, neuroimaging and neuropsychological investigations.
8. References


CLINICAL DOSSIER

OVERVIEW

This section contains an overview of the clinical experience gained during the course and brief summaries of the five clinical case reports submitted. Full details of the case reports, as well as placement contract, log books of clinical experience and placement evaluation forms can be found in Volume II of the portfolio. This is held within the Psychology Department of the University of Surrey due to the confidential nature of the information that it contains.

Please note that all client names and identifiers in this section have been changed to preserve anonymity.
Adult Mental Health Summary of Placement Experience

Placement Location: Linwood Community Mental Health Team and Princess Royal Hospital
Trust: Mid-Sussex NHS Trust
Dates: October 1998 – April 1999
Supervisor: Mary Dobbin (Consultant Clinical Psychologist)

Summary of Experience
This placement provided a broad experience of working within a cognitive-behavioural perspective with a variety of adult mental health problems in the context of a community mental health team and out-patient psychology department. Methods of assessment included structured and semi-structured interviews, standardised questionnaires (e.g. BDI, BAI) and psychometric testing (e.g. WAIS-R). Short-term and medium term interventions with specific mental health problems were carried out within cognitive-behavioural, behavioural and solution focused frameworks.

A total of 9 clients were seen on this placement and their ages ranged from 18 to 55 years. They were from a variety of socio-economic backgrounds but the clients were predominantly white.

Clinical skills gained
Experience was gained of a range of presenting problems including depression as a result of a psychotic illness, chronic schizophrenia, obsessive-compulsive disorder, health phobia, anxiety, eating disorder, panic attack and family issues. Particular strengths were noted to be the evaluation of clinical interventions and multi-disciplinary work and liaison with professional colleagues.

Meetings, seminars and research
Monthly Psychology Department and Community Mental Health Team meetings were regularly attended. Presentation made to two Community Mental Health Teams’s with respect to the Service Related Research Project which was also undertaken on this placement. A one-day workshop on ‘Cognitive-Behavioural Therapy for Psychosis’ organised by the BABCP was attended.
Adult Mental Health Case Report Summary

The assessment and formulation of an adult mental health client with a first incident of psychosis: an example of early intervention work.

Main presenting problem
Ms. White was a 17-year old white female referred by her Consultant Psychiatrist following an informal in-patient admission for a first episode of psychosis. A formal assessment was requested for the suitability of early intervention work in an attempt to avoid chronicisation of the illness.

Assessment procedure
The assessment was undertaken primarily through a comprehensive interview over four sessions. This was supplemented by a psychometric assessment using the Beck Depression Inventory (BDI), the Hospital Anxiety and Depression Scale (HADS) and the Social Activities and Distress Scale (SADS).

Formulation
A cognitive-behavioural model of depression (Beck, 1976) provided the theoretical framework from which the formulation was developed. Ms. White’s depression was considered to stem from appraisals of loss that impacted negatively on her self-esteem. Feelings of anxiety and anger conflicted with her ideal self-image and activated dysfunctional beliefs about control and success. Precipitating factors included the breakdown of Ms. White’s first sexual relationship and self-imposed and parental pressure for academic achievement. These factors and the utilisation of some non-adaptive coping strategies ensured a vicious cycle of cognitions, affect and behaviour. An early intervention approach (Birchwood et al, 1992) was deemed appropriate given that this was Ms. White’s first episode of psychosis, that she had relatively good insight and the availability of family support.

Intervention
The formulation was shared with Ms. White and therapeutic goals were agreed and set. The cognitive-behavioural intervention focused on various cognitive techniques to modify and reduce negative thoughts. These included distraction from ruminating, belief modification, cognitive restructuring, social skills training and behavioural experiments to challenge her beliefs and fears. This enabled Ms. White to develop an alternative account of her difficulties.
In addition relapse prevention work was conducted to identify Ms. White's 'relapse signature'.

**Outcome**

After 12 intervention sessions spanning six months, Ms. White reported being more optimistic about her future and confident about re-building relationships. In terms of daily functioning Ms. White reported being happier and more relaxed and this was verified by parental reports. Although she was concerned about relapsing she reported that she was surer about monitoring her own mental health. Her BDI, HADS and SADS scores all fell to within normal ranges.
People with Learning Disability Summary of Placement Experience

Placement Location: Geoffrey Harris House, Coombe Road, Croydon
Trust: Surrey Oaklands NHS Trust
Dates: April 1999 – October 1999
Supervisor: Jeanne Males (Consultant Clinical Psychologist)

Summary of Experience
Experience was gained of working from a behavioural, cognitive-behavioural, developmental and neuro-psychological perspective in the context of a psychology service that provided input to a community team for people with learning disabilities. Work with team members and staff groups facilitated the development of consultative skills. Clinical experience involved working with people with mild, moderate and severe learning disabilities in settings that included residential accommodation, day services, in-patient secure unit and the homes of clients. A total of 10 clients were seen on this placement and their ages ranged from 19 to 34 years. They were from a variety of socio-economic and ethnic backgrounds.

Clinical skills gained
This placement developed skills such as behavioural assessment and intervention (including functional analysis) as well as liaison and consultative work with multi-disciplinary professionals. Clinical work was undertaken with clients and service professionals around problems that included challenging behaviour, self injurious behaviour, autism and severe learning disability, loss, transition and change, anxiety, parenting skills and relationship difficulties. Cognitive-behavioural approaches were modified to the needs of clients and a range of assessments were undertaken including evaluating the parenting skills of a young mother with a learning disability. Experience was gained in a variety of assessment procedures including the WAIS-R, WORD, WOND and WOLD, Parenting Stress Index and direct observations.

Meetings, seminars and research
Fortnightly attendance of the psychology department meetings was regularly attended. NHS and Social Services Day Centres as well as private and social services residential accommodation were visited. Participation in and contribution to a 2-day workshop on Anger Management training was a salient experience.
People with Learning Disability Case Report Summary

The assessment and formulation of a male client with a learning disability who requested contact with his birth parents: an example of capacity to consent.

Main presenting problem
Mr. Jones, an 18-year old white male with a mild learning disability, had requested contact with his birth parents. His healthcare specialist had therefore referred Mr. Jones to the psychology service by for psychological support.

Assessment Procedure
The assessment comprised of information from Mr. Jones’ adopted mother, his care manager and a comprehensive assessment of Mr. Jones including cognitive and emotional issues. This initial information suggested that it was likely that Mr. Jones would find reaching a decision about meeting his birth parents a stressful and anxiety provoking process. More fundamentally, there was the question of whether Mr. Jones had the capacity to make an informed decision with respect to the potential implications of meeting his birth parents. Psychometric measures such as the WAIS-R, WORD and Recognition Memory Test and a capacity to consent exercise adapted from a procedure described by Arscott et al (1998) were implemented.

Formulation
A cognitive-behavioural framework was used in the formulation of the client’s anxiety and anger about meeting his birth parents. Vulnerability factors included having a learning disability, being a victim of sexual abuse, having feelings of being rejected by his birth parents, communication problems particularly with reference to being able to talk about his emotional needs and the risk of future sexual exploitation. Protective factors include having an attractive personality, having a mild learning disability and a secure attachment with his adoptive family. It was hypothesised that the central question was not whether Mr. Jones has the capacity to consent but the possible repercussions of him meeting his birth parents. Consequences might include increased confusion, anxiety and anger and the possibility of aggression towards personal property or even self-harm. Such negative emotions and actions match Beck’s (1976) cognitive model that it is the interpretation of events rather than the events themselves which trigger anxiety.
Follow-up and outcome
The capacity to consent exercise was repeated at 2-week and 10-week follow-up and in both instances Mr. Jones was able to satisfactorily demonstrate capacity to consent. At the final session Mr. Jones affirmed categorically that he did not wish to pursue contacting his parents at the present time having thought about the issues and discussed them with his adoptive mother. Mr. Jones was reassured that this decision was acceptable.
Children, Adolescent and Family Summary of Placement Experience

Placement Location: Oak Glade Psychology Service for Under 5's and Epsom CAMH's
Trust: Surrey Oaklands NHS Trust
Dates: October 1999 – March 2000
Supervisors: Penny Bebbington (Consultant Child Clinical Psychologist) and Shona Lowes (Clinical Psychologist)

Summary of Experience
Experience of working with children across the developmental span and their families was gained using behavioral, cognitive-behavioural, systemic and neuro-psychological approaches in the context of an Under-5's clinic and a CAMH's team. Clinical experience included work with children with developmental, adjustment and mental health problems. Neuro-psychological assessment skills were developed to incorporate the assessment of problems such as Asperger's Syndrome and cognitive impairment. Sixteen clients were seen whose ages ranged from 3 years to 16 years and they were from a mix of socio-economic and ethnic backgrounds.

Clinical skills gained
Experience was gained in working with children with a variety of presenting problems including Asperger's syndrome, sexualised and aggressive behaviour, issues around bullying, bizarre behaviour, sleep difficulties, adjustment, anorexia nervosa, divorce, trauma, learning difficulties and ADHD. Multi-disciplinary liaison and presenting clear and sensitive feedback to parents and schools were key experiences. A number of school observations were undertaken to facilitate the formulation process and experience was gained in assessment procedures such as WISC-III, WPPSI, WORD, CBC, PSI, RBMT-C, BDS, KIDCOPE, Life in School Checklist and SCAS.

Meetings, seminars and research
Visits to a nursery and infant and junior schools were attended to meet with teachers and observe children in their normal daily activity. Fortnightly attendance of a family therapy clinic, including participation in a reflecting team. Fortnightly attendance of Child Psychology team meetings and monthly attendance of Psychology meetings.
A neuro-psychological assessment of possible memory deficit in a child with an initial diagnosis of Asperger’s Syndrome.

Main presenting problem
Jack was referred to the Child and Adolescent Mental Health Service by his Consultant Paediatrician following a preliminary diagnosis of Autistic Spectrum Disorder probably of the Asperger’s type. Concerns about Jack’s early and on-going communication difficulties was expressed as well as more general behavioural difficulties.

Assessment procedure
Jack and his mother were seen for an initial assessment interview where it became apparent that Jack’s mother had a different understanding of the nature of Jack’s difficulties, describing him as having memory problems as well as behavioural problems. Jack’s developmental, medical, educational and social histories were assessed to determine whether there was a need for cognitive assessment. This led to a number of hypotheses to guide the formulation, which were essentially teasing out whether his difficulties were due to memory, comprehension or Asperger’s Syndrome. The WISC-III, WORD, and RBMT-C were administered.

Formulation
Due to the complexity of the case only tentative conclusions could be drawn. There was specific evidence of working memory impairment rather than general impairment in memory functioning and weaker evidence of some lack of comprehension. There was some evidence, although clearly not conclusive, for the paediatrician’s preliminary diagnosis of Autistic Spectrum Disorder, probably of the Asperger’s type, but the referral did not specifically ask for clarification of the diagnosis and the assessment did not focus on this issue. It was tentatively proposed that when commands are simple then Jack is able to comply with the demands made of him. When more complex demands are made Jack’s vulnerability with respect to his poor working memory results in genuine compliance difficulties. Protective factors include good family relationships and the forming of a recent friendship providing Jack with positive feelings that enhance his self-esteem.
Intervention and recommendations

Clear feedback to Ms. Todd to facilitate her understanding and reduce her anxiety was considered to be essential. A report was sent to the paediatrician which outlined the neuropsychological findings and the behavioural intervention conducted. Behavioural guidelines (Ollendick and Hersen, 1984) for the future management of Jack’s difficulties were provided with emphasis being placed on Jack’s mother giving him clear, simple instructions and maintaining a consistent parenting style.
Paediatric Oncology Summary of Placement Experience

Placement Location: Department of Psychological Medicine, Royal Marsden Hospital
Trust: The Royal Marsden NHS Trust
Dates: October 2000 – September 2001
Supervisor: Lesley Edwards (Child and Adolescent Clinical Psychologist)

Summary of Experience
This placement provided experience of working within a paediatric oncology service in a hospital recognised as a Centre of Excellence. Referrals were made internally and made either by the paediatric team or family members. Clinical experience involved working with children, young people and families experiencing a severe and often chronic major illness and liaising effectively with multi-disciplinary professionals within a highly specialist health service. Clients were seen in a range of settings including the paediatric in- and out-patient service and the psychology department. Moreover, home and school visits were often conducted. The ages of the 11 children seen ranged from 2½ years to 17 years and the families were from a range of socio-economic and ethnic backgrounds.

Clinical Skills Gained
Skills in assessment formulation and intervention were consolidated using behavioural, cognitive-behavioural and systemic frameworks. Although clients were seen in the context of an oncology service the presenting problems were typical of those that might be referred to a CAMH’s team and included anxiety, depression, adjustment difficulties, behavioural difficulties, personality issues and neuro-psychological assessment. One of the most challenging aspects of the placement was of work with clients coping with impending death and the associated bereavement and family issues. Assessment methods included semi-structured interviews, cognitive and psychometric assessments. In addition, a one-day ‘group for adolescents with a sibling with cancer’ was both planned and implemented with co-facilitators. Interventions were based on cognitive-behavioural therapy, behavioural models and systemic therapy.

Meetings, seminars and research
Weekly paediatric team meetings were attended to discuss new referrals and review cases. The major research was commenced during this placement.
Paediatric Oncology Case Report Summary

The assessment and social learning theory formulation of behavioural problems in a child cancer patient using behavioural interventions and parenting work

Main presenting problem
Thomas, a 9-year old boy with a history of cancer was referred by his Consultant Oncologist as Thomas’s mother had complained about his difficult and inappropriate behaviour and the negative impact that this was having on the family.

Assessment Procedure
Assessment was carried over four sessions due to the complex nature of the family’s history and background factors. The assessment was primarily in the form of a semi-structured interview and standardised questionnaires. Thomas’s medical history was examined and contact with his school was made to establish their view of Thomas’s functioning. The family was split with Thomas’s father and older brothers living in New Zealand. During assessment, Thomas’s mother expressed concern about a number of issues related to Thomas’s behaviour, including infantalised behaviour, separation anxiety, restricted diet and sleeping problems. However, she was also reflective about her own anxiety and difficult life experiences. Thomas’s psychometric score suggested higher than expected levels of anxiety.

Formulation
It was hypothesised that Thomas’s behavioural problems arose from a combination of child and parental factors and within the context of a severe childhood illness. Personal factors, such as temperament, levels of independence, history of vulnerability, locus of control and contextual factors, such as environmental stress, parental management techniques and parental history were identified as relevant in the development and maintenance of Thomas’s behavioural problems. Applied social learning theory underpinned the development of the formulation, its key premise being that learning occurs actively within a social context.

Intervention
A number of actions were implemented. Firstly, Thomas’s mother was referred for cognitive-behavioural work to address her own generalised anxiety and depression. Secondly, education was provided about childhood problems to promote understanding of the importance of consistent parenting styles and to provide Thomas’s mother for a rationale for
the behavioural intervention. Thirdly the use of various behavioural techniques were discussed and implemented with respect to the target behaviours, including differential use of reinforcement contingencies, setting appropriate limits and boundaries. Finally, individual work with Thomas using modelling and play was incorporated into the main sessions to facilitate communication about his illness fears.

**Outcome**
At the end of intervention Mrs. Douglas reported that Thomas’s dietary preferences had widened although his issues with food were not completely resolved. Thomas had more progress with sleeping independently as well as his separation anxiety with respect to his mother. Mrs. Douglas also reported an improvement in Thomas’s interaction with other family members and with hospital staff when he had outpatient appointments.

Thomas was reluctant about completing the post-intervention measures but this did not appear to be attributable to fear of the issues. His post-treatment score on the ‘How I feel Questionnaire’ reduced from 17 to 5 and suggested that he was no longer anxious whilst his score on the ‘B’ Questionnaire remained the same at 7 confirming that Thomas was not depressed.

Mrs. Douglas also reported feeling personally more optimistic about her ability to parent consistently as well as about Thomas’s prognosis.
Older Adults Summary of Placement Experience

Placement Location: Springfield Hospital
Trust: South West London and St. George’s NHS Trust
Dates: October 2000 – April 2001
Supervisor: Sara Turner (Consultant Clinical Psychologist)

Summary of Experience
This placement provided experience of working with older adults within the context of a community mental health team based in a large teaching hospital and the provision of a psychology service to a day hospital. There were opportunities to consider life span issues as well as refining existing skills in cognitive therapy and neuro-psychological assessment.

Clients were seen in a range of settings including the nursing, residential, warden controlled and private homes, Day Centres and in the day hospital. The ages of the 11 clients seen ranged from 69 years to 88 years and they were from a range of socio-economic and ethnic backgrounds.

Clinical skills gained
Experience was gained in working with a variety of presenting problems pertinent to older people including functional and vascular dementia, anxiety, depression, relationship difficulties, memory difficulties, dealing with loss due to health difficulties and adjustment issues. Assessment procedures included the WAIS-III, NART-R, MEAMS, MMSE, Doors and People, CRNLT, BDI, and BAI. Interventions were based predominantly on behavioural and cognitive-behavioural models.

Meetings, seminars and research
I attended monthly Psychology Department meetings and weekly community team meetings which incorporated new referrals and the clinical review of people admitted to the in-patient unit and day hospital. I also participated in a 2-day Audit of a nursing home in the Trust. This involved taking part in observations as well as the collection, recording and coding of information and the provision of brief feedback to the management of the nursing home.
Older Adults Case Report Summary

Main presenting problem
Mrs. Johnson, an 82-year old white woman was admitted to an older people’s in-patient service. This followed a complaint from the manager of Mrs. Johnson’s residential home that the former was displaying persistent behavioural problems. The Consultant Psychiatrist subsequently made a referral to Psychology.

Assessment Procedure
Assessment, using standardised and non-standardised means, was undertaken in Mrs. Johnson’s home over 6 one-hour sessions and included information from Mrs. Johnson, the manager of the residential home and Mrs. Johnson’s son. Mrs. Johnson presented as an articulate but highly anxious lady who identified a number of issues as causing her difficulty. These included anxiety about frequently needing to use the toilet during the day and particularly during the night, reliance on ‘night-pads’ to preemt ‘accidents’, ruminating about less than stable relationships with staff members and worrying about her decreased independence. Mrs. Johnson scores on the BDI and BAI were indicative of mild depression and moderate to severe anxiety respectively.

The manger of the residential home described Mrs. Johnson’s difficulties in terms of ‘attention seeking,’ including behaviours such as repeatedly seeking verbal reassurance from staff and creating disturbances that brought staff into closer contact with her.

Formulation
Taking the above a formulation was developed of Mrs Johnson’s use of night-time pads based upon operant conditioning principles. Mrs. Johnson’s first experience of enuresis resulted in anxiety that this would occur again. The provision of continence pads to limit the aversive consequences of wetting the bed reduced, but did not eliminate, Mrs Johnson’s fear. The pads thus became negative reinforcers. Eventually Mrs Johnson became caught up in a cycle in which the context of going to bed elicited rising anxiety that was halted initially by the use of continence pads, but then continued to rise until only use of the commode had any impact upon the anxiety experienced.

The cycle of rising and falling anxiety could be repeated numerous times within the space of one night and thus Mrs Johnson was frequently attempting to get out of bed. Her perception of hostile responses from staff inhibited her calling for assistance — in this case the hostility
can be also seen as negative reinforcement as it also led to a reduction in assistance seeking behaviour.

Mrs. Johnson's anxiety about night-time enuresis generalised to the day. She became hypervigilant about going to the toilet both day and night to 'prevent an accident from happening.'

**Intervention**
The intervention was conducted weekly over 12 one-hour sessions at Mrs. Johnson's residential home and was principally via behaviour modification. The focus of the direct collaborative work with Mrs. Johnson included reducing and eventually eliminating the dependency on night-time pads using shaping and extinction, encouraging asking for appropriate assistance via social reinforcement and reducing the frequency of needing to use the toilet or commode at any time by the use of 'in vivo' behavioural experiments.

**Multi-disciplinary case conference**
During both the assessment and intervention the trainee was aware of and concerned that the staff-client boundaries did not always seem appropriate and of emerging reports of inappropriate practices occurring in the home. As a result of these concerns all professionals and individuals involved in the care of Mrs. Johnson were invited to a case conference. General issues about the management of the home as well specific issues about Mrs. Johnson's care were raised and discussed.

**Outcome**
When therapy was concluded there was evidence that Mrs. Johnson had made significant progress with respect to her night-time difficulties. The behavioural experiments resulted in Mrs. Johnson developing the confidence to decrease the frequency with which she visited the toilet during the day and she started to discriminate between physiological and psychological needs to empty her bladder.

In summary this case formed an exceptional learning experience for the trainee and served as an introduction to the complexity and multi-dimensionality of what seemed like a straightforward referral of anxiety management. It was also an example of the trainee working both as a therapist and in a consultative role, a dual role that clinical psychologists are increasingly expected to adopt.
Systemic Therapy Summary of Placement Experience

Placement Location: Child and Adolescent Mental Health Service, Richmond Royal.
Trust: South West London and St. George’s NHS Trust
Dates: August 2001 – February 2002
Supervisor: Jennifer Wallis (Clinical Psychologist)

Summary of Experience
This placement provided an excellent experience of working with children, adolescents and families from a systemic and narrative therapy perspective. I worked individually and jointly with my supervisor seeing families with complex as well as less severe problems. Awareness was developed of the importance of attending to the families previous relationships with health and social services as well as other agencies that become involved when families experience difficulties.

A total of 17 children and young people with their families were seen on this placement and their ages ranged from 4 to 17 years. They were from a variety of socio-economic and ethnic backgrounds. A highly successful anxiety management group for adolescents was planned and implemented during this placement with an Assistant Psychologist.

Clinical skills gained
Skills in assessment, formulations and intervention were developed using systems theory, drawing on Structural, Milan, Post Milan and Narrative models. I worked as a lead therapist as well as a member of the observing and reflecting team in Family Therapy sessions.

Meetings, seminars and research
I attended weekly CAMH’s business meetings which were organised to have a reflecting team as per the systemic therapy ethos as well as fortnightly Psychology meetings. In addition I participated in a CAMH’s Team Away Day, attended two one-day conferences on domestic violence and social communication disorders respectively and visited a boarding school for children with severe emotional and behavioural difficulties. I presented the preliminary findings of my major research at the end of this placement.
RESEARCH DOSSIER

OVERVIEW

This section includes the Service Related Research Project completed on the Adult Mental Health placement in Year 1, the Literature Review completed in Year 2 and the Major Research Project completed in Year 3.
EVALUATING THE IMPACT OF A MULTI-DISCIPLINARY TEAM 'AWAY DAY'
ON TEAM CLIMATE AND MEMBERSHIP

July, 1999
Year 1
Abstract

Title: Evaluating the impact of a multi-disciplinary team ‘Away Day’ on team climate and membership.

Objective: The present work aimed to explore issues surrounding the views of a multi-disciplinary team, given, that team members simultaneously belong to ‘the team’ and also belong to their own individual profession. These views were explored within the context of an ‘Away Day.’ Key areas of interests included the relationship between team identification and professional identification, the relationship between team identification and factors such as job satisfaction, burnout and team role clarity and the impact, if any, of the use of a team ‘Away Day’ to enhance team identification.

Design: A within-group design was used to explore the relationship between a number of variables. There were two main independent variables: time, having three levels: baseline, Away Day and 4 weeks post-Away Day and gender. Dependent variables were measures on team/professional identification, team/personal role clarity, job satisfaction, burnout, job satisfaction and psychological distress. A quantitative methodology was utilised to investigate the above aims.

Setting: A community mental health team (for adult mental health services) was approached in a mid-Sussex NHS Trust and team members were invited to participate.

Main Outcome Measures: There were five outcome measures: General Health Questionnaire, Occupational Stress Indicator, Maslach Burnout Inventory, Team Identification Scale and Professional Identification Scale and Personal/Team Role Clarity Scale.

Results: The main conclusion drawn from the results of the first hypothesis evaluating the impact of the Away Day, is that in general, the Away Day was not successful in improving team members perceptions on the key variables under consideration. There were no improvements in job satisfaction, team identification, personal or team role clarity, and indeed, in some cases burnout and psychological distress actually increased following the Away Day. Overall team members reported identification with both the team and their own profession across all three measurement times.
1. Introduction

1.1 Multi-disciplinary teams

Multi-disciplinary teams (MDT's) have been established to meet the needs of a variety of client groups living in the community (Ovretveit, 1986).

There are many reasons for developing models of care delivery based on team work: one important reason for this may be that the needs of clients can be addressed using skills from a variety of professionals in a flexible way; consequently clients have quicker and easier access to a wide range of therapist's skills and therapeutic approaches (Ovretveit, 1986). Ideally, professional liaison could be seen to be most effective when people are working under the same roof where information and joint objectives can be readily shared and discussed and team working can potentially provide a 'safe' context in which professionals can discuss their own anxieties and stresses (Moss, 1994).

1.2 The concept of a 'Team'

A general definition of a team is of it being a collection of people brought together to complete a task and who perceive themselves as a group (Cushway and Lodge, 1993). Ovretveit (1986) uses the concept of 'formal teams' with respect to MDT's to suggest a very clear membership and a collective responsibility among members for undertaking certain work.

There is now a large body of literature in clinical psychology evaluating the significance of working in teams for clinical psychologists (for example, Anciano and Kirkpatrick, 1990), and given the supposed benefits discussed above, comments from psychologists have tended to describe negative experiences rather than positive ones (Paxton, 1995). Onyett and Ford (1996) suggest that the difficulties of some community mental health teams may due to a failure in effective implementation, which includes unfocused aims and confusion about accountability and responsibility. However, this sense of confusion may be present amongst all team members and not just a perception in Clinical Psychology. Moreover, implications of low staff morale, defined by variables such as job satisfaction and burnout, may have a severe impact on service users requiring continuous, co-ordinated and consistent care (Onyett, Pillinger and Muigen, 1997).
1.3 Background to present study

Researchers have started to become interested in how MDT's function, particularly as professional workers in such teams are in effect members of two groups: their own profession and their team. It has been suggested that this may result both in role conflict and ambiguity about achieving a positive sense of identification within the team coupled with a sense of professional identification (Onyett, Pillinger and Muijen, 1997).

The background to the present study is that the multi-disciplinary team (in the setting of a Community Mental Health Centre for Adult Services) was at the point of reviewing how referrals to the team were allocated to primary or secondary care. This was considered to be a complex process and one, which was contributing to some friction between team members. An Away day had been scheduled for all team members and the Consultant Clinical Psychologist considered that this may be an appropriate forum to consider factors such job satisfaction, burnout, team identification and role clarity.

2 Aims and hypotheses of present study

2.1 Objectives

The present work aimed to explore a number of issues surrounding the views of a multi-disciplinary team, given, that the team members simultaneously belong to ‘the team’ and also belong to their own individual profession. These views were explored within the context of an ‘Away Day.’ Key areas of interests were:

(a) The relationship between team identification and professional identification,
(b) The relationship between team identification and factors such as job satisfaction, burnout and the clarity with which an individual perceives their role to be within the team, and,
(c) The impact, if any, of the use of a team ‘Away Day’ to enhance team identification (an explicit purpose of the Away Day was to facilitate greater team identification).

Specific research hypotheses are detailed below.
2.2 Hypotheses

Hypothesis 1: Team identification, role clarity and job satisfaction will be more positive and burnout will be lower immediately after the Away Day and will be sustained at follow-up one month later. There will also be an effect of gender on the dependent variables.

Hypothesis 2: Professional identification in the MDT will initially be higher than the level of team identification, but following the Away Day team identification will become stronger than professional identification.

Hypothesis 3: There will be an inverse relationship between psychological distress, as measured by the General Health Questionnaire, and levels of team identification and job satisfaction. Also, with respect to burnout, there will be positive associations between scores on the GHQ and high levels of emotional exhaustion and depersonalisation, but a negative association between GHQ scores and personal accomplishment.

Hypothesis 4: High team identification will be associated with high job satisfaction and low burnout.

Hypothesis 5: High personal role clarity and high team role clarity will be associated with high team identification, high job satisfaction and low burnout.

3 Methodology

3.1 Design

A between-subjects design was initially considered but poor responses from other MDT teams in the region who were invited to participate hampered the feasibility of this. The present study must therefore be regarded as an exploratory piece of work that employed a within-group design to explore the relationship between a number of variables described below. The cohort of participants was from an adult mental health multi-disciplinary team in a mid-Sussex NHS Trust.

There were two main independent variables: time, having three levels: baseline, Away Day (4 weeks post-baseline) and 4 weeks post-Away Day and gender. Dependent variables were measures on team/professional identification, team/personal role clarity, job satisfaction, burnout, job satisfaction and psychological distress. A quantitative methodology was utilised to investigate the above aims.
3.2 Setting
A community mental health team (for adult mental health services) was approached in a mid-Sussex NHS Trust and team members were invited to participate.

3.3 Participants
Participants comprised all members of the CMHT, which included the following disciplines: Administration, Community Psychiatric Nursing, Day Nursing, Occupational Therapy, Psychiatry, Psychology and Social Work.

3.4 Procedure
In the first instance the Team leader was approached and the nature of the research was briefly outlined to him. The rationale of the research was then discussed with the entire team through the use of a presentation (see Appendix I). A consent form and a letter reiterating the aims and voluntary nature of participation in the research (see Appendix II and III) then followed this up.

The team was informed that measures would be obtained from them over three time periods: at baseline, immediately following the Away Day and four weeks post-Away Day. The team's Away Day had already been scheduled and aspects of team functioning were planned to be explicitly discussed (see Appendix IV). The following points were made clear to the team members:
1. All information would be confidential and would not be made available to anyone other than the researcher.
2. Scoring and publication of the results would not identify any individual by name.
Informed consent was sought and obtained (See Appendix II).

3.5 Outcome measures
3.5.1 12-item General Health Questionnaire (GHQ) (Goldberg and Williams, 1988)
(See Appendix V for copy of GHQ)
This is a widely used self-report questionnaire used to screen for the presence of psychiatric distress of recent onset in adults. The GHQ has been shown to have high internal consistency and high test-retest reliability (Goldberg and Williams, 1988).
3.5.2 Occupational Stress Indicator (OSI) (Cooper, Sloan and Williams, 1988)
(See Appendix VI for a copy of OSI)
The Occupational Stress Indicator is a published scale consisting of 22 items measuring job satisfaction. Higher scores on the measure indicate greater satisfaction. The reliability and validity of the scale is established (Robertson, Cooper and Williams, 1990) and the scale has been applied to a variety of health service workers (for example, Onyett et al, 1997).

3.5.3 Maslach Burnout Inventory (MBI) (Maslach and Jackson, 1986)
(See Appendix VII for copy of MBI)
The Maslach Burnout Inventory (Maslach and Jackson, 1986) is a 22-item scale assessing three aspects of burnout: emotional exhaustion, depersonalisation and lack of personal accomplishment. A high score on the first two sub-scales indicates higher levels of emotional exhaustion and depersonalisation, whereas a low score on the third scale indicates lower personal accomplishment. Reliability and validity is well established (Maslach and Jackson, 1986).

3.5.4 Team Identification Scale (TIS) and Professional Identification Scale (PIS)(Onyett, Pillinger and Muijen, 1997)
(See Appendix VIII for copies of TIS and PIS)
The Team Identification Scale consists of eight items: four, which affirm, and four of which deny team identification. A high score is indicative of greater team identification. A similar 8-item scale measures professional identification; again a high score on this indicates greater professional identification. Both scales have established reliability and validity (Brown, Condor, Mathews, Wade and Williams, 1986).

3.5.5 Personal/Team Role Clarity Scale (Rizzo, House and Lirtzman, 1970)
(See Appendix XI for copy of Personal/Team Role Clarity Scale)
Personal and team role clarity were measured using scales adapted from the role ambiguity scale developed by Rizzo et al (1970). Personal role clarity assesses the extent to which an individual is clear about his/her responsibilities, who s/he is accountable to and how his/her work will be evaluated. Team role clarity refers to the extent to which the team is seen as having clear aims and priorities, including clarity about whom the team is trying to help. Each scale consists of seven statements, and a higher score indicates greater role clarity. Reliability and validity have been established (Rizzo et al, 1970).
4 Results
The scores on each main variable collectively for the team are presented followed by the results of the research hypotheses, along with the statistical analyses and key findings.

4.1 Make-up of multi-disciplinary team and response rates
Table 4.1 illustrates the number of participants from each of the disciplines in the MDT based on their gender.

Table 4.1: Data on number of participants from each discipline and their gender.

<table>
<thead>
<tr>
<th>Discipline</th>
<th>Males (n = 6)</th>
<th>Females (n = 10)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration staff</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>Community Psychiatric Nurses</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Day Nurses</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Occupational Therapists</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Psychiatrists</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Psychologists</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Social Workers</td>
<td>0</td>
<td>2</td>
</tr>
</tbody>
</table>

All 16 of the team members returned their questionnaires over each time period, representing a 100% response rate.
4.2 Testing of main hypotheses

4.2.1 Hypothesis 1: Team identification, role clarity and job satisfaction will be more positive, and burnout will be lower, immediately after the Away Day and will be sustained at follow-up one month later. There will also be an effect of gender on the dependent variables.

Table 4.2 depicts the means and standard deviations over the three time periods and between genders for scores on the General Health Questionnaire and the Occupational Stress Indicator.

Table 4.2: Means and standard deviations for scores on the General Health Questionnaire and Occupational Stress Indicator.

<table>
<thead>
<tr>
<th>Time</th>
<th>Gender</th>
<th>N</th>
<th>GHQ Mean</th>
<th>GHQ SD</th>
<th>OSI Mean</th>
<th>OSI SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baseline</td>
<td>Male</td>
<td>7</td>
<td>21.29</td>
<td>3.04</td>
<td>95.50</td>
<td>8.98</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>23.66</td>
<td>6.76</td>
<td>76.33</td>
<td>14.32</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>22.63</td>
<td>5.44</td>
<td>84.00</td>
<td>15.51</td>
</tr>
<tr>
<td>Away Day</td>
<td>Male</td>
<td>7</td>
<td>21.86</td>
<td>3.67</td>
<td>89.67</td>
<td>12.24</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>20.67</td>
<td>5.05</td>
<td>82.56</td>
<td>7.32</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>21.19</td>
<td>4.40</td>
<td>85.40</td>
<td>9.86</td>
</tr>
<tr>
<td>Post Away Day</td>
<td>Male</td>
<td>7</td>
<td>22.43</td>
<td>5.74</td>
<td>95.00</td>
<td>12.41</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>20.67</td>
<td>6.46</td>
<td>87.00</td>
<td>11.42</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>21.44</td>
<td>6.02</td>
<td>90.20</td>
<td>12.08</td>
</tr>
</tbody>
</table>

Table 4.3 (see page 126) depicts the means and standard deviations over the three time periods and between genders for scores on the Emotional Exhaustion, Depersonalisation and Personal Accomplishment sub-scales of the Burnout Inventory. Table 4.4 (see page 127) depicts the means and standard deviations over the three time periods and between genders for scores on the team/professional identification and team/personal role clarity.

Two-factor repeated measures ANOVA’s were carried out to test the effect of time and gender on the dependent variables.

1) There were no main effects of either time or gender on GHQ scores. An interesting, yet not quite significant interaction effect was obtained between time, gender and GHQ scores...
(p = 0.054); the means show that the GHQ scores of females at baseline were lower (but not significantly) compared to immediately after the Away Day and post-Away Day.

2) Results of the three sub-scales of the burnout variable indicated the following:

Emotional Exhaustion: there was no main effect of time on emotional exhaustion. There was a main effect of gender on emotional exhaustion (F(1,6) = 9.58, p < 0.05, \eta^2 = 0.62). No significant interaction effect was found.

Depersonalisation: there was no significant main effect of time on depersonalisation, although p was approaching significance (p = 0.067). There was, however, a main effect of gender on depersonalisation (F(1,6) = 9.06, p < 0.05, \eta^2 = 0.60) and there was also a significant interaction effect (F(2, 12) = 5.19, p < 0.05, \eta^2 = 0.46). The means show that females have significantly higher scores at 4 weeks post-Away Day (see Table 4.3).

Personal Accomplishment: there were no main effects of either time or gender on personal accomplishment. However, there was a significant interaction effect (F(2,12) = 5.08, p < 0.05, \eta^2 = 0.46). The means suggest that females had significantly higher personal accomplishment scores at baseline compared to Away Day and post-Away Day.
Table 4.3: Means and standard deviations for Emotional Exhaustion, Depersonalisation and Personal Accomplishment subscales of the Burnout Inventory.

<table>
<thead>
<tr>
<th>Time</th>
<th>Gender</th>
<th>N</th>
<th>Emotional Exhaustion</th>
<th>Depersonalisation</th>
<th>Personal Accomplishment</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
</tr>
<tr>
<td>Baseline</td>
<td>Male</td>
<td>7</td>
<td>9.86</td>
<td>3.53</td>
<td>2.00</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>21.78</td>
<td>11.98</td>
<td>3.44</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>16.56</td>
<td>10.90</td>
<td>2.81</td>
</tr>
<tr>
<td>Away Day</td>
<td>Male</td>
<td>7</td>
<td>13.14</td>
<td>7.38</td>
<td>1.57</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>17.22</td>
<td>11.18</td>
<td>4.44</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>15.44</td>
<td>9.63</td>
<td>3.12</td>
</tr>
<tr>
<td>Post Away Day</td>
<td>Male</td>
<td>7</td>
<td>11.14</td>
<td>6.01</td>
<td>0.86</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>18.67</td>
<td>10.36</td>
<td>8.44</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>15.36</td>
<td>9.30</td>
<td>5.13</td>
</tr>
</tbody>
</table>
Table 4.4: Means and standard deviations for team/professional identification and team/personal role clarity.

<table>
<thead>
<tr>
<th>Time</th>
<th>Gender</th>
<th>N</th>
<th>Team Identification</th>
<th>Professional Identification</th>
<th>Team Role Clarity</th>
<th>Personal Role Clarity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td>Mean</td>
<td>SD</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Baseline</td>
<td>Male</td>
<td>7</td>
<td>23.86</td>
<td>1.87</td>
<td>24.14</td>
<td>1.87</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>24.25</td>
<td>2.32</td>
<td>23.88</td>
<td>1.96</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>24.07</td>
<td>2.05</td>
<td>24.00</td>
<td>1.85</td>
</tr>
<tr>
<td>Away Day</td>
<td>Male</td>
<td>7</td>
<td>23.86</td>
<td>0.90</td>
<td>24.57</td>
<td>2.30</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>21.63</td>
<td>2.67</td>
<td>24.00</td>
<td>3.67</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>22.67</td>
<td>2.29</td>
<td>24.27</td>
<td>3.01</td>
</tr>
<tr>
<td>Post Away Day</td>
<td>Male</td>
<td>7</td>
<td>23.86</td>
<td>1.07</td>
<td>24.29</td>
<td>1.50</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>9</td>
<td>24.25</td>
<td>2.32</td>
<td>24.00</td>
<td>0.76</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>16</td>
<td>24.07</td>
<td>1.79</td>
<td>24.13</td>
<td>1.13</td>
</tr>
</tbody>
</table>
3) There were no main effects of either time or gender on team identification. An interaction effect approached significance \((p = 0.065)\), with the means showing that females scores on team identification dropped immediately after the Away Day (but not significantly).

4) There were no main effects of either time or gender nor were there any interaction effects on the following variables: job satisfaction, professional identification or team/personal role clarity.

4.2.2 **Hypothesis 2:** Professional identification in the MDT will initially be higher than the level of team identification, but team identification will become stronger following the Away Day.

As there were two dependent variables a double multi-variate repeated measures Anova was carried out to test the effect of time (independent variable) on Team Identification and Professional Identification (dependent variables). This revealed no significant difference between scores on the 2 dependent variables over time; hence hypothesis 2 is rejected.

4.2.3 **Hypothesis 3:** There will be a relationship between psychological distress, as measured by the General Health Questionnaire, and high levels of team identification and job satisfaction. Also, with respect to burnout, there will be positive associations between scores on the GHQ and high levels of emotional exhaustion and depersonalisation, but a negative association between GHQ scores and personal accomplishment.

a) There were no significant correlations between scores on the GHQ with either high job satisfaction or high team identification at any period of time. This part of the hypothesis is therefore rejected.

b) Results from the burnout variable indicated that only the Emotional Exhaustion sub-scale was pertinent. There was a positive correlation between scores on the GHQ and the emotional exhaustion sub-scale at all three measurement times. At baseline, the correlation coefficient was 0.45 but \(p\) did not reach significance levels. Immediately following the Away Day, the correlation coefficient was 0.67 \((p < 0.01)\) and at 4 weeks post-Away Day the correlation coefficient was 0.56 \((p < 0.05)\). Therefore, this part of the hypothesis can only be partially accepted.
4.2.4 Hypothesis 4: high team identification will be associated with high job satisfaction and low burnout.

a) High team identification was not associated with job satisfaction at any of the three measurement times nor was it associated with any of the burnout sub-scales at any of the three measurement times. Therefore hypothesis 4 is rejected.

4.2.5 Hypothesis 5: High personal role clarity and high team role clarity will be associated with high team identification, high job satisfaction and low burnout.

Neither high personal role clarity nor high team role clarity were significantly correlated with high team identification, high job satisfaction or low burnout at any of the three measurement times. Hence, hypothesis 5 is rejected.

5 Discussion

The main findings from the study are summarised and discussed in relation to the research literature. Limitations of the research and methodological points are reviewed and issues raised by this study for consideration in future research are discussed. The implications of the findings for clinical practice are also evaluated.

5.1 Discussion of main findings

The main conclusion one can draw from the results of the first hypothesis evaluating the impact of the Away Day, is that in general, the Away Day was not successful in improving team members perceptions on the key variables under consideration. In fact, for some measures the impact of the Away Day actually appeared to lead to an increase in negative scoring, particularly for females. For instance, female team members actually reported more distress on the GHQ immediately following the Away Day and 4 weeks post-Away Day than at baseline (although this was not at a significant level). In the de-personalisation and personal accomplishment sub-scales of the burnout variable, the former increased and the latter decreased over time, although this was a significant finding for female team members only. Female team members were also more likely than male team members to feel more emotional exhaustion at all three times that the measures were taken. This effect of burnout and gender is in line with Schaufeili’s (1990) research with psychiatric nurses, although not with Boakes’ (1998) study of clinical psychologists.

There is no previous research literature on evaluations of Away Days, this apparently being the first study to have evaluated a NHS Away Day in this way. Arguably, the actual process of the Away Day may have created more ‘tension’ in the team precisely because issues were
discussed in an open and honest forum. It is also possible that people’s personal expectations of the Away Day had not been fulfilled: team members may have anticipated the function of the Away Day as a way of facilitating a sense of cohesiveness within the team and reaching a mutual understanding of common goals. Confusion and/or disappointment may have been a consequence of a perceived failure in this process and is thus reflected in the scores on the measures.

With respect to gender, the differences between male and female team members may be a reflection of what the two sexes bring to their work as well as suggesting something about how they work. Perhaps females felt more personally distressed at the issues discussed in the Away Day and carried this back to their workplace, whereas males were more able to detach themselves, possibly conceptualising the Away Day as an event independent of work.

Overall team members reported identification with both the team and their own profession across all three measurement times: this finding is in common with Onyett et al’s (1997) analysis of these two variables in their large scale study of CMHT’s. Such findings are particularly positive given the claim that CMHT’s are conceptually problem ridden (Galvin and McCarthy, 1994).

The association between emotional exhaustion and psychological distress warrants attention, partly as the correlation becomes significant following the Away Day, which is again suggestive of the negative impact of the Away Day itself, and also as it is congruent with Carson, Fagin and Ritter’s (1995) finding that similar proportions of CPN’s had high emotional exhaustion and reached ‘psychiatric caseness’ on the GHQ.

5.2 Methodological critique

The 100% response rate is strongly indicative of the salience and perceived relevance of this exploratory piece of work for this particular MDT. However, a major limitation of this study was it’s very small sample size: this hindered comparison between disciplines but may also have led to the failure of finding some significant effects (that is, Type II error).

A control group who did not have an Away Day, but were given the same measures over similar time periods, may have shed further clarification on the present results and strengthened its methodological validity. A useful next step may be to expand the study to include other CMHT’s. This would simultaneously increase the sample size and allow the use of a between-subjects design to investigate differences between disciplines.
Some individual qualitative work with the team members may have shed greater light on people’s subjective experiences of being in a team and their impressions of the Away Day thus amplifying the quantitative analysis. It may also have been useful for participants to have described both the rewarding and dissatisfying areas of their work in the context of a MDT.

5.3 Implications for clinical services

Prior to the Away Day, most of the team members were actively looking forward to the exercise of discussing their own team dynamics in an open but safe forum. Given the main finding that there were no improvements in job satisfaction, team identification, personal or team role clarity, and indeed, in some cases burnout and psychological distress actually increased following the Away Day one must question the use of NHS resources in this way. Possibly it was the case that the expectations of team members at the Away Day were not realised. If that was the case, then this suggests that the team’s aims and objectives for the day need to be explicitly identified and planned before future Away Days are organised.

CMHT’s are indeed an important part of the way local services are now delivered and integrated teams working to common goals are an essential requirement of effective participation and collaboration.
6 References


Appendix I: Overheads for team presentation of nature of research:

**MULTI-DISCIPLINARY TEAMS:** Evaluating the Impact of a Team Away Day

**On the Perception of Team Membership:**

**WHAT IS A TEAM?**

- Collection of people brought together to complete a task.
- They tend to interact with one another and perceive of themselves as a group.

**Advantages of multi-disciplinary teams?**

**Ideally:**

- can draw upon the skills of a variety of professionals.
- clients have quicker and easier access to a wider range of therapist’s skills.
- facilitates DISCIPLINES working together.
- opportunities for the provision of advice / support from other team members.
- can provide safe context in which professionals can express anxieties.
- may result in creativity.

**Important concepts when looking at how well teams are working:**

- Team identification vs. Professional identification.
- Personal Role Clarity vs. Team Role Clarity.
- Job Satisfaction.
- Burnout.
Your commitment:

- complete questionnaires over 3 time periods:

  4 weeks before Away Day
  Immediately after Away Day
  4 weeks after Away Day.

My commitment:

- confidentiality assured.
- will report back results of project.
- willing to provide individual feedback to those who want it after data analysis.
Appendix II: Consent Form

Title of research study
Evaluating the impact of a multi-disciplinary team (MDT) 'Away Day' on team climate and membership.

Investigator
Dr. A. H. Hashemi

I (name)

of (work address)

hereby consent to take part in the above study, the nature and purpose of which has been explained to me.

Any questions regarding the nature of this study, or its aims and method have been answered to my satisfaction.

In addition the following items have been explained to me:

1. That my anonymity will be preserved and that any information gathered from the questionnaires which could lead to my identification will be withdrawn from subsequent stages of the research.

2. I also understand that I am able to withdraw from the research at any stage, without having to explain my reasons for doing so.

3. I understand that once Dr. Hashemi has completed her data analysis, she will shred all copies of the questionnaires.

Signed ........................................ Date ........................................
Appendix III: Information form

Dear

I am writing to invite you to take part in the present study which I am conducting as part of my Service Related Research Project, in Clinical Psychology, at the University of Surrey. In return for your support, you will receive a report on the main findings, and if you wish individual feedback. In this way you will be able to compare your own scores with those of the main sample. This report will be presented to the Linwood team, upon completion of the study, and as promised in the original presentation that I made to your team.

The rational and main aims of the study are outlined in the proposal form attached. Essentially, I am investigating how people experience working within multi-disciplinary teams. In the current work, I wish to explore aspects of the team structure, and the roles of different professions, to see how, if at all, they relate to job satisfaction and burnout. The findings may resolve whether there is any conflict between the concepts of ‘team identification’ and ‘professional identification’ and this may have implications for how people work within teams.

Whilst I do appreciate how precious your time is, I hope that, nevertheless, you will be interested in participating, so that the findings will be representative of your team’s experiences. I would also like to add that this is exciting research taking place within the Trust, and I am confident that the findings will be both important and illuminating.

You should already have received a pack containing a number of measures, which if you would like to participate, I would be grateful if you could complete and return to the above address via internal mail. I will be asking you to complete the same questionnaires over three time periods: baseline, 4 weeks and 8 weeks. I would like to reiterate that I am very aware how busy people are. However, I would be grateful if forms could be returned as soon as possible, so that there is a constant time period between each measure. Based on pilot data, I estimate that the questionnaires should not take longer than 30 minutes to complete.

If you would like additional information, please do not hesitate to contact me at the above address, and I will be more than happy to answer any questions that you may have.

Your participation is entirely voluntary and all responses will be treated in the strictest confidence. All data will be shredded once that analysis is complete. If you do not wish to give you name, that is okay, but I do need your occupations for analysis purposes.

Thank you for taking the time to read this letter and I hope to hear from you soon.

Yours sincerely

Dr. Amtul Habib Hashemi
Clinical Psychologist in Training
**Project Title**
Evaluating the impact of a multi-disciplinary team (MDT) 'Away Day' on team climate and membership.

**Theoretical rationale**
Very little research to date has been conducted which has paid attention to how members of Community Mental Health Teams (CMHT’s) perceive the significance of working in teams, or indeed, their role within it. This study will attempt to make the first tentative steps to redress that balance.

**Objectives**
The current study aims to explore a number of issues surrounding multi-disciplinary teams:
1. team member's views of the climate of the team and how this is related to general well being, job satisfaction and burn out.
2. The relationship between team identification and professional identification.
3. The impact of a specific intervention, via the use of a team 'Away Day' to enhance team identification.

**Design**
A within group design using a cohort of participants from a multi-disciplinary team will be employed. A quantitative methodology will be utilised to investigate the above aims.

**Setting**
A community mental health team (CMHT), for adult services, in the West Sussex region will be approached and invited to participate.

**Participants**
Participants will comprise of all members of the CMHT. The professions involved are: Administration staff, Community Psychiatric Nurses, Day Nurses, Occupational Therapists, Psychiatrists, Clinical Psychologists and Social Workers.

**Procedure**
Each of the participants will be informed of the project by the researcher giving a presentation, followed by a letter reiterating the aims and the voluntary nature of participation in the research. Informed consent will be obtained.

Three sets of measures are to be obtained over a 2 month period. The Linwood CMHT has an Away Day organised where aspects of team functioning are planned to be explicitly discussed. This will form the basis of an intervention.

**Main hypothesis**
Team identification, role clarity and job satisfaction will be more positive immediately after the Away Day and will be sustained 1 month after the intervention.
Main outcome measure
The main outcome measure will be to assess whether there is a significant change in scores on the outcome measures between baseline, 4 weeks (i.e. 'Away Day' week) and 4 week post 'Away Day.'

Outcome measures to be used will be:
1. 12-item General Health Questionnaire (Goldberg and Williams, 1988)
2. Occupational Stress Indicator (Cooper, Sloan and Williams, 1988)
3. Maslach Burnout Inventory (Maslach and Jackson, 1986)
4. Team Identification Scale and Professional Identification Scale (Onyett, Pillinger and Muijen, 1997).
5. Team and Personal Role Clarity Scale (Rizzo, House and Lirtzman, 1970).

University Supervisor: Jonathan Foulds
Field Supervisor: Mary Dobbins

Name of Ethics Committee to which project will be submitted: N/A

Signature of Trainee: Signature of Supervisor:

Date: 24.1.99

Amtul Habib Hashemi –
Linwood team; Haywards Heath.
Tel: 01444 416 606 ext. 2123
Appendix IV: Programme for Team Away Day:

Facilitating the Away Day were two external facilitators.

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>9.00 a.m.</td>
<td>Registration and coffee</td>
</tr>
<tr>
<td>9.30 a.m.</td>
<td>Introduction to the day</td>
</tr>
<tr>
<td></td>
<td>Ground Rules</td>
</tr>
<tr>
<td></td>
<td>Whole Group Session - Team Working:</td>
</tr>
<tr>
<td></td>
<td>(a) group clock - stages of group development</td>
</tr>
<tr>
<td></td>
<td>(b) group sculpt - working relationships</td>
</tr>
<tr>
<td>11.10 a.m.</td>
<td>Coffee</td>
</tr>
<tr>
<td>11.30 a.m.</td>
<td>Sub Groups - Team Development</td>
</tr>
<tr>
<td></td>
<td>reflection on group sculpt</td>
</tr>
<tr>
<td>12.30 p.m.</td>
<td>Presentation on Edronax</td>
</tr>
<tr>
<td>12.45 p.m.</td>
<td>Lunch</td>
</tr>
<tr>
<td>1.45 p.m.</td>
<td>Whole Group Session - Feedback from morning session and prioritising areas to develop</td>
</tr>
<tr>
<td>2.45 p.m.</td>
<td>Sub Groups - Seeking Solutions</td>
</tr>
<tr>
<td></td>
<td>'The individual is accountable to and responsible for the team.'</td>
</tr>
<tr>
<td></td>
<td>How will the team make this happen?</td>
</tr>
<tr>
<td>3.15 p.m.</td>
<td>Tea</td>
</tr>
<tr>
<td>3.30 p.m.</td>
<td>Whole Group - Feedback solutions and action planning</td>
</tr>
<tr>
<td>4.30 p.m.</td>
<td>Plenary</td>
</tr>
<tr>
<td>5.00 p.m.</td>
<td>Close</td>
</tr>
</tbody>
</table>
Appendix V: The General Health Questionnaire

Please read this carefully:

We should like to know if you have had any medical complaints and how your health has been in general, over the last few weeks. Please answer ALL the questions simply by underlining the answer to which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL the questions.

Thank you very much for your co-operation.

Client’s Name:............................................ Date:............................................

<table>
<thead>
<tr>
<th>HAVE YOU RECENTLY:</th>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less than usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Been able to concentrate on whatever you’re doing?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Lost much sleep over worry?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Felt that you are playing a useful part in things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Felt capable about making decisions about things?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Felt constantly under strain?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Felt you couldn’t overcome your difficulties?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Been able to enjoy your normal day to day activities?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Been able to face up to your problems?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Been feeling unhappy and depressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Been losing confidence in yourself?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Been thinking of yourself as a worthless person?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Been feeling reasonably happy, all things considered?</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Sub-totals

Total

142
Appendix VI: Occupational Stress Indicator: *How you feel about your job* (Cooper, Sloan & Williams, 1988)

This section looks at how satisfied you feel about your present job within the team. The questions below are concerned with the extent to which you feel satisfied or dissatisfied with your job. Try not to be put off by any other reactions you might have - simply rate the items against the satisfaction/dissatisfaction scale provided.

Please answer by circling the number of your answer on the scale shown:

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>Very much satisfaction</td>
<td>5</td>
<td>Much satisfaction</td>
<td>4</td>
<td>Some satisfaction</td>
</tr>
<tr>
<td>3</td>
<td>Some dissatisfaction</td>
<td>2</td>
<td>Much dissatisfaction</td>
<td>1</td>
<td>Very much dissatisfaction</td>
</tr>
</tbody>
</table>

1. Communication and the way information flows around the team
   - 6 5 4 3 2 1
2. The relationships you have with other people at work
   - 6 5 4 3 2 1
3. The feelings you have about the way you and your efforts are valued
   - 6 5 4 3 2 1
4. The actual job itself
   - 6 5 4 3 2 1
5. The degree to which you feel ‘motivated’ by your job
   - 6 5 4 3 2 1
6. Current career opportunities
   - 6 5 4 3 2 1
7. The level of job security in your present job
   - 6 5 4 3 2 1
8. The extent to which you may identify with the public image or goals of the team
   - 6 5 4 3 2 1
9. The style of supervision that your supervisors use
   - 6 5 4 3 2 1
10. The way changes and innovations are implemented in your team
    - 6 5 4 3 2 1
11. The kind of work or tasks that you are required to perform
    - 6 5 4 3 2 1
12. The degree to which you feel that you can personally develop or grow in your job
    - 6 5 4 3 2 1
13. The way in which conflicts are resolved in the team
    - 6 5 4 3 2 1
14. The scope your job provides to help you achieve your aspirations and ambitions
    - 6 5 4 3 2 1
15. The amount of participation which you are given in important decision making
    - 6 5 4 3 2 1
16. The degree to which your job taps the range of skills which you feel you possess
    - 6 5 4 3 2 1
17. The amount of flexibility and freedom you feel you have in your job
    - 6 5 4 3 2 1
18. The psychological ‘feel’ or climate that dominates the team
    - 6 5 4 3 2 1
19. Your level of salary relative to your experience
    - 6 5 4 3 2 1
20. The design or shape of the team’s structure
    - 6 5 4 3 2 1
21. The amount of work you are given to do whether too much or too little
    - 6 5 4 3 2 1
22. The degree to which you feel extended in your job
    - 6 5 4 3 2 1
Appendix VII: Maslach Burnout Inventory (Maslach & Jackson, 1986)

(A)

The purpose of this section is to discover how people in multi-disciplinary teams view their jobs and the people with whom they work closely. Please read each statement carefully and decide if you ever feel this way about your job. If you have never had this feeling, circle the ‘0’ after the statement. If you have had this feeling indicate how often you feel it by circling the number (from 1 to 6) that best describes how frequently you feel that way.

<p>| | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel emotionally drained from my work</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2</td>
<td>I feel used up at the end of my working day</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3</td>
<td>I feel tired when I get up in the morning and have to face another day at work</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4</td>
<td>I can easily understand how clients/patients feel about things</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5</td>
<td>I feel I treat some clients/patients as if they were impersonal objects</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6</td>
<td>Working with people all day is a real strain for me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7</td>
<td>I deal effectively with the problems of clients/patients</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8</td>
<td>I feel burned out from my work</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9</td>
<td>I feel I’m positively influencing other people’s lives through my work</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10</td>
<td>I’ve become more callous toward people since I took this job</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11</td>
<td>I worry that this job is hardening me emotionally</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>I feel very energetic</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13</td>
<td>I feel very frustrated by my job</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14</td>
<td>I feel I am working too hard on my job</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15</td>
<td>I don’t really care what happens to some clients/patients</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16</td>
<td>Working with people directly puts too much stress on me</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17</td>
<td>I can easily create a relaxed atmosphere with clients/patients</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18</td>
<td>I feel exhilarated after working closely with clients/patients</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19</td>
<td>I have accomplished many worthwhile things in this job</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20</td>
<td>I feel I’m at the end of my tether</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21</td>
<td>In my work, I deal with emotional problems very calmly</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22</td>
<td>I feel clients/patients blame me for some of their problems</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
(B) Sub-scales for the Maslach Burnout Inventory

I. Emotional Exhaustion

1. I feel emotionally drained from my work.
2. I feel used up at the end of the workday.
3. I feel fatigued when I get up in the morning and have to face another day on the job.
6. Working with people all day is really a strain for me.
8. I feel burned out from my work.
13. I feel frustrated by my job.
14. I feel I'm working too hard on my job.
16. Working with people directly puts too much stress on me.
20. I feel like I'm at the end of my tether.

II. Depersonalisation

5. I feel I treat some clients/patients as if they were impersonal objects.
10. I've become more callous towards people since I took this job.
11. I worry that this job is hardening me emotionally.
15. I don't really care what happens to some clients/patients.
22. I feel clients/patients blame me for some of their problems.

III. Personal Accomplishment

4. I can easily understand how clients/patients feel about things.
7. I deal effectively with the problems of clients/patients.
9. I feel I'm positively influencing other people's lives through my work.
12. I feel very energetic.
17. I can easily create a relaxed atmosphere with clients/patients.
18. I feel exhilarated after working closely with clients/patients.
19. I have accomplished many worthwhile things in this job.
21. In my work, I deal with emotional problems very calmly.
Appendix VIII: Team Identification and Professional Identification Scale (Onyett, Pillinger and Muijen, 1997)

**TEAM IDENTIFICATION:** This section looks at your feelings about the team. Please answer by circling the number below:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Slightly Agree</th>
<th>Neither Agree</th>
<th>Slightly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I feel strong ties with the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I don’t fit in with other members of the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I try to hide belonging to the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. I consider the team important to me</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. I’m embarrassed to say I’m a member of the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. I make excuses for belonging to the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>7. I see myself as belonging to the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8. I’m glad to belong to the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

**PROFESSIONAL IDENTIFICATION:** This section looks at your feelings about your profession. By this we mean your core profession, i.e. Clinical Psychology. Please answer by circling the number below:

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Slightly Agree</th>
<th>Neither Agree</th>
<th>Slightly Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I’m embarrassed to say I’m a member of the profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2. I see myself as belonging to the profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3. I make excuses for belonging to my profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4. I feel strong ties with my profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5. I’m glad to belong to my profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6. I don’t fit in with other members of my profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>7. I consider my profession important to me</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8. I try to hide belonging to my profession</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix IX: Personal/Team Role Clarity Scale (Rizzo, House & Lirtzman, 1970)

This section asks you to rate your agreement with various statements about your work. Please answer by circling the number of your answer below:

<table>
<thead>
<tr>
<th>Statement</th>
<th>strongly agree</th>
<th>slightly agree</th>
<th>Neither agree nor disagree</th>
<th>slightly disagree</th>
<th>strongly disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1  I feel uncertain about how much authority I have</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2  I'm not certain of where the team’s responsibilities begin and end</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>3  I seldom know whether I’m doing my job well or poorly</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>4  I know exactly what is expected of me</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>5  I know what my responsibilities are</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>6  I'm clear about who the team is trying to help</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>7  I feel the team has a clear purpose to its work for clients/patients</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>8  I’m not sure who I’m accountable to for my work with clients/patients</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>9  I am not certain what the team’s priorities are</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>10 I do not feel the role of the team is clearly defined</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>11 I am clear what my work priorities are</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>12 I know exactly what is expected of the team</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>13 I feel most of my tasks are clearly defined</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>14 It is difficult to tell whether the team is doing it’s job right or not</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix X: Letter from placement supervisor confirming dissemination of findings

Dr. Amtul Hashemi,
School of Human Sciences,
Department of Psychology,
University of Surrey,
Guildford,
Surrey, GU25 5XH.

21st September 1999

Dear Amtul,

Re: Service Related Research Project

Thank you for sending me a copy of the report on your service related research project. I am sorry that we have been unable to negotiate our diaries so that you could present the findings to the team personally.

The results were interesting although given the atmosphere at the Team Away Day I will need to think carefully about how to disseminate these findings to the team. I am sure that these findings will foster much discussion, on the value or otherwise of Away Days. Thank you again for the time that you spent on this project.

Yours sincerely,

MARY DOBBIN
Consultant Clinical Psychologist.
Literature Review

Childhood cancer: factors contributing to the psychological adjustment of children and parents.

December 2000
Year 3
1. Introduction

The diagnosis of childhood cancer has an immense impact on the patient, parents and family members. Data on the epidemiology of childhood cancer can be equivocal, for example, one set of research concludes that medical treatment has advanced to the stage where the treatment of different paediatric malignancies has resulted in an overall survival rate of approximately 60% (Granowetter, 1994). However, cancer has also been cited as the most common cause of death among children younger than 15 years of age (Neglia and Robinson, 1988). Moreover, at best, it is often described as a chronic life-threatening illness (Michael and Copeland, 1987).

Parents' immediate concern and apprehension of the possible death of their child is particularly strong when diagnosis is first made but can continue as parents live under the shadow of relapse or death for many years (Koocher and O'Malley, 1981). Indeed, arguably the very essence of parenting, that is, nurturing and protecting children, becomes a challenge for parents because of the life-threatening nature of cancer and the often-distressing side effects of the treatment. Multiple stressors post-diagnosis, such as repeated hospital stays, invasive procedures, distressing side-effects, disruption of family routine and changes in family roles and responsibilities coupled with prolonged uncertainty about the future have many implications not just for the parents but for the family as a system (Kazak, 1994).

Perhaps given all these factors, it is not surprising that Wallander and Varni (1998) have reported considerable individual variability in the adjustment of parents of chronically ill children and thus argue for the need to specify the elements that may hinder or facilitate family adaptation.

The structure of this literature review will be as follows: firstly, the context will be set by presenting a brief summary of the current medical understanding of the aetiology of childhood cancers. How the child with cancer copes with and adjusts in terms of the diagnostic, treatment and social processes will be scrutinised in order to better understand the parental reaction. The main aim of this critical review is to discuss and assess the major findings and conclusions for the most important factors that impact on family adjustment when a child is diagnosed with cancer. Hence, the use of differing coping strategies, the uptake of social support, and the parental relationship will be examined and appraised. Sibling's adaptation to childhood cancer is also a function of family system variables and as such it is important that these studies are also briefly reviewed. Finally, it is an interesting and important observation that not all families experience difficulties and the literature will be tentatively explored in a
bid to understand what implications this may have for future research and designing interventions to support families who do have particular needs.

2. Aetiology of childhood cancers
Almost any type of cancer can occur in children but the common childhood cancers tend to be leukaemia, lymphoma, neural tumours and sarcomas (Bleyer, 1993). However, a single causative agent for malignant growth is still unknown in the majority of both childhood and adulthood cancers (Steinherz and Simone, 1998). Current research with adult cancers suggests that a complex interaction of host, environmental and genetic factors contribute to its aetiology rather than a single agent (Shwartzbaum, George, Pratt and Davis, 1991). It is known that certain environmental factors such as radiation, drugs and chemicals and viruses lead to an increased incidence of cancer. Moreover, specific types of cancer vary widely in different geographic locations and diverse social and dietary habits suggest a number of factors that might contribute to carcinogenesis (Steinherz and Simone, 1998).

However, while the majority of adult malignancies may be due to the kinds of environmental factors cited above, the long latency period and different features preclude the likelihood that this mechanism plays a primary role in childhood cancers. More likely causes of childhood cancer are thought to be genetic, congenital and familial determinants (Shwartzbaum, George, Pratt and Davis, 1991).

3. The adjustment of the child with cancer
The diagnosis of cancer and the subsequent treatment challenge issues of control and competence for a child at almost every stage of their illness. When one considers basic developmental psychology, it becomes clear that from infancy onwards, the child’s development moves towards a greater sense of control of self, of relationships and of the surrounding environment (Brunquell and Hall, 1982). It is therefore paradoxical that cancer therapy, a potentially life-prolonging action, also poses a real threat to the natural process of self-control and autonomy for the ill child. Die-Trill and Stuber (1998) have cited a number of problems for a child with cancer apart from the illness itself. Difficulties with eating are relatively common in children with cancer and can be used by them as a way of achieving control over a seemingly uncontrollable situation. Limitations due to restriction and impairment in mobility and activity as a result of essential medical procedures as well as physical restrictions secondary to surgery, pain or vomiting can also adversely interfere with a child’s normal development. For older children, having to remain in a bed may have
regressive implications and may suggest to them, rightly or wrongly, that their illness is very serious. It may also heighten a sense of social isolation.

Results from a two-year prospective study of childhood cancer (Sawyer, Antoniou, Toogood and Rice, 1997) suggest that immediately after their diagnosis, children with cancer experience considerable emotional distress. They were likely to be more anxious, dependent and tearful and to experience more sleep disturbance than children in the community were. The authors conclude that these problems were likely to be reflecting the impact of the hospitalisation, chemotherapy and other invasive procedures on the children with cancer. Several other researchers have also reported behavioural and emotional disturbances manifested in increased anxiety, depression, regression and withdrawal among children with cancer (for example, Dongen-Melman and Sanders-Wondstra, 1986). One team of investigators provide startling data that 98% of paediatric cancer patients had diagnosable DSM-III axis I disorders, 52% of which were adjustment disorders (Rait, Jacobsen, Lederberg and Holland, 1988). Moreover, greater frequencies of adjustment problems were reported in boys compared with girls. Extreme separation anxiety as well as pathological attachment have also been documented in both genders (Pfefferbaum, 1989).

3.1 Distress associated with medical procedures

Paediatric cancer treatments often involve multiple administrations of highly aversive and invasive medical procedures over a prolonged period of time. Because of the pain and distress caused by such procedures and, in particular, younger children's limited understanding of treatment, they either actively resist treatment or become highly apprehensive in anticipation of the procedures (Jacobsen, Manne and Gorfinkle, 1990). Common fears include disfigurement, losing all their blood and death; moreover, frequently older children are also likely to experience a sense of shame for not being able to control themselves.

Where children try to engage in coping behaviours during the anticipatory period of the procedure, it has been found that they then continue to cope adequately. However, when children are distressed and crying at the onset of treatment then they are more likely to continue to do so during the procedure (Manne, Bakeman and Jacobsen, 1992).

The presence of parents during invasive procedures can either reduce distress or actually worsen the situation. Parental explanations about the process at the beginning of medical procedures have been associated with a reduction in distress later on in the procedure in children who were initially distressed at the outset. However, for those children who were not
Literature Review

distressed in the beginning, subsequent parental explanations can lead to an increase in
distress (Manne et al, 1992)

3.2 Alterations in physical appearance

A changed physical appearance is a reminder to the child not only of the illness itself but also
of how different they are from their contemporaries. Weight changes, hair loss (alopecia),
placement of catheters to facilitate treatment administration and surgical scars may represent
to the child frightening physical changes in the body. Consequently, this may impact
adversely on their self-esteem (Varni, Ruberfield, Talbot and Setoguchi (1989). Moreover,
fear that the body will never return to its original appearance or fear of not being recognised
by others can often lead to shame, social isolation and regressive behaviours in children across
the age span.

A common side-effect of chemotherapy, alopecia, can be traumatic for children of all ages and
although some adjust well to hair loss, others find it extremely anxiety provoking and also
worry about teasing. Indeed, significant changes in body image have been reported with
alopecia and alopecia is generally perceived by patients as being a threat to their well being,
resulting in yet more anxiety (Wagner and Bye, 1979).

Coping with alterations in physical appearance may be equally distressing for the child’s
parent even when such changes are clearly temporary ones. Indeed, parental reactions to
disfigurement strongly affect how the child views him/herself. If the parent is able to accept
this and still be able to provide consistent support, this will play an important and positive role
in the patient’s global psychological adjustment as well as increase acceptance of continued
treatment (Die-Trill and Stuber, 1998).

3.3 School adjustment

Spinetta (1982) strongly argues the case that school represents the continuation of a child’s
normal life as well as the primary source of social activity. Regular school attendance is
crucial to foster normal development and to prevent isolation from peers and early school
return is considered an important part of a child’s successful rehabilitation. Moreover,
positive school experiences can help to reduce a child’s potentially maladaptive response to
the illness and its treatment by supporting the child to feel academically accomplished and
socially acceptable.
However, although most patients are able to resume at least some degree of school activity, some do develop increased anxiety and phobic reactions about the thought of returning to school and school-refusal can be a typical problem for parents and educational staff following a child's prolonged and aggressive treatment. This is often due to a fear of falling behind, fear of negative social reactions from peers and school staff to treatment side-effects and shame stemming from the need to depend more closely on school staff. High rates of absenteeism have been reported in paediatric cancer patients and have been attributed to these reasons (Lansky, Cairns and Zwarties, 1983).

3.4 Social adjustment

Studies of the social adaptation of children with cancer give conflicting results. Some researchers describe increased isolation and a reduced number of friends in children with cancer as perceived by their peers and teachers (Noll, LeRoy and Bukowski, 1991). Cancer patients whose teachers perceived them as less socially competent and whose parents reported fewer effective coping responses were found to demonstrate greater adjustment problems (Sanger, Copeland and Davidson, 1991). Compared to a control group of healthy children, paediatric cancer patients played less with children of their own age, spent more time alone and had greater feelings of isolation. However, these differences between patients and controls were not borne out by the ratings of parents and teachers (Spirito, Stark and Cobiella, 1990). Other studies, (for example, Noll, Ris and Davies, 1992) have not obtained such negative results, providing evidence that the socialisation of children with a chronic illness such as cancer is not necessarily negatively affected by the illness or its treatments.

4. The adjustment of the parent

4.1 Demographic and illness related variables for parental adjustment

A number of cross-sectional studies with parents following diagnosis of childhood cancer have looked at the relationship between various demographic and illness related variables and psychological functioning. The strongest finding appears to be that mothers seem more at risk for stress than fathers and this is discussed in greater detail in a later section.

Other demographic risk factors of parents, which have been discussed in the literature, include younger age, lower educational and/or occupational level, lower socio-economic status, less income and the lack of a religious affiliation (Veldhuizen and Last, 1991). However, Hoekstra-Weebers, Jaspers, Kamps and Klip (1999) have commented that not all of these demographic variables have been found to be significant prospective predictors of parental adjustment at one year post-diagnosis.
Illness variables such as the child’s estimated likelihood for survival, type of cancer, response to treatment, length of time in or since treatment, number of days hospitalised and functional impairment have not been found to be associated with parental adjustment (Hoekstra-Weebers et al, 1999). Kazak et al (1998) have suggested that subjective appraisals of illness and treatment may be more pertinent in explaining parental adjustment.

4.2 Psychological variables and parental adjustment

Early research on the psychological effects on parents indicated that the child’s own adjustment to cancer may depend on the parent’s ability to cope with their anxieties and distress caused by this traumatic experience. In one of the first comprehensive studies of this kind (Binger, Ablin, Fecerstein, Kushner, Zoger, S. and Mikkelsen, 1969) parents reported that the actual experience of the diagnosis of cancer in their child was the most difficult phase of the illness and that this phase was accompanied by physical distress, depression, inability to function, anger, hostility and self-blame. Koocher and O’Malley (1981) substantiated these findings in a later study.

In very recent research high levels of psychological distress in parents during the acute diagnostic phase when compared to a norm population has been reported by Hoekstra-Weebers, Heuvel, Boskamp, Kamps and Klip (2000). However, there is mixed evidence as to how well parents adjust to the continuing and changing demands made on them during the therapeutic process. Some studies report that parents cope well given time and are eventually able to continue with a normal day to day life (Kazak and Meadows, 1989). Others, however, suggest a less optimistic picture: Brown, Kaslow, Maidan-Swain, Doepke, Sexon and Hill (1993) have demonstrated that although parental levels of distress decreased and stabilised over the first year, they still remained high relative to a norm population one year after diagnosis.

As well as having to deal with elevated levels of general distress there is also evidence that parents report expressing continuing and wide ranging concerns about the physical, emotional and cognitive development of their child as well as concerns about their child’s future opportunities. These preoccupations appear to arise from quite an early stage once diagnosis has been established (Greenberg and Meadows, 1992). Moreover, parental feelings of uncertainty and loneliness are reported to persist even after the end of treatment (Dongen-Melman, Pruyn, DeGroot, Koot, Hahlen and Verhulst, 1995). Raising a child with cancer may alter a parent’s ability to parent effectively (Chesler and Barbarin, 1987). Patterns that
have emerged have suggested that parents have problems related to over-protectiveness, difficulty with consistent discipline and expression of ‘appropriate’ anger towards the child.

Hoekstra-Weebers, Heuvel, Boskamp, Kamps and Klip (1996) have suggested that some of the variation in the research findings may be directly attributed to the non-homogeneous use of psychometric instruments in research studies. These have included measures as diverse as the General Health Questionnaire, the Langer Symptom Check List and the Post-traumatic Stress Disorder Reaction Index. Clearly such methodological issues potentially limit the generalisation of findings, particularly when research instruments vary on key variables such as actually experienced psychiatric symptoms versus perception of psychological distress.

4.2.1 Parental coping
Conflicting information has also been published with respect to parental coping and adjustment strategies. Early work, for example, Kaplan, Grobstein and Smith (1976) demonstrated that parent’s initial coping responses were predictive of later levels of stress. Following on from this it was suggested that a family’s ability to be flexible is directly correlated with their positive psychological adjustment (Kupst and Schulman, 1988).

Hoekstra-Weebers et al (2000) tried to test the validity of this argument by designing a prospective study to investigate a number of factors. Firstly, whether parents used a number of different coping styles, secondly, to identify the concurrent and prospective contribution of coping styles on distress and thirdly, whether change in coping were associated with change in the level of distress. Their results revealed that on the whole, parents use of more effective coping strategies, such as active problem focusing, seeking social support and comforting cognitions significantly decreased over the period of the year following diagnosis. Moreover, they decreased their use of different problem solving and emotion regulatory strategies over time and as the demands of their child’s cancer treatment changed.

Barbarin and Chesler (1986) used a very different approach to examine parental coping ability by focusing on its correlation with the family’s relationships with medical staff. This yielded some very interesting information in terms of a correlation between the parent’s level of education and the quality of their relations with the medical staff. Less well educated parents reported better relationships with the staff than did better educated parents. Furthermore, parent’s level of education was positively correlated with the use of information seeking and problem solving and negatively correlated with the use of denial. Parent’s relationships with the medical staff were positively correlated with accepting the diagnosis and negatively
correlated with the use of problem solving. The authors argue that these results are novel because they appear to lend greater weight to the hypothesis that it is the medical context which is related to individual coping strategies rather than the actual amount of stress parents experience. Furthermore, Barbarin and Chesler (1986) suggest that parents who actively sought information and were highly educated may have been more threatening to the medical staff than other parents because they were inadvertently more difficult to deal with and control. Furthermore, medical staff may have sub-consciously reinforced the use of more passive coping styles among less well educated parents because these parents seemed easier to help.

Wittrock, Larson and Sandgren (1994) make the point that the way parents cope during the early stages of treatment may differ greatly from the way they cope at later points. Therefore, assessing parental coping ability at regular intervals as well as the use of supportive groups during the course of the child’s illness and treatment may be the most efficacious method for professionals to help parents cope with and adapt to their child’s illness.

4.2.2 Parental social support
The general association between social support and psychological adjustment is well established (Cohen and Wills, 1985) and there is consistent evidence that among parents of children treated for cancer, social support throughout the treatment is linked to the former’s psychological adjustment (for example, Kupst and Schulman, 1988). Parents of childhood cancer survivors, particularly fathers, who experience low levels of social support are more likely to be at risk for psychological distress (Speechley and Noh, 1992). Neither is this contingent on actual uptake or quantity of social support: Kazak, Barakat, Meeske, Christakis, Meadows, Casey, Penati and Stuber (1997) have reported that fewer post-traumatic symptoms have been found in parents of cancer survivors who report higher levels of perceived support.

When studies have conducted prospective analyses (Hoekstra-Weebers, Jaspers, Kamps and Klip, 1998a) they have shown that a father’s (but not mother’s) level of distress at 12 months was predicted by initial support. Moreover, the more fathers were satisfied with the level of support at initial diagnosis and the more they became dissatisfied over time, the more psychological distress they reported a year after diagnosis. Overall, this suggests that social support is a much stronger predictor of the psychological functioning of father’s than that of mother’s.
In a study examining the needs and responses of parents following the diagnosis of cancer, Sloper (1996) noted that many parents emphasised the importance of having someone to talk to who was not emotionally involved with the situation. Indeed, friends and extended family were cited more often than partners were as the people parents wanted to talk to about their feelings and as being particularly helpful. However, for a minority of respondents there seemed to be no avenue of social support and this not surprisingly was strongly related to psychological maladjustment.

4.2.3 Parental sex differences and marital satisfaction
Researchers have also focused on the demands placed on the husband and wife dyad. Larson, Wittrock and Sandgren (1994) have indicated that parents have to make a number of difficult decisions as they come to terms with their child's diagnosis including how to divide the physically and emotionally challenging tasks that face them and how to personally cope with such devastating news. This can exacerbate an already stressful situation.

Research in this area supports a difference in the degree of stress experienced by mothers and fathers. Koocher and O'Malley (1981) have reported higher levels of guilt in mothers and in other studies mothers have reported significantly higher levels of distress to fathers in the form of depression, anxiety and obsessive-compulsiveness (Magni, Messina, De Leo, De Mosconi and Carli (1983). Kupst and Schulman (1988) found that mothers tended to express more extreme bereavement, feel more responsible for their child's illness and have overall poorer adjustment than did fathers.

However, research has also suggested that fathers initiate ways to be absent or distant during the illness as a way of dealing with their distress, for example, by withdrawing into their jobs or increasing their alcohol use (Koocher and O'Malley, 1981). Some fathers also cope by relying on extreme denial more than mothers (Koocher and O'Malley, 1981). A more recent study (Larson, Wittrock and Sandgren, 1994) also offers similar conclusions to previous research. These authors did not find support for their study's main hypotheses that fathers would use more maladaptive coping strategies, use different social support systems to mothers and would be less anxious and depressed than mothers.

Researchers have hypothesised about why parental sex differences in coping are so pronounced. Koocher and O'Malley (1981) have conjectured that one reason may arise from societal expectations regarding traditional sex roles. Payne, Goff and Paulson (1980) have considered the father's primary role as financial provider and Spinetta and Spinetta (1981)
discuss the possibility of the father’s sense of isolation from the child because of the stronger role of the mother as primary carer.

It is likely that parents need each other most when dealing with the multiple stresses of childhood cancer; hence, the quality of the marriage is of importance. Some studies have reported that a higher percentage of parents report marital distress compared to a norm population (for example, Dahlquist, Czyzewski and Jones, 1996) whereas others report that marital satisfaction either remained unchanged or even improved (Kupst and Schulman, 1988). A very recent study (Hoekstra-Weebers, Jaspers, Klip and Kamps, 2000) showed that although both mothers and fathers reported significantly more marital dissatisfaction during the year following diagnosis, their level of dissatisfaction remained comparable with that of a norm population and significantly lower than that of a group with recognised marital problems. An earlier study conducted by the Hoekstra-Weebers team (Hoekstra-Weebers, Jaspers, Kamps and Klip, 1998b) suggests that for some parents the experience of childhood cancer strengthened their relationship although a larger sub-group within their study reported the opposite. This appears to tie in with research which suggests that perceived level of partner support as well as open communication about the illness plays an important role in facilitating the parent’s as well as the child’s longer term adjustment (Jessop, Reissman and Stein, 1988).

It has been suggested that difficulties in a marriage may arise when partners use different coping styles (Koocher and O’Malley, 1981). Again the findings of studies have been ambiguous. When looking at this Hoekstra-Weebers et al (1998b) have demonstrated that discrepancies in coping within couples were positively associated with marital distress in both partners. Conversely, Dahlquist et al (1996) showed that differences in coping were unrelated to marital distress.

5. Sibling adaptation
Research has also focused on the psychological adjustment of child and adolescent siblings of children with cancer because this life circumstance is viewed as stressful for siblings thereby placing them at risk for adjustment problems. The early assumption was that changes in family routines, organisation and roles as well as disruption of parent-sibling and patient-sibling relationships and patterns of interaction could contribute to siblings feeling neglected and alienated. This could then lead to impaired patterns of communication, limited understanding of the illness, jealousy, anger and sadness (Sourkes, 1980).
However, as with parental studies, the actual research findings appear not to have a consistent thread. Indeed, they have ranged from evidence for considerable sibling maladjustment, to little or no effect, to indications of a positive influence on the psychological development of the sibling (Sahler, Roghmann, Mulhern, Carpenter, Sargent, Copeland, Barbarin, Zeltzer and Dolgin, 1997). Siblings have been found to be vulnerable to distress and reporting feelings of not having their needs met (Sargent et al, 1997) and parents have reported negative changes in behaviour during the acute illness phase (Breyer, Kunin, Kalish and Patenaude, 1993). Conversely, parents have also reported positive changes in siblings: in one of the largest studies of siblings of paediatric cancer patients, parents of over 250 siblings reported improvements in the sibling’s maturity, supportiveness and independence (Barbarian, Sargent, Sahler, 1995).

The lack of convergent findings with respect to the risk of clinical disturbance for siblings is in part the result of both conceptual and methodological differences between findings. Arguing for a new conceptual approach, Dolgin, Blumensohn, Mulhern, Orbach, Sahler, Roghmann, Carpenter, Barbarin, Sargent, Zeltzer and Copeland (1997) have suggested that a multivariate approach incorporating, individual, family, medical and environmental factors is likely to be a more useful method over the usual bi-variate approach to research in sibling adaptation. Their rationale for this is that any specific predictive variable tends to explain only a small proportion of the overall variance in adjustment. In a comprehensive review of the psychological adjustment of siblings of children with chronic illnesses, Drotar and Crawford (1985) point out that there are many methodological issues that make it difficult to draw general conclusions. These include studies differing in sample size and study design, selection bias, criteria for psychological disturbance, methods of measurement and controls for potentially confounding variables.

6. Implications for future research

There is clear research evidence that many parents after the initial and devastating shock of the diagnosis of cancer in their child return with time to a level of psychological functioning that could be considered normal. However, there also remains a substantial sub-group of parents who remain within the realms of clinical depression even though their children are cancer survivors (Hoekstra-Weebers et al, 2000). It is these latter, more vulnerable parents which future work should more closely involve in an effort to examine risk factors associated with psychological maladjustment.
Dolgin and Phillips (1996) argue that there is a clear case for assessing the functioning of fathers in greater detail. The level of distress in fathers has been shown in many studies to be similar to the level of distress experienced and reported by mothers but there are many differences between the genders in terms of variables predicting adjustment. There is also the issue of the psychological adaptation of siblings. Therefore, future research should focus on all family members to address the fact that individual characteristics and family processes interact in complex, multi-functional ways.

Hoekstra-Weebers et al (2000) make the point that have researchers have not paid much attention to the relationship between interpersonal factors and parental adjustment. Trait anxiety has been found to be a strong predictor of future distress and changes in trait anxiety and assertiveness appear to be associated with changes in distress. This finding seems incongruent to the often considered notion that personality factors remain stable over time. Hence, a longitudinal study to confirm this would be useful.

The number of parents of childhood cancer patients in the majority of the studies reviewed is small and this limits statistical power and as a consequence the conclusions that can be reliably drawn. It is true that childhood cancer is a relatively rare disease (Miller, Young and Novakovic, 1995) but multi-variate studies are required to obtain large enough samples to test more complex multi-variate models.

The inconsistent findings concerning parental adjustment can at least partly be attributed to the type of outcome measure used in studies. There is clearly a need for an instrument that can provide information, firstly, about several dimensions of generic quality of life and secondly, that is also sensitive to areas specifically affected by cancer and its treatments.

Between group differences and within group differences should also be more closely investigated. Differences among children surviving cancer and their families are likely to arise as a result of functioning before the illness, the characteristics of the illness and the child and the family's response to it. These may have long term effects via processes that involve the child, the family, the medical context, educational and wider social influences. This reinforces the need for prospective longitudinal studies that can bring together research assessments, rationales and hypotheses that are developmentally sensitive.

Good quality intervention studies are essential if the research already established is to be used in a clinically viable way. While the majority of children and parents appear to adjust well at
some period after diagnosis, a minority continue to experience problems. Future research should continue to focus on isolating factors that will enable the early identification of these children and families so that more effective support can be offered to them. Both from professional and ethical perspectives it should be a clinical goal once psychological distress is determined in an individual (be it patient, parent or sibling) that levels of concern and stress are alleviated. Family focused interventions may be the most comprehensive and far-reaching approach.

Moreover, factors such as culture and ethnicity have been sorely neglected, in particular by British researchers. These are important considerations given that there is evidence that culture shapes responses to pain, identification and selection of medical care, compliance with treatment, support networks utilised during medical illness and meaning attached to physical symptoms (Die-Trill, 1998).

7. Summary and conclusion
In summary, the research reviewed has demonstrated a number of clear outcomes. The diagnosis of cancer in a child is devastating for patients and families and because of the treatment of increasingly complex and aggressive therapeutic methods treatment may itself constitute as significant a stressor as the illness itself. On the whole demographic and illness variables are not substantially related to parental distress. Coping styles and social support appear better predictors for fathers rather than mothers. One reason for this may be that the mother's psychological functioning is influenced more by general variables such as family functioning and the mother-child interaction and indicative perhaps of the mother's unique care-taking role in the family. Moreover, there is evidence that there is a clear reciprocal relationship between children's functioning and parent's functioning. The experience is equally distressing for siblings and this is now readily acknowledged in the literature. In conclusion, when childhood cancer is diagnosed the entire family is forced to re-negotiate their life circumstances and this inevitably has a debilitating effect on many family members.
8. References


Literature Review


Major Research project

THE EXPERIENCE OF WHITE AND ASIAN PARENTS WHEN THEIR CHILD IS DIAGNOSED WITH CANCER: USING AN INTERPRETATIVE PHENOMENOLOGICAL APPROACH

February 2002

Year 3
1. Abstract

This study aimed to explore how two groups of people, that is, Asian and white parents, whose child has been diagnosed with cancer understood and represented that experience. It employed a qualitative research methodology, Interpretative Phenomenological Analysis (Smith, 1996), to elicit in-depth personal accounts and experiences.

The sample consisted of two groups of indigenous white and British South Asian parents. Of the white parents three were fathers and seven were mothers and their ages ranged from 32 years to 45 years. Within the Asian parents there were four fathers and six mothers and their ages ranged from 34 years to 51 years. Participants were interviewed using a semi-structured interview schedule. The interviews were then transcribed verbatim and served as raw data for the analysis.

Analysis revealed that the parents in this study, irrespective of their cultural and ethnic background shared more similar experiences to one another than differences. Furthermore, these experiences appeared congruent with the limited literature on families coping with cancer. Themes indicated that parents found the experience of childhood cancer overwhelming and complex. Moreover, the commencement of treatment did not always provide resolution of either the child or the family's distress and indeed parents came to realise the limitations of medicine. The role of support both from personal and professional repertoires was welcomed and valued by parents but they also spoke candidly of experiences that were not so helpful. Although the similarity in parental experiences across the two groups was striking cultural influences illustrated the breadth and richness of the human experience as well as having some important implications for service provision.

Themes were considered in relation to the existing paediatric oncology and cross-cultural literatures. In addition, methodological issues and the challenges of undertaking research with parents of sick children were discussed along with the clinical implications of the study and directions for future research.
2. Introduction

This study is an exploration of cultural influences on the experience and understanding of parents when their child has been diagnosed with cancer. The aim is to understand how white and South Asian parents represent their experiences of their child's diagnosis of cancer through the qualitative analysis of semi-structured interviews.

In the preceding section of this Research Dossier, the Literature Review presented a critique of key factors established as contributing to the psychological adjustment of children and parents following the diagnosis of childhood cancer. The conclusions drawn in the Literature Review suggested that despite decades of research on the psychological processes of childhood cancer for the ill child and his/her parent(s) there remain significant gaps and inconsistencies in theoretical and clinical knowledge. In particular, cultural and ethnicity factors have been over-looked. These are important not just because Britain is a multi-cultural and multi-ethnic society but as there is evidence that such elements can shape the treatment and care that a patient receives, their compliance with treatment and the meaning attached to disease and illness by both patients and carers (Die-Trill, 1998).

The structure of this section is as follows: firstly, the epidemiological data on childhood cancer is discussed. This will include data for all British children and separated out for British children of South Asian origin. As the Literature Review already provides a comprehensive discussion of parental needs and adjustment following the diagnosis of childhood cancer only a brief summary of the existing literature ensues along with a predictive model of factors associated with psychological adjustment. The literature on cultural beliefs and practices with respect to cancer will also be drawn upon but as this body of research is limited relevant studies from both adult and childhood cancers will be considered. Finally a rationale of the present study is presented as well as the main objectives.

2.1 Epidemiology of childhood cancer in the UK

Incidence of childhood cancer in the general British population

Childhood cancer in children under 15 years of age is rare, accounting for less than 1% of malignancies diagnosed each year in developed countries (Coleman, Babb, Dameicki, Grosclaude, Honjo, Jones, Knerer, Pitard, Quinn, Sloggett and De Stavalo, 1999). Approximately one child in every 10,000 is diagnosed with the disease each year in the UK and about one in every 600 child develop it before their 15th birthday (Coleman et all (1999).
Incidence of childhood cancer in the British South-Asian population

An increasing proportion of the childhood population of the UK are members of diverse ethnic groups. Specifically, there are more than 1.4 million residents in England alone with ethnic origins in the Indian sub-continent, representing approximately 3% of the total population and 5.4% of the population aged 0-14 years (Office of Population Censuses and Surveys, OPCS, 1993). Little has been published of cancer incidence rates of British children from ethnic minorities and most earlier studies that had reported on the ethnicity variable had been limited to regional geographical areas (for example, Muir, Parkes, Mann, Stevens and Cameron, 1992).

Recent research (Cummins, Winter, Marie, Cheng, Silcocks, Varghese and Battle, 2001) combining data from four regional cancer registries plus data from the 1991 Census have derived the first near national sex-specific estimates of childhood cancer incidence for children aged 0-14 years in the South Asian population of England. A South Asian case was defined as a person whose name was identified as consistent with an ethnic origin in people indigenous to India, Pakistan or Bangladesh. Incidence rates of 1.5 per 10,000 were recorded for South Asian children as compared with just over 1 per 10,000 for non-Asian children suggesting a significant excess of childhood cancer among the South Asian population in England. The authors argue that this is predominantly due to higher rates in South Asian boys and confirms previous reports of a higher proportion of male cases among Asians compared to non-Asians (Varghese, Barrett, Johnston, Shires, Rider and Forman, 1996).

Survival

The types of cancer that occur in children are generally more responsive to chemotherapy than those in adults and improved treatment protocols have resulted in significant increases in survival for a wide range of diagnostic groups (Doll, Roman, Day, Law, Birch, Greaves and Taylor, 2000). Despite this, Neglia and Robinson (1988) have presented data that suggests that it is the most common cause of death among children younger than 15 years of age.

With respect to survival rates in relation to ethnicity, the UK Children’s Cancer Study Group have presented a national analysis of survival from childhood cancer differentiated by ethnic group (Stiller, Bunch and Lewis, 2000). They reported no significant differences for 5-year survival rates according to ethnic groupings including South Asians.
Researchers and clinicians agree that childhood cancer remains a significant health problem and is a disease that has an immense impact on the patient and the family (Hoekstra-Weebers, Jaspers, Klip and Kamps, 2000). At best, it is chronic and life-threatening (Michael and Copeland, 1987), not helped by the fact that even though its treatment has made considerable advances over the last twenty years similar progress has not been made in the understanding of its aetiology (Draper, 1995).

2.2 Adjustment and coping

Because childhood cancer has such a devastating impact on the family there has been much research literature that has focused on the psychological functioning and coping skills of the parent (Kristjansen and Ashcroft, 1994). Good psychological adjustment for parents is reported to be contingent on variables such as coping styles (Kupst and Sculman, 1988), social support (Speechley and Noa, 1992), the quality of the marital relationship (Hoekstra-Weebers, Jaspers, Klip and Klams, 2000) as well as gender differences (Larson, Wittrock and Sandgren, 1994).

Nevertheless, the findings of psychological disturbance in family members of children with cancer have tended to be equivocal, although the experience clearly constitutes a significant family stressor and coping challenge (Carpenter and LeVant, 1994). Limitations on family and social functioning, decreased attention to personal needs and issues of communication between family members are potential negative outcomes of such a diagnosis (Dolgin and Jay, 1989). For the parents, the uncertainty and loss of control over life and death matters concerning their child are further complicated by feelings of responsibility and guilt and engagement in superstitious behaviour.

In attempting to explain the variability in parental psychological functioning Hoekstra-Weebers, Jaspers, Klip and Kamps, (2000) have proposed a predictive model of factors associated with parental adjustment based on the stress-coping-outcome theory of Folkman, Lazarus, Dunkell-Schetter, DeLongis and Gruen (1986). Hoekstra-Weebers et al (2000) propose that childhood cancer might best be viewed as an on-going stressor to which each parent has to adapt. The diagnostic phase is considered an acute traumatic stressor. When the initial treatment phase brings the child into remission, parents enter a stage characterised as a chronic stressor. Relatively stable factors, such as demographic variables and personality characteristics are distinguished from variables that are likely to change as a function of the course of disease, that is
coping strategies, social support and marital satisfaction. Figure 1 is a diagrammatic representation of the model proposed by Hoekstra-Weebers et al (2000).

![Diagram of model](image)

**Figure 1:** Predictive model of factors associated with parental adjustment

It is argued that the model may be relevant to the present study for understanding and incorporating the general process that parents undergo when they experience the diagnosis of their child’s cancer.

At this point it is also relevant to briefly discuss two studies that have examined the more general effects of childhood cancer on parents both with respect to the experience immediately following the diagnosis and the experience of late consequences. In a British study using a quantitative methodology Sloper (1996) reported findings that as well as high levels of psychological distress in both mothers and fathers, there were wider-ranging negative effects on parental employment, finance and family relationships. Moreover, parents expressed concerns about delays in diagnosis and unmet needs with respect to professional support. Thereby, this study suggests a more complete picture of the parental life experience following a child’s cancer diagnosis. Shifting the focus to the views of parents of childhood cancer survivors Van Dongen-Melman, Zuuren, Verhulst (1998) implemented a wholly qualitative framework to provide a description of the parental experiences. The study’s findings suggested that Dutch parents experienced changes of a long-lasting and definitive nature and feelings of loss and perseveration of problems prevailed in spite of the child’s survival. Moreover, the authors stressed that the employment of a qualitative
methodology was fundamental in enabling the description presented of what it is like to live through childhood cancer. For this reason it is particularly relevant to the present study. Essentially, the present study is unique in the sense that it will adopt a qualitative framework to look at the experience of childhood cancer following a recent diagnosis and from the personal perspective of the parent.

2.3 Cultural issues

Studies looking at the impact of ethnicity and culture on cancer have been neglected. Research has tended to focus, without exception, on adult samples of European and American whites, despite the fact that cancer outcomes vary by ethnicity (Meyerowitz, Richardson, Hudson and Leedham, 1998). British research in this area is particularly sparse.

The majority of evidence for psycho-social cultural differences tends to originate from relevant American studies. They have found differences in issues such as autonomy and the role of the family, desired level of medical communication, health beliefs and treatment compliance. Information deficits have been reported to be greater among non-whites than whites in American adult cancer studies across areas such as knowledge about cancer risk, symptoms and type of treatments (Cotugna, Subar, Heimendinger and Kahle, 1992). Beliefs about cancer may also vary by ethnicity: Mexican immigrants were more likely to identify injuries to the breast, substance abuse or never breast feeding as high risk factors for breast cancer. Moreover, Vietnamese women were more likely to report that breast or cervical cancer could be caused by poor hygiene (Pham and McPhee, 1992). Ethnic differences with respect to treatment outcomes, quality of life and adherence to treatment have all been reported with knowledge deficits appearing to be greater among non-whites than whites (Meyerowitz et al, 1998).

A recent American-Israeli study is of interest as it examined the role of religious and spiritual beliefs in Israeli adults coping with a malignant melanoma (Baider, Russak, Perry, Kash, Gronert, Fox, Holland and Kaplan-Denour, 1999). The study suggested a positive correlation between religious beliefs and practices and engagement in an active-cognitive coping style. The latter has been shown to be associated with lower levels of anxiety and greater flexibility in those patients with a malignant melanoma (Fawzy, Fawzy and Hyan, 1993). The study’s findings would therefore seem to indicate that religiosity could be a protective behaviour in highly stressful situations.
Notwithstanding the above discussion and as Cook-Gotay (1995) argues information about the effect of cultural factors on family adjustment to cancer is virtually absent due to lack of research. She suggests that cultural factors could potentially influence attitudes to cancer, response to pain, coping styles and the possibility of death. Moreover, she adds that in some traditional Asian cultures shielding the patient from medical information is considered appropriate, and therefore, that the Western practice of full disclosure may be a source of conflict.

General research investigating health behaviour in South Asian populations does not necessarily offer any further clarification. For example, focusing on Muslim Mirpures from Pakistan living in West Yorkshire, Aslam and Healey (1983) describe an ‘alternative’ health service and suggest that belief in ‘traditional’ concepts can interfere with adherence to physician’s advice. However, Bhopal (1986) suggests that although knowledge of traditional Asian medicine is high amongst Muslim, Sikh and Hindu participants, its use was not extensive.

One area where deficits in knowledge about South Asian health behaviour and beliefs have recently started to be addressed in the UK is research on the perspectives of South Asian parents with respect to the issue of consanguinity and childhood disability (Ahmad, Atkin and Chamba, 2000). The authors argue that such constructions are located in the social lives of parents as well as in their relationships with services and describe two qualitative studies (where in both cases the vast majority of parents were of Pakistani origin) that illustrate this point. The first is a study focusing on the parents of pre-school deaf South Asian children (Ahmad, Darr and Jones, 2000) and the second looks at the accounts of parents of children with thalassaemia major (Atkin, Ahmad and Anionwu, 2000). The findings suggested that parents had concerns about their child’s diagnosis. They also perceived that health professionals had not given them satisfactory answers about causation. Emotional responses included feelings of guilt and anger about their child’s diagnosis and distrust, anger and ambivalence towards health professional’s, particularly with respect to the issue of parental consanguinity. The latter response was attributed to service professionals racialized constructions of disability and chronic illness among minority ethnic communities and Ahmad et al (2000) submit that ultimately this denies South Asian families equal access and care entitlements.
2.4 Rationale

The present study focuses on two groups: indigenous British white participants and South Asians participants (i.e. Indians and Pakistanis) living in Britain. The latter is chosen as this composite group accounts for 2.7% of the total British population and 49.2% of the ethnic minority population (Office of Population Censuses and Surveys, OPCS, 1993). Arguably, the two Asian groups can be contrasted with one another in terms of their age structure, patterns of migration to Britain, geographical distribution within the UK, initial and subsequent employment and housing (Robinson, 1996). However, it has also been suggested that cultural/regional identity and certain similarities of beliefs amongst South Asians cut across ethnic identity so that they can be considered to have a homogenous identity (Sissons-Joshi, 1998).

It is noteworthy that the way in which patients of South East Asian origin and their families respond to a crisis such as cancer in the family and the effect of their traditional ethno-semantic constructions of health and illness has been largely ignored. There is some evidence to suggest that South Asian patients are often the recipients of direct emotionally-toned prejudice in their encounters with health professionals (Bowler, 1995). Therefore, it is argued that this research may contribute to a more sensitive understanding of the responses and needs of both white and Asian patients and their families. Moreover, given, that there is clear evidence for the under-utilisation of mental health facilities and services by the Asian community (Cochrane and Sashidharan, 1996) findings from the proposed study may have service implications, particularly with respect to the uptake of psychological support.

On a final note it is worth highlighting that there is no British research providing a comprehensive account of the range and breadth of parental experiences when a child is diagnosed with cancer, irrespective of the cultural variable.

2.5 Objectives

There are two main objectives to this study:

1. To explore the way in which white and British South Asian parents experienced their child’s diagnosis of cancer.

2. For the study to consider how those parental experiences could be understood in relation to the existing literature on childhood cancer.
3. Method

3.1 Research Design

3.1.1 Rationale for research methodology
The scarcity of research investigating how parents experience their child’s diagnosis of cancer and the absence of British cross-cultural research meant that this study was exploratory. This implied the need for a research method capable of capturing detailed individual accounts from a small number of participants allowing an investigation of the meaning and understanding that they made of their experiences. Moreover, given the difficult subject matter, the ability of the researcher to be sensitive and flexible was deemed to be crucial in fostering participation.

To address these issues, a qualitative methodology was employed. Such a methodology also supports the interaction between the researcher and participant and acknowledges the influence that this may have placed upon the data collected (Smith, 1996). Indeed, it has been suggested that the qualitative paradigm is particularly useful in understanding topics that are under-researched as it provides a framework for the generation of new theoretical perspectives (Turpin, Barley, Beail, Scaife, Slade and Walsh, 1997).

3.1.2 Principles of qualitative research
Most qualitative research methods begin with the ontological assumption that there are many world realities that are socially and experientially based (Chamberlain, Stephens and Lyons, 1997). When viewing reality in this way researchers need to acknowledge that each individual may experience, perceive and represent their own reality differently. The research process must adequately reflect these multiple views and meanings and identify any similarities between individuals.

Moreover, the principles of qualitative research incorporate the idea that researchers cannot separate themselves from their own experiences and knowledge, and in fact, have to draw upon these in order to understand the position of others (Sciarra, 1999). Thus in qualitative research it is accepted that the researcher plays a key role in the research process (Smith, Harre and Van Langenhove, 1995).

Qualitative approaches vary widely in their associated epistemologies and the methodologies that they employ. Turpin et al (1999) argues that choosing an appropriate qualitative method for a
particular study is achieved through an active reflection and understanding of the project’s characteristics, the research questions to be addressed and the principles and procedures of the different qualitative methods. For this study, interpretative phenomenological analysis (IPA) was selected as the most viable method of collecting and analysing data as it enables the participant to ‘tell their own story, in their own words’ (Smith, Osborn and Flowers, 1997, p.68) and is sensitive to the perspective and interpretation of the researcher.

3.1.3 Description of Interpretative Phenomenological Analysis

Interpretative Phenomenological Analysis (IPA) draws on two theoretical frameworks: phenomenology and symbolic interactionism (Smith, 1996). Phenomenological approaches try to ‘explore the participant’s view of the world’ and recognises the importance of an individual’s ‘personal perceptions or accounts’ (Smith, 1996). The influence of symbolic interactionism is a recognition of the research interview as a dynamic interaction between two people (Smith, 1996) and acknowledges that the process is shaped and ultimately limited by the researcher’s own beliefs and experiences (Smith, Jarman and Osborn, 1999). The account that results from the interpretative phenomenological analytic process is consequently considered to be a co-construction between participants and researcher (Osborne and Smith, 1998). In contrast to quantitative research, the open acknowledgement of the influential role of the researcher is held as a particular strength of IPA. This differs significantly to positivist approaches where neutrality and objectivity are desired qualities and subjectivity is perceived as compromising both the research project and the research process (Sciarra, 1999).

As the aim of IPA methodology is to encourage participants to share their views in their own words (Smith, Osborn and Flowers, 1997), the information is obtained using semi-structured interviews, which are transcribed verbatim. Themes are identified that are considered to summarise the core meaning within the transcripts and these are then discussed in relation to the relevant existing literature. This study was concerned with elucidating how people whose child has been diagnosed with cancer understand and represent that experience. IPA’s commitment to drawing out and making sense of an individual’s experience was considered highly relevant in achieving this aim. In addition, the anticipated role of the researcher in actively supporting the participants to reflect upon and articulate their experiences was incorporated and acknowledged by IPA’s explicit recognition of the resultant accounts being co-produced by the researcher as well as the participant.
3.2 Instruments used in the study

3.2.1 Construction of the interview schedule

Smith (1995) argues that the use of semi-structure interviews as opposed to more formal structured interviews facilitates rapport building and affords the researcher the flexibility to follow the participant’s thoughts and ideas; thus ultimately producing richer data. In terms of constructing the semi-structured interview, the existing literature was consulted in fields such as paediatric oncology, chronic childhood illness as well as general qualitative research to identify broadly relevant subjects (Appendix II). The questions were structured to avoid jargon, to ensure that they were neutral and open-ended and that they followed a logical order.

Four main topics made up the semi-structured interview:
1. Knowledge and beliefs about the child’s illness
2. Effects of the illness and the family’s coping strategies
3. Treatment and service provision
4. Hopes and fears for the future.

The interview began with general questions about the family and the child’s early history essentially to foster engagement between researcher and participant. More complex and emotionally demanding questions such as the quality of their child’s treatment and the family’s plans for the future were placed towards the end of the interview. The questions outlined in the schedule were intended to guide the researcher during the interview and the actual wording of each question was assimilated into the discussion between the researcher and participant. In using the interview schedule in this way the researcher retained significant flexibility to explore each participant’s beliefs about their child’s illness and was thus able to facilitate his/her expression of their individual experiences and their understanding of that.

3.2.2 Piloting the interview schedule

The interview schedule was piloted on one white and one Asian parent who met all of the research criteria as outlined in sections 3.3.4. Following feedback from both these parents and professionals involved in advising on the research study (Dr. Edwards and Ms. Patel) it was considered unnecessary to make alterations to the interview schedule. Moreover, as research procedures were fully adhered to, both of these interviews were included in the final analysis.
3.3 The sample

3.3.1 Demographic data
Twenty-nine parents were originally approached whose ethnic origin were white British and British South Asian. Four white and three Asian parents declined participation citing reasons such as family and work commitments or stating that they did not wish to talk about their child’s illness.

Of the participants who agreed to take part in the study there were three white fathers and seven white mothers whose ages ranged from 32 years to 45 years (mean age of 38.4 years, s.d. = 4.99). Within this group there were three married couples. The four remaining female participants were married and living with their spouses but their husbands did not participate in the study. Within the South Asian group there were four fathers and six mothers whose ages ranged from 34 years to 51 years (mean age of 41.7 years, s.d. = 6.63). None of the ten Asian respondents were married to one another although all reported living with their spouses. All of the South Asian participants stated that they spoke English as a second language and every interview was conducted in English.

With the exception of two Asian fathers who were unemployed, white and Asian participants reported being either full-time mothers, self-employed or professionals.

3.3.2 Sampling method
In accordance with the principles of IPA participants were not selected to be representatives of any particular sub-population or expected to speak on behalf of experiences other than their own. Instead, they were selected according to certain shared characteristics which permitted ‘specific instantiations of the psychological experience’ (Osborn and Smith, 1998, p. 68) for the phenomena under investigation. Hence the sample was heterogeneous with respect to the age of the children and the type of cancer, the rationale being that the main variable under investigation was the parental experience from a cultural perspective.

3.3.3 Source of the sample
Participants were recruited from the Paediatric Oncology unit of a specialist oncology hospital by conducting a search of the paediatric medical records to identify all children who were three-months post-diagnosis and had received or were receiving in-patient treatment. The named nurse of each child identified was contacted to discuss initial contact with the family for the research purpose.
3.3.4 Inclusion criteria

Eligibility criteria for entry to the study were as follows:

1. Participants who understood the aims, purpose and method of the study.
2. Participants who gave written consent to the study.
3. Participants who were either British white or whose cultural heritage originated from South Asia (specifically, India or Pakistan).
4. Participants who were able to understand and speak English, Urdu or Punjabi.
5. The patient was diagnosed at least three months previously with a first incidence of cancer. The methodology relies on a high degree of 'richness and complexity' in the interview material; thus it is important that the events surrounding the child's illness were reasonably recent in the minds of the parents. However, asking parents to engage in such a discussion, immediately following such a diagnosis was considered to be unethical and possibly result in further trauma and distress for participants.
6. Participants were to be the main primary caregivers to the patient, related either genetically or legally recognised as the parent.
7. When there were both parents in a family they were to be invited to participate in the interviews separately.

3.3.5 Ethical approval

The proposal outlining the main aims, objectives and methods in the study, accompanied by copies of the interview schedule, letter to participants, information sheet, consent form and letter to participant's GP were submitted to the hospital's Trust research and ethics committee (Appendices II, III, IV, V, VI). The Committee's letter of approval can be found in Appendix I.

3.4 Procedure

3.4.1 Recruitment of participants and informed consent

An initial letter was sent to parents giving brief details of the purpose of the study, an indication of the level of commitment and the fact that the interview would be audio-taped. The voluntary nature of their participation was emphasised. This letter was followed by a telephone call approximately one week later in order that the study could be fully explained verbally and so that parents were given the opportunity to ask questions, express any concerns and on that basis to agree or refuse to become involved. Written and verbal reassurances were given in all cases that whether or not they agreed to participate would not affect the treatment that their child received and that they could change their minds about speaking to the researcher at any time without giving a reason. Appointments to conduct the interview were
arranged with those parents who gave initial verbal consent and participants chose whether the interview was conducted at the hospital or at their own home. Immediately prior to the interview an information sheet was given. Written informed consent was then obtained and this was repeated at the completion of the interview (Appendix V). A letter was also sent to the participant’s GP advising them of the patient’s participation (Appendix VI).

3.4.2 Interview Procedure

Following consent, participants completed a short questionnaire to obtain demographic information. The interview began with a short reminder of the procedures outlined in the participant information sheet and followed the general format outlined in the interview schedule (Appendix II). All participants were also reminded that they were free to stop the interview at any time or to withdraw from the study completely if they decided that they no longer wished to continue. A tape-recorder was switched on at the start of the interview. A flexible and sensitive approach was adopted according to the context of the interview, the individual style of the participant and to encourage the free expression of each participant’s individual experiences. On completion of the interview, the researcher addressed any outstanding questions and re-obtained consent to use the material. Interviews ranged from 55 minutes to over 2 hours and all tapes were transcribed verbatim, coded to ensure anonymity and stored in a locked drawer at the researcher’s home. The participants were advised that the audio-tapes would be erased on completion of the study.

3.4.3 Data Analysis

Smith et al’s (1999) description for conducting IPA was adapted for the purposes of this study (see Appendix VII for an example transcript). All the interviews were transcribed (half by the researcher and the other half by two medical secretaries) and read by the researcher. One interview transcript was then examined in detail during which patterns of interests and significance to the research topic were noted. The development of preliminary themes was refined until they seemed to summarise the essential elements of the participant’s account of his or her experience; moreover, supporting evidence from the transcript text was identified for each theme.

The above steps were repeated with each transcript and the individual theme lists were consolidated to create a list of super-ordinate themes. Accompanying extracts of text from the transcripts were simultaneously noted to allow the analysis to remain grounded in the words of the participants. Furthermore, the analysis process was deliberately kept separate for the two ethnic groups so that an idiographic analytic approach could be feasibly adopted. This
approach is usually considered appropriate for studies of approximately 10 participants because of the requirement for the researcher to hold in mind the emergent themes (Smith et al, 1999).

After the themes had been identified and organised to provide a consistent and meaningful account of the experiences relayed, they were considered in relation to the literature.

3.4.4 Validity and reliability
There is currently an on-going debate with respect to the reliability and validity of qualitative methodology (e.g. Turpin et al, 1999, Elliott et al, 1999, Yardley, 2000) especially as such methods are now frequently being used in clinical and health service research. Merrick (1999) argues that research concepts stemming from a positivist paradigm cannot easily be transferred to qualitative research. Others take the view that it is possible to delineate criteria for assessing the quality of qualitative research which parallel the traditional evaluative criteria used in quantitative research (e.g. Lincoln and Guba (1985) cited in Merrick, 1999).

Having recently reviewed the literature Elliott, Fischer and Rennie (1999) have developed guidelines and principles that identify standards of good practice for evaluating qualitative research. These were used to address the issues of reliability and validity in the present study and are outlined as follows:

1. **Owning one's perspective**
Elliott et al (1999) argue that qualitative researchers should recognise their own values and assumptions in communicating their understanding of the phenomenon under study. Thus, the author acknowledges that she is herself an Asian female, born and educated in Britain and who has experienced the death of two close friends, one white and one Asian, from cancer. She has no children.

The lack of literature in this field illustrates that the experiences of parents of children with cancer particularly those from an ethnic origin outside the indigenous white culture are only superficially understood (Cook-Gotay, 1995). In undertaking this project the researcher hoped to demonstrate that although there are likely to be similarities between the two groups of parents there may also be important differences that may contribute to enhanced understanding of differing perspectives and to service provision.
2. **Situating the sample**
This describes the research participants so that the range of persons and situations to which the findings might be relevant can be judged.

3. **Grounding in examples**
Examples of the raw data are provided to illustrate the analytic procedure.

4. **Providing credibility checks**
As an independent check of the derived themes another clinical psychologist read three transcripts. The psychologist agreed with the themes originally elicited by the researcher and suggested some new themes, which were discussed and incorporated into the analysis. However, the aim of this exercise was not to reach consensus and identify a definitive account of the participant’s texts but to validate the researcher’s interpretation of the data and to ensure that the theme was represented in the extract provided.

5. **Coherence**
The study is presented in a structured, coherent format and any contradictions between themes or with the literature noted and discussed.

6. **Accomplishing general versus specific research tasks**
The present findings are acknowledged to be limited to these two particular groups of parents and illustrate how they conceptualise their experiences of their child having cancer. They aim to provide information that contributes to the scientific literature in the general field of paediatric psycho-oncology but is not intended to be representative of this population as a whole.

7. **Resonating with readers**
The author tried to present the findings of the study so that they accurately captured the participant’s beliefs about their experience of their child’s illness and enabled readers to broaden their understanding of this area.
4. Results

4.1 Analyses

4.1.1 Overview

Participants spoke about a range of issues including the impact of their child’s diagnosis, making difficult treatment choices, support or the lack of and the influence of cultural beliefs. The analysis focused on the themes that emerged from the interviews which seemed most pertinent to the parental experiences. White and Asian interviews were analysed separately but on the whole they are presented and discussed as if they were one cohort because of the high degree of similarity in the themes that emerged. Comparisons between the two ethnic groups were made specifically in the context of the super-ordinate theme of the influence of culture.

4.1.2 Interpreting the data

A number of factors informed the interpretation process. Firstly, the interpretation of individual extracts was informed by the reading of the whole of each transcript. Ambiguities were addressed by searching individual transcripts for additional clarifying material.

The length of interviews varied according to the extent to which participants required prompting questions and/or became distressed during the interview. This may in turn have influenced the content and the number of themes available in individual interviews. The author strived to remain aware of the influence of her own knowledge, beliefs, personal experiences and cultural position.

4.1.3 Presentation of themes

Four super-ordinate emerged through the analysis: (1) the complexity of a severe childhood illness, (2) the application of medical knowledge, (3) accessing support from different systems and (4) the influence of culture. Within each of these were further subordinate themes that encapsulated the experiences and perspectives of the participants. A detailed discussion of these themes is presented which incorporates verbatim extracts from the transcripts to define and illustrate the themes. Pseudonyms were assigned to each participant and their family members to ensure confidentiality.
4.2 THEME 1: The complexity of a severe childhood illness
Each transcript demonstrated the complexity and multiplicity of issues involved when a child is diagnosed with a serious illness. These incorporated factors such as the difficulty of the diagnostic process, the initial impact of the diagnosis on parents as well as a subsequent impact when parents began to reflect on the implications of their child’s illness. Figure 2 summarises these sub-ordinate themes.

Figure 2: Themes within the super-ordinate theme of the complexity of a severe childhood illness

4.2.1 Process of diagnosis
 Difficulty of the diagnostic process
Parents seemed to accept that reaching a diagnosis could be a long and distressing process. Children presented with symptoms that seemed innocuous, such as bruises or changes in appetite. Furthermore, symptoms could have a very gradual onset making it more difficult for the parent to report a history or pattern to the physician. Mr. Brown, a father of a six-year old girl with leukaemia commented that his daughter had numerous bouts of illness before he became particularly concerned:

_AH_ Okay, can you tell me a little more about how Lily came to be diagnosed with cancer?
_Mr. Brown_ ...she was ill and took a couple of weeks of school with a flu type thing which... was no great concern. Then, New Years Eve, she again was not well...she was then ill for a couple of weeks...about that time she got a rash under her chin which we took her to the Dr’s and the Dr gave her a course of antibiotics and it finally cleared...

_AH_ How long did that take...?
_Mr. Brown_ Erm...I can’t remember if it was three or four weeks but it was quite a long time...
(Mr. Brown: Lines 21-28)
Parental experiences of not being treated seriously

Only a few parents believed that health professionals treated them seriously when they first noticed and reported their child's symptoms. In general, parents reported having to make numerous trips to their GPs and facing further ambivalence when they reached hospital departments. Mrs. Hussain, a mother of a five-year old girl with a rare brain tumour describes her frustration at trying to convince doctors that something was seriously wrong with her daughter:

Mrs. Hussain And then I went to hospital and they said uh she's...they said oh she has had chicken pox and maybe she is feeling better... she was uh with her daddy and then he went to GP...Same thing he said oh she has had chicken pox maybe she is getting better...Um so the last one I went to ... he didn't notice ... he said ...oh you are everytime worry you know .... children get better..this and that... you know ...and then this lady one I went...

AH Um...
Mrs. Hussain And... she examined her and she said Mrs. Hussain there is nothing problem I can see... and I said okay you are my Doctor uh can I ask you something... can you... walking her you know in this corridor... and then you can find out maybe something because I feel something wrong with Saira... and then she noticed and she said okay and she a few times you know walking with Saira and she said uh she said... I saw her face you know... something she feel something...

(Mrs. Hussain: Lines 96-140)

Despite parents acknowledging the complexity of diagnosing a child with a malignancy, they maintained that their overall experience of professionals was of scepticism and dismissal. Moreover, Asian and white parents who shared such experiences seemed to harbour feelings of anger and frustration which were still apparent at the time of interview. Mrs. Baker, a mother of a seven-year old girl with leukaemia, provides an example of the depth and intensity of her feelings that was echoed in other transcripts:

Mrs. Baker ... I mean I know he retired subsequently and sometimes I see him in the street and ...I couldn't give him the time of day...

AH How did you feel at the time...or now?
Mrs. Baker Well I'm angry...because he failed to take note which he should have done...I mean she was really ill at that point...it was obvious to everybody ... and I'm still angry and I'll never forgive him...

(Mrs. Baker: Lines 72-77)

4.2.2 Initial impact

Emotional impact

When parents described their initial feelings at the time of diagnosis a range of responses were typically expressed. Once their child's diagnosis was confirmed parents described their immediate response as being one of relief. The acknowledgement of a serious problem was not only a vindication of their concern for their child but was also construed as a step towards treatment. Like the two parents above, Mrs. Adams also had a difficult experience of the
diagnostic process. She described her relief embedded in a range of other emotions when Tony’s condition was eventually clarified:

Mrs. Adams  Thank God they found it ...oh my God! Shit! This is my baby! Panic...I’m shaky now... I’m there and I can see it all. We had to wait about an hour for the ambulance and then they rushed us to AM...sirens flashing...everything...and poor Tony... and I was having to hold my stomach...and I remember I kept saying I knew it...I knew it...in my heart of hearts I knew it...
(Mrs. Adams: Lines 122-143)

Unsurprisingly every parent indicated that their child's cancer was the most overwhelming experience in their life. Indeed, there was not a single parent who was not visibly distressed at some point during the interview epitomising the powerful emotional impact of childhood cancer. Repeatedly in the interviews parents talked about the shock that they felt coupled with their immediate understanding of the worst implication of the diagnosis. For Mrs. Bashir, a mother of a three-year old girl with leukaemia, such a diagnosis was catastrophic:

Mrs. Bashir  The minute she said it I just looked at her face... as if I had just gone dumbfounded and I said I don’t know what it means and the next minute I said to her 'I know what it means' so it obviously must be the shock that did it to me ... at that time all I knew is that it was cancer end of story. I really thought she was going to die and basically there is no cure for it.
(Mrs. Bashir: Lines 241-245)

And for Mrs. Ali, the mother of an eleven-year old boy with leukaemia, such was the emotional impact of the knowledge that her son had leukaemia that another unfortunate consequence was physical damage to herself:

A H  ...Can you recall what the atmosphere was like...?
Mrs. Ali  Well everyone was very upset...in fact I was so upset when they told us that I fainted...I broke my arm from falling when I fainted ...because when they told us I couldn’t bear it...
(Mrs. Ali: Lines 33-37)

Disbelief at the diagnosis was a common reaction and this seemed to be compounded as the reality of the diagnosis and treatment sunk in. Parents seemed bewildered and would point to the lack of cancer in the family history. This and never having considered that children could also get cancer reinforced parental feelings of disbelief as poignantly evidenced by Mrs. Adams:

Mrs. Adams  Then I thought cancer... in someone so little ...I kept looking at Tony and thinking cancer you can’t have it ...you’re too young to have it... And no-one in my immediate family has got cancer... I’d never met any children who’d had cancer...[...] And then we went to the RM and initially I felt sick ...you know there were all these children and they were so poorly ...I had no idea that there was a life like that ...
(Mrs. Adams: Lines 146-185)


**Looking for meaning**

Virtually every parent had asked themselves the question ‘why my child?’ Some tried to rationalise this by saying that they could understand an adult developing a life threatening illness but could not cope with the idea of their child having such an illness. Mr. Patel, the father of a twelve-year old boy with sarcoma admitted his despair and anger:

> Mr. Patel That’s what was burning me at the time was that in an adult it’s different...he’s only ten and I couldn’t take it...why should this happen to my son...?

(Mr. Patel: Lines 272-274)

Similarly, parents also asked what had caused cancer in their child and ruminated about whether they could have prevented the illness. Ultimately this resulted in an enduring sense of anxiety. Mrs. Kaur, whose fourteen-year old daughter, Shakti had a brain tumour, could only wonder as to why her daughter had developed this and was aware that she had no answers while remaining very distressed:

> AH ... I mean have you any ideas what might have caused it?
> Mrs. Kaur There’s no answer ...I have no answer.... (cries)...but...they explained that the blood and the cells...but I don’t know...and we just think...family... that one day she will be better ....(pause)...(cries)

(Mrs. Kaur: Lines 205-210)

One exception was Mr. Brown who had a sound knowledge of factors that might contribute to the risk of getting cancer but he did not think it necessarily a useful endeavour to search for a reason or cause:

> AH ... what ... might have caused this illness...can you attribute a cause to it?
> Mr. Brown I can’t...No, I can’t...You hear ... so many things that might be linked... I’m fairly pragmatic in the sense that I say yes it’s a chance that a few children will get it...it happens...I’m not looking for somebody to blame (laughs) ... There maybe a genetic cause, it’s possible, there may be an environmental factor ... but I don’t know what it is and I’m not going to search for it and try to find it...it’s highly unlikely to help anybody else...

(Mr. Brown: Lines 72-82)

**Self-blame and guilt**

Many of the parents experienced feelings of guilt and soul-searched whether they could be responsible for their child’s cancer. Mrs. Hampton, a mother of a six-year old with a rare bone sarcoma implied that her feelings of guilt persisted despite reassurances from the oncology consultant:
Mrs. Hampton, you wonder... I thought did he fall down, did he bump his head... did I not know?... every child falls down and bumps their head you know... you just sort of think you know I should have seen it earlier...

AH and what did Emma (consultant) say about it?

Mrs. Hampton No... she said that nothing you could have done differently, that would have caused it and not caused it, it just one of those things... but still...

(Mrs. Hampton: Lines 183-190)

4.2.3 Reflecting on the implications of their child's illness

Re-framing the initial impact of diagnosis

Following the initial impact and as parents obtained more information about their child's condition, they described experiencing a secondary process where they began to reflect on the implications of the diagnosis. This contained elements of fear for the future as well as optimism that medicine would provide a cure. In describing his initial emotions Mr. Patel spontaneously went on to talk about how his feelings evolved once he started to read about cancer:

Mr. Patel Erm... I've started reading more about cancer, but my fears seem to have disappeared now... at least more than before... because I'm more informed. Earlier, I thought, 'ok that's it... no more life after that...' but now to me it's like a casual thing... yes he's ill but we're going along with that... so because I've educated myself about it I've come to realise that it might not be the end of the road...

(Mr. Patel: Lines 262-265)

Mrs. Kaur described her and her family's initial fear about Shakti's prognosis, which then subsided as a result of the confidence of the doctors and the subsequent success of the operation:

Mrs. Kaur When the doctor told her... and she was so crying and she was upset all day... It was upsetting but we reckoned that she would be all right... because they give us this promise that afterwards she would be all right... and err... then she was all right... walking and talking... err...

AH So the operation was successful?

Mrs. Kaur Yes!

(Mrs. Kaur: Lines 48-53)

Coming to terms with the diagnosis

The initial feeling of disbelief recurred at various stages, particularly when parents were either informed of or saw some of the side effects of treatment. This was most evident in the transcripts of those parents whose child either had a rare type of cancer or where there were complications in the treatment. Moreover, it evoked such a sense of suspended reality that it seemed to the researcher to stem from the parent's realisation that their child had something that was both dangerous and uncontrollable. This is epitomised in a comment made by Mrs. Smith, the mother of a seven-year old girl with a brain tumour:
Mrs. Smith: After the operation... Sally could do nothing... They put her in this chair and it was a wheelchair... And I suddenly thought what on earth has happened? What? I just could not take it in. Just could not believe that this was my daughter, err... All the things that they were beginning to put in place for when we came home, like a wheelchair and everything like that... and I would think, 'no this is Sally they are talking about... she's not going to need a wheelchair... she's not going to need any of this'...

(Mrs. Smith: Lines 217-224)

Most parents wanted statistical information about the probability of their child's survival. Parents who received the news that their child had a good prognosis inevitably felt relieved, despite having the enduring worry of the risk of relapse. However, parents given relatively bad news dealt with the information in a much more complex manner. For example, Mr. and Mrs. Flowers had very different ways of interpreting and understanding the information that their son, Thomas, had a poor life-time probability of survival. Mr. Flowers understood probability theory but rejected it as a useless tool:

Mr. Flowers: ... so they've given him a 30-40% chance of not making it...

AH What does that mean to you...?

Mr. Flowers: Basically, it doesn't mean anything to me... it just means that it's a percentage... you're either meant to live or you're not meant to live... so he's either in one category or the other... and that's just the way it is... I mean it wasn't important for me to know...

(Mr. Flowers: Lines 110-125)

Mrs. Flowers: despite wanting and seeking answers actually found the harsh reality of her son's prognosis extremely difficult to deal with:

Mrs. Flowers: ... Because Thomas's prognosis isn't very good... and I wanted to know what the prognosis was... and then he... Adam (Consultant)... said 30% chance of recovery... and that was very, very upsetting... I mean I was absolutely devastated... and for me I really thought it meant he was going to die... I just took it very badly, even though I know that I asked the question and I wanted to know the answer I got quite a jolt... because I think I thought they were going to tell me that it would be the standard 75% that children get through...

(Mrs. Flowers: Lines 215-223)

Parents seemed to accept that doctors could not give them guarantees about their child's health but this sometimes led to parents reaching extreme conclusions. It seemed to the researcher that when parents were uncertain that they had all the information available from the medical team this could result in increased ruminations and anxiety about their child's condition. For instance, Mr. Kumar, father of six-year old Anjula with Ewing's sarcoma, clearly demonstrates in his comment that he thought his daughter's cancer to be different and perhaps more serious than other children's:
Mr. Kumar...firstly you want to know what's the chance of my child recovering...but the doctor's won't always tell you that...if somebody comes in with this kind of cancer they're not gonna tell you what their chances are...but then I did think that that wasn't a good sign...I know certain children that had been through that stage and had been told that they had a good chance but they never said that to Anjula because there wasn't a good chance...she was really ill...
(Mr. Kumar: Lines 362-371)

4.3 THEME 2: The application of medical knowledge

This theme related to dealing pragmatically with the information that a child had cancer. As part of this process parents seemed to become involved in a symbiotic relationship with health professionals to ensure that their child had the best possible survival chance. Ultimately, this involved the application of medical knowledge to provide the most effective intervention. Figure 3 provides a diagrammatic summary of the sub-ordinate themes that emerged from the transcripts.

Figure 3: Themes within the super-ordinate theme of application of medical knowledge

4.3.1 The nature of the treatment

In almost every case the parents reported that treatment started immediately after they were told the diagnosis. Often the urgency of the situation meant that parents rarely had an opportunity to assimilate or process much of what they were told. Furthermore, although the treatment process provided initial reassurance that something was being done to alleviate the child's symptoms, on the whole parental experiences of it were ambivalent.
Handing responsibility of care over to others

Parents reported that even whilst coming to terms with a devastating diagnosis they were then unprepared for the difficult nature of the treatment and handing over responsibility of the care of their child to a medical team. A typical dilemma would be parents torn between standing back during invasive treatment while simultaneously wanting to be with and reassure their ill child. Mrs. Baker seemed aware of this conflict:

Mrs. Baker ...they had to put a line in which was extremely distressing ... and she fought and screamed and they had to sedate her ...and there were loads of doctors and nurses and they were trying to hold her down...and I've never left her but in the end I just had to let go and walk out...because I couldn’t bear it...I mean she was sedated but she was fighting...
(Mrs. Baker: Lines 73-78)

Parents stated that even though they were given reasonably clear accounts of the treatment protocol this did not necessarily prepare them for the reality of treatment. Moreover, the onset of treatment seemed to only temporarily reassure parents and was often followed by the development of new fears as illustrated in the following extract by Mrs. Hussain:

Mrs. Hussain ...and she needs radiotherapy and the side effects of radiotherapy are, I know are so bad...And now still...But still she is not feeling um well. She had um... urine infection... And a eating problem ... and I explained to them that ... so far its two, two months since they stopped... nearly two months.

AH The radiotherapy stopped two months ago?
Mrs. Hussain Stopped but she is still the same and is not getting better ...And um the radiotherapy went on for two months...but I am not happy...no I am not happy because she had a lot of problems...
(Mrs. Hussain: Lines 291-311)

Learning about cancer treatment

In fact the new lexicon of drugs, surgery, bone marrow transplants and fast-moving, complex medical technology that parents had to cope with sometimes negated the reassurance that they were seeking from the treatment process. Thus their experience appeared one that was more synonymous with trauma and parents repeatedly used metaphors such as ‘hurdles’ and ‘battles’. Mrs. Flowers, provides a lucid example of the multiplicity of concerns that parents typically described:

Mrs. Flowers you know if you’d never heard of leukaemia to be suddenly thrown in and have to take all this stuff on board...I remember being very fazed by the names of the drugs and them rattling things off ...I was beside myself... and I remember thinking what’s going to happen to him? I mean is his hair going to suddenly fall out ...is he going to just lie in bed flat out, sick and miserable...I just didn’t know what to expect...
(Mrs. Flowers: Lines 231-237)

Mr. Gulbar, father of five-year old Kausar diagnosed with leukaemia, appeared to talk stoically about a complex treatment regime. However, when discussing the reality of seeing
his daughter having lines and portocaths inserted his feelings were more evident from the tone of his voice, his silences between his words and his body language:

Mr. Gulbar  ...first they put the Hickman line...after two or three weeks she got portocath...because the Hickman line got infected ...and all these things were new to us you see...we had never heard of lines or ports...and it was very hard for us...very hard... (sighs) and for her mum...it was very hard...

(Mr. Gulbar: Lines 205-209)

The stress of treatment

Some parents spoke of how the treatment experience perpetuates a sense of isolation and enduring stress for parents. Mrs. Brown, mother of Lily, provided a vivid description of this:

Mrs. Brown  ...It’s probably a generalisation... the nurses and doctors they do this everyday... they must become detached ...I think they’re just so used to it that they don’t realise how it impacts on the family, how upsetting the whole thing is...I mean every time you go there... it’s just so anxiety provoking and just so stressful and you just feel like they don’t ... no-one really understands how difficult it is to live this life...and we just don’t know what’s going to happen and there’s so much uncertainty...

(Mrs. Brown: Lines 112-120)

Related to the previous theme, there also seemed an additional stressor of trying to understand and learn complex medical information about the child’s illness and treatment protocol. This was not a criticism of the oncology department but simply an acknowledgement of the type of indirect pressure parents’ experience. Mrs. Baker’s comment is typical of the type of remark parents made:

Mrs. Baker  it was an awful lot of information to take in at once... which you did want and all the information was extremely positive...which obviously helped...but an awful lot to take on...

(Mrs. Baker: Lines 76-77)

All of the parents reported that the hospital encouraged them to talk candidly with their child about the illness and treatment and on the whole parents themselves gauged how much information to give. However, in a minority of cases parents reported experiences where they believed that staff disclosed too much information in front of the child. For Mrs. Hampton being told that six-year old Mark might have facial disfigurement after radiotherapy was difficult enough for her to hear but her son’s reaction of terror resulted in her (temporarily) suspending the discussion with the professionals involved:
Mrs. Hampton ...these two doctors unfortunately spoke to us but with Mark in the room... and used words that he would understand... and he got a bit edgy ... and when I got him outside the room he just burst into tears. And he said mum I don’t want my face to change...

AH How did you feel about that?

Mrs. Hampton I refused to go back into the room, because it upset him and then I was upset... and ...I felt that I couldn’t help him (cries) ...and Emma (Consultant) did speak to them...we weren’t getting at the doctors we just felt... he didn’t need to know certain things...a child doesn’t understand that he might not grow properly...or that his face might change...

(Mrs. Hampton: Lines 292-327)

The above example demonstrates how parents not only had their own fears to deal with but also the concerns of their child. Mr. Kumar explicitly brought up his experience that the actual treatment initially appeared to make his daughter feel worse followed by the difficulty that he had explaining to her the importance of such seemingly adverse treatment. His views presented in the following extract, were also described by other parents:

Mr. Kumar ...I mean she was surrounded by doctors and nurses ...and she used to cry... Why? Why do you need to do this...? Why do we have to do this...why is my hair falling out? So I had to tell her, you know, that there’s something inside you...tried to explain in a simple way...that they’ve got to give you medicine to make you feel better...but she would say that the medicine was making her worse...

(Mr. Kumar: Lines 271-276)

Mr. Gulbar made a similar point about his daughter relaying that Kausar would vigorously complain about being left in hospital or about her painful treatment. He, also raised the issue of the team giving the child information, but for Mr. Gulbar and his family, this was helpful as it seemed to allay some of Kausar’s fears, facilitate her compliance with the medical regime as well as provide a model for them:

Mr. Gulbar ...first she don’t understand and doctor tells her and said you got something so we need to do this...and then the doctor told us to explain to her in our language... and it was right that they told her because after that we could explain that this medicine will help you with this...because sometimes she don’t want injection and cry ...and sometimes she’d say ‘no I don’t want to stay in hospital’ ...so we could then explain things to her...

(Mr. Gulbar: Lines 49-55)

4.3.2 Working in the dark

Parents stated that they welcomed open communication and without exception, parents paid tribute to the expertise of the paediatric oncology team and their commitment to the care of children. However, some parents admitted being taken aback when professionals conceded to working on an experimental basis. This seemed to reinforce beliefs about the uncontrollability of cancer. Parents coped with this in different ways. Mrs. Smith seemed to accept the fact of the rarity of her daughter’s tumour and that doctors do not always have a framework to follow:
Mrs. Smith ...because we have been on the internet looking for other children with this and we can never actually find this diagnosis... And ... the RM... said that there was nobody in England that we could contact...so it is very rare. And I know that before Sally started chemotherapy, that Henry (consultant) said that there was only 25 children in the whole world that had had chemotherapy as treatment for this type of tumour. So they were working in the dark...

(Mrs. Smith; Lines 340-346)

By contrast, the high level of frankness from the hospital over the issue of experimental treatment seemed to elicit anxiety, anger and a realisation that medicine could not always provide a cure in parents whose children had complicated or unusual treatment regimes. Mrs. Flowers explained that even though she understood that Thomas had a very rare condition it was still difficult to hear vague answers from doctors:

Mrs. Flowers you just can't imagine how you are going to cope ...and that's one of the big problems that I had because everything that they told us was ...they'd say if we had any questions...but then they weren't quite sure because Thomas was the first year that they were going onto the new protocol... and their stock answer would be well we don't really know because this is all new ...and this was very unhelpful to us ... we still didn't get answers...

(Mrs. Flowers: Lines 162-167)

4.3.3 Moving from novice to expert

An important issue for parents was one of comprehending large amounts of medical information about their child’s illness. Understandably, many parents found this information difficult to understand and assimilate. Mr. Flowers, whose son Thomas had a particularly complex form of leukaemia, described researching the condition but his last sentence seems to question the value of investing energy in this way:

Mr. Flowers Erm...when we first got the diagnosis ... I did at that stage go on the internet...and there was so much information ...especially this genory arrangement thing... [...]...it was just beyond me in terms of medical jargon and technical information about just how these genes are arranged ...and to my mind it’s irrelevant...I mean I’ve forgotten it all now everything that I read... (laughs)

(Mr. Flowers: Lines 163-174)

With or without seeking extra information all of the parents discussed learning about and becoming adept at administering medications, cleaning lines, noticing when their child was developing an infection and making reasoned decisions about when to take their child into hospital. In fact parents argued that their level of expertise sometimes seemed to be in stark contrast to staff in local hospitals so that sometimes they would find themselves in the position of advising the latter. A striking example comes from Mrs. Bashir’s transcript:
Mrs. Bashir  Fatima was having a blood transfusion and suddenly the blood was not going in so instead of calling a consultant and shutting it the right way... the blood started clotting so she put it back again and I said to her 'what did you do that for?' And she said 'it was getting elotted' so I said 'what do you think it is going to do now?' The next minute the blood did not go up at all... then the consultant at MD hospital spent two and a half hours of struggling... and every time I saw her face I said 'I am not having this nurse for my child...'

(Mrs. Bashir: Lines 681-687)

Although this type of experience ultimately did give parents a sense of empowerment, it could also result in feelings of frustration not because parents begrudged caring for their child but because they perceived that this was placing them under further pressure.

4.3.4 Hopes and fears for the future

Within the interview schedule there was a section aiming to access parent's perceptions about their family's future. Both in cases where it was spontaneously raised by a parent and in those instances when the researcher posed the question (at the end of the interview), parental responses were thoughtful and candid. Parents seemed clear in their minds that the future contained uncertainty and their discourse on this topic seemed to reflect this ambivalence encompassing fears as well as hopes.

Fears for the future

This theme contains a number of complex issues including mortality, the possibility of relapse and the long-term consequences of the disease and treatment.

Most parents had considered the possibility of their child's death. Although this was always distressful it was also a method by which parents tried to psychologically prepare themselves for such an eventuality, as illustrated by Mrs. Adams:

Mrs. Adams  You know they said to us you know that Tony could die and yet I never ever...just one time I said to my mum...one time I said if we bury him do we bury him with his favourite teddy bear or a substitute bear?... and that was the only time that I ever thought...you know (cries)...that was awful...

(Mrs. Adams: Lines 166-169)

The possibility of this experience seemed so unimaginable to parents that for some the interview was the first time that they had actually disclosed this fear. Mr. Flowers' interpretation to an open question about the future clearly demonstrates his underlying tension and his response was striking because of the many layers of meanings within the extract:
A final question is what are your plans for the future?

Mr. Flowers  ...We’ve not really spoken about what would happen if he dies ...we just know that it would be awful so we don’t speak of that ...erm...I think we would handle it quite differently ...I mean I do think about it ...but I don’t dwell on it ...erm...he’s absolutely fine at the moment... so we’re very happy about that ...erm...but plans for the future is just to carry on as normal for the moment...and if things change then we’ll have to re-assess that obviously...

(Mr. Flowers: Lines 354-363)

For some parents the fact that their child’s disease was in remission or even ‘cured’ did not subside their fear of the disease returning and this hindered their ability to completely relax as explained by Mr. Kumar:

Mr. Kumar  ...well they don’t guarantee your child’s health and so even when the cancer is gone it’s still always in your mind ...when she complains of chest pains you always think the worst ...

(Mr. Kumar: Lines 347-348)

Another major area of concern parents cited related to the uncertain nature of their child’s future because of the long-term consequences of medical intervention. Parents explained that treatment was seldom a finite process and the repercussions of invasive medical interventions would mean continued trips to out-patient departments over several years. For parents this implied that there was little escape from the spectre of cancer and as Mrs. Brown’s reflections demonstrate much to worry about:

Mrs. Brown  ... but the outcome, there isn’t... you still don’t know, you still don’t know if after five years or ten years whether it will come back. So it’s difficult really, I don’t know what to tell you...

AH  I was just, you know, checking out if you had started to think about that...

Mrs. Brown  I think a lot about her future and I worry about it, I worry, about the jobs, about going through school, about her hair the way it is...I don’t know I could worry myself into an early grave really. I worry about it but I also think lets get there and then worry about it cos otherwise I could worry about nothing...

(Mrs. Brown: Lines 541-548)

Hopes for the future

Despite these fears most of the interviews closed on an optimistic note. Parents seemed determined to continue to battle against their child’s disease, resume normality in their family life and, most importantly, maintain hope.

Many parents talked about a change in their philosophy on life. They explained that this experience had reminded them of the fragility of life and one consequence was a re-appraisal of how they lived their life. Mrs. Smith poignantly describes this:
Mrs. Smith ...when the children would say 'mum can we do this?' it used to be 'yes in a minute, I just have to get this done...'. Now she says 'mum can we...?' and its 'Yep, come-on then lets do it...'. It's completely re-prioritising. And nothing is as important as the family and particularly children. [...] And I do that for myself as well...I enjoy giving them and myself this different way of things...like now when Sally goes to bed I'll read her the Harry Potter books and I enjoy them as much as she does...

(Mrs. Smith: Lines 632-644)

By shifting personal and parental lifestyles and by accepting future uncertainty participants talked enthusiastically about less planning and more acts of spontaneity. Mrs. Hampton's ambitions for her children were now simple:

_AH_ my last question is well... what are your plans for the future...?

Mrs. Hampton Just to live...to make Chris live... and for us and Chris to do all the things that we want to do...anything he wants to do... he's very arty...not academic (laughs) but he's still young! Definitely arty...he loves drawing and things like that...sporty...typical boy! And I'm not going to stop him doing anything ...

(Mrs. Hampton: Lines 473-480)

Indeed, the longing for normality hinted at in the above extract was strongly evident in other transcripts. This seemed to be at the crux of parental aspirations for the future as eloquently stated by Mrs. Rahman:

Mrs. Rahman We just try to be as normal as possible and I think we've put it behind us now... we used to be very concerned but now we get on with our lives...

(Mr. Rahman: Lines 392-393)

**4.4 THEME 3: Accessing support from different Systems**

When a child becomes seriously ill even the most nuclear of families inevitably encounter and access outside assistance. Moreover, families reported deriving support from a range of sources although not all avenues of support were viewed as positive. The sub-ordinate themes are summarised in Figure 4.
The experience of support from the wider community

The experience of support from other hospitals and the issue of Shared Care

ACCESSING SUPPORT FROM DIFFERENT SYSTEMS

The experience of support from family and friends

4.4.1 Support from family and friends

All of the parents with the exception of one reported accessing support from family and friends. They relayed how this helped them to cope as well as maintain a semblance of normality. However, the pressures of having a chronically ill child also put strains on the marital relationship.

The effect on the marital relationship

The strain of an ill child was frequently reported to have an adverse effect on marital relationships. Although not all parents spoke about this issue those that did admitted that their marital relationship had suffered. Mrs. Baker disclosed that she started to emotionally withdraw from her marriage when her husband made it clear that he could not cope with Annie’s illness. The following extract demonstrates not just her anger towards him but a clear acknowledgement that they were and are unable to support one another:

Mrs. Baker: I don’t know...I mean men don’t cope... I don’t think...he was terribly upset and distressed and then I think I dealt with it...but he didn’t... and I think men...they shut it out...they don’t talk about it to other men...they don’t talk about it to you...as far as I know he didn’t talk about it to anyone...and I just decided that I would deal with it alone and that’s what I did...and I never talked about it with him... and I think if I did...talk to him it would just blow up...so it’s easier to leave it...

(Mrs. Baker: Lines 655-661)

By contrast, Mrs. Adams recognised that whilst at the moment she relies more on her mother for support, she anticipates that she and her husband would be able to return to the good quality of marriage that they had before Tony’s diagnosis:
Mrs. Adams Yeah, it has changed our relationship. Its unfortunate Guy works away so much ... but mum being here has filled that gap ... [and I think we're just waiting for it to end so we can resume a normal life...we put our life on hold ... and I think ... we know it will get back to how it was once Tony finishes treatment .... So I don't think we are too concerned about it...
(Mrs. Adams: Lines 424-439)

Some Asian parents also talked about how the illness had affected their marital relationship describing experiences similar to those of the white participants. Mrs. Mir, whose 4-year old son Amjad has leukaemia, spoke openly of the difficulties that she and her husband had with adjusting to his illness and how this ultimately resulted in marital discord:

Mrs. Mir Yes...we did have our arguments...a lot of arguments...
AH What about?
Mrs. Mir About the way we approached things...I think because we were not having enough time with each other and whatever time we had we were in hospital or with Amjad because, it was interrupting everything... because the initial six months were very crucial, I think we were taking it out on each other, that was our outlet...
(Mrs. Mir: Lines 871-877)

Help from family and friends
Parents acknowledged and welcomed the opportunity to share their difficult experience with close friends and were also grateful for the practical and emotional help that they received. Mr. Razak initially seemed surprised at the researcher for asking an open-ended question about the support that he received from his extended family. His response seemed to suggest that the level of support was nothing less than he expected but his gratitude was still apparent:

AH What about the extended family, how involved are they ...?
Mr. Razak Well, they helped a lot, yes...obviously...they were all here, all my family was here...I was in Pakistan at the time when she was diagnosed, so I left my two boys in Pakistan and came here...and I got tremendous help from my family...you know, everything...for travel everything. I was without pay, as I was working in Pakistan at the time...so it was a very difficult time and so they helped me emotionally and financially as well...
(Mr. Razak: Lines 31-35)

What was somewhat surprising to this researcher, was that this kind of support did not seem to be determined by cultural factors. Mr. Razak’s family in providing financial help might have been interpreted as an example of the strong bonds between members of Asian families. However, the transcripts of white families also contained instances of practical and financial aid alongside emotional support. One example is of Mrs. Smith who paid tribute to her friends and neighbours in organising a charity event as a way of supporting the family:
4.4.2 Support from the wider community

Support from outside the immediate circle of family and friends was also reported to be readily available and in particular parents talked about the support that was put in place for them by employers and schools.

The majority of working parents touched on the fact that they and their partner had worried about taking time off work and the potential financial implications. For many this worry was eased in terms of the pragmatic support of employers who offered paid leave or flexible arrangements such as 'working from home.' Mr. Flowers described his experience of the latter and is a typical experience:

**Mr. Flowers**

Yes...I took quite a bit of time off...work has been very good to me in terms of ...I mean whenever Thomas was in hospital they would allow me to work from home but they knew that I wasn’t doing much work...that I was on the internet or in hospital with him...so I wasn’t really at work...

(Mr. Flowers: Lines 183-188)

Parents also praised the role of schools. For most parents there were two key sources of anxiety about their child returning to school following treatment: an appropriate and safe transition and the possible issue of bullying.

Of the parents who chose to speak of this experience, their evidence suggested that school staff were managing to balance empathy and concern for the child’s illness with resuming the child’s education, and thereby facilitating normalisation. Mr. White seemed to remain surprised at the degree of pro-activity and flexibility that Luke’s school’s demonstrated:

**Mr. White**

But they were very keen to have him at school and ... on whatever basis um...you know if it was an hour ...or a day you know they were quite happy to have him there...And I thought...it must be quite a worry because you know to have responsibility ... a child who looks so pathetically unwell and couldn't move about so... they were really forward thinking ...

(Mr. White: Lines 875-895)

An even greater stressor seemed to be fears about teasing and bullying perhaps because of the child’s absence or because of an altered physical appearance and particularly as a result of hearing accounts from others where such instances had been ineffectively managed. Therefore, when her son, Chris experienced some initial bullying and the school’s response
was both prompt and successful, Mrs. Hampton remained confident of her child remaining in school:

Mrs. Hampton ... the school I must admit have been brilliant, he went through a difficult stage, when he was losing his hair ... but we managed to keep him going to school, and the school talked to the rest of the school and he did have a little bit of bullying and that was dealt with very, very quickly ...  
(Mrs. Hampton: Lines 273-278)

An important avenue of support was from other parents of ill children. Overall, parents found sharing their experiences with, as well as listening to the experiences of other families both supportive and cathartic. For some seeing children and families who were going through more extreme treatment measures helped them to rationalise that perhaps their situation was not so bad, as the following extract illustrates:

Mrs. Hampton I talked to a lot of people in the unit...You listen to them ...and you understand what they’re going through ...but each child, each family have got their own specific worry... we were fortunate that Chris only had a short time in his course of treatment ...and that’s quite hard to take on board ...we were only here for six months and some families have been here years...
(Mrs. Hampton: Lines 254-258)

Interestingly, one couple were clear about not overly engaging with other parents or family support groups. They both raised the issue in their respective interviews that whilst remaining polite they maintained their distance from other families. Underpinning this position was a clear rational: one of self-preservation and reducing the risk of personal vulnerability and grief:

Mrs. White  ... quite early on we went to outpatients ... and there was a mum there with her son and they were both sobbing and ... ‘I said are you all right’ and she said ‘well a little boy that he got quite close to has just died’ ... and I just thought actually you know if I ...get involved with their families and get fond of their kids I don't need another families grief ...to deal with...Because I may have my own ... and why open yourself to vulnerability when you have got enough vulnerability possibly in your own life ...
(Mrs. White: Lines 1214-1236)

4.4.3 Support from the Paediatric Oncology Team

A fundamental source of support was from the paediatric oncology team which manifested itself in a number of different ways. Mr. Gulbar remembered being impressed by the friendliness of the paediatric team:

AH What was it like at the hospital?
Mr. Gulbar They made us feel very welcome...there were no problems at all there...no we had no problem...they welcome us...and they help...they were very helpful...
(Mr. Gulbar: Lines 176-178)
Mr. Patel, a father who had great difficulty coming to terms with his son’s illness talked poignantly about the sensitive way in which he was supported by the Consultant:

---

**AH**  
*I wonder what support at the hospital has been like?*

**Mr. Patel**  
Erm... I mean I think David (Consultant) was very helpful... initially he wasn’t doing anything other than just supporting. It was like having a relative... a brother... we were very touched, yes, by him. Quite a lot of staff were the same sort of people as well...

(Mr. Patel: Lines 244-247)

However, experiences were not always so positive and parents complained when the inherent structure of the paediatric unit seemed to hinder their apparent needs. Examples included restrictions on the use of the play-room and play therapists, parents denied the use of the hospital’s library facilities and the lack of co-ordination of information between departments.

Mrs. Murthi, mother of ten-year old Dippen with Hodgkin’s Lymphoma, had formed an impression that doctors were too busy to talk to her about the specifics of her son’s treatment:

---

**Mrs. Murthi**  
... I check with the nurse and I say I want to talk to the consultant ... and she said 'ok' and I am waiting and waiting for one hour and then ... and he just said ‘ok everything is fine.’... I don’t want to know everything is fine... This morning I said to one of the... doctor’s... I said ‘if you have time will you come after that and talk with me?’ and he said ‘right now I am so busy why don’t you talk with any doctor in my staff,’ you know, I don’t want that type of answer...

(Mrs. Murthi: Lines 420-435)

---

### 4.4.4 Support from other hospitals and the issue of Shared Care

Shared Care is a system where local hospitals take over some aspects of the care of the child but the child is not discharged from the overall care of the oncology Trust. From the perspective of parents Shared Care was arguably the most contentious issue that they raised over the course of the interview and universally parents complained of dissatisfaction with the quality of care that they and their child received within this resource.

Negative comparisons were frequently drawn between the level of expertise at the oncology hospital and that of local hospitals. Most notably parents argued that given a choice they would opt for the entirety of their child’s treatment to be completed at the former despite any inconvenience that might cause. This seemed to suggest that these parents had experiences that had resulted in a lack of trust in the capability of local hospitals to deliver an appropriate treatment service. Mrs. White, a nurse by profession, and who worked at the same hospital that Luke received his Shared Care from was unequivocal in her thoughts:
One of the most frequently cited objections of Shared Care was of staff at local hospitals not demonstrating a clear understanding of paediatric oncology. This seemed to heighten parental tensions that their child’s health could be compromised and in some cases this resulted in a break down in relations between parents and staff. For Mrs. Bashir a lack of basic hygiene at the local hospital, despite her own best efforts, suggested to her that her neutropenic child would be more vulnerable to infection. It also raised the question in her mind of whether local hospitals could reasonably be expected to look after such children:

Mrs. Bashir I mean I did everything that I could to help to make life easy for the hospital as I don’t mind but they have got to really make an effort to understand that your child has an illness which is very critical...and that every time you come to the hospital...if they get some kind of infection they could be there for week...[...] I mean the reason you have to have Shared Care is when a child goes down with an infection a normal hospital can take care of it but I think they just don’t have the facilities to offer for such a sick child...

(Mrs. Bashir: Lines 747-763)

Like Mrs. Bashir, Mrs. Baker also had a negative opinion of the quality of care that her local hospital offered. As a consequence she questioned the very professionalism of staff:

Mrs. Baker ... it was so horrendous the whole experience...by which point you’re so stressed out ... and all you’re thinking is that this should not happen...you know it wouldn’t happen if I was running that ward and ...there’s no excuse for it...I mean the hospital is filthy ... when you’ve got an ill child that has potentially got a life threatening illness...then you don’t want that...I mean they hadn’t got a clue...

(Mrs. Baker: Lines 77-84)

Parents also complained that Shared Care staff seemed to be dismissive of their children’s predicament. Mrs. Brown suggested that this might be due to a lack of understanding about childhood cancer but such was her poor personal experience of Shared Care that she formed an impression that staff simply did not care:

Mrs. Brown ...and then we get thrown into the joys of Shared Care and it was such a shock! ...I was so pissed off with the way that they treated this poor child...you got the distinct impression that they didn’t think leukaemia was that serious anyway...and it was the pits...there was this nurse there and it was clear she didn’t know how to take blood pressure and I could have throttled her! And she kept coming in and complaining ... and I did say to her ‘do you have any idea what we’re going through here...?'

(Mrs. Brown: Lines 528-539)

As a result of such experiences parents argued that there was greater potential for local hospitals to make mistakes. Implicit in this was the question of whether adequate resources
were in place for an effective and safe transition from the RM to local services. Moreover, parents were cynical about the ethos of Shared Care and some stated that they had come to understand it to as a 'cheap option' for the NHS. Mrs. Flower's extract seemed to sum up the frustrations that many parents reported experiencing with this model of care:

Mrs. Flowers...that's what's really so exhausting...I mean I haven't even really said that...I mean I have been so disenchanted with the system...many, many times, you know...mistakes with his treatment, lack of continuity... lack of understanding...lack of care...

(Mrs. Flowers: Lines 1034-1035)

4.5 THEME 4: The influence of Culture

![Diagram](attachment:image.png)

**Figure 5:** Themes within the super-ordinate theme of cultural influences

4.5.1 Faith and the role of prayer

Every Asian parent, without prompting, referred to his/her faith and belief in God as a way of positively coping not just with their child's diagnosis but also with treatment and the uncertainty of the future. This was in contrast to the white participants who tended not to raise the issue of religion at all or discussed it in a manner that suggested ambivalence.

**Prayer**

Asian parents, irrespective of religious denomination, were confident with the idea that prayer could ultimately help their child to achieve good health. Nevertheless, although prayer was a daily routine in the lives of many of the Asian participants this did not mean that western medicine was abandoned. For example, whilst adamant about having a strong faith Mrs. Murthi intended to actively pursue medical intervention:
Mrs. Murthi  ... we believe in religion ... I know God is there and he is helping me ...like he's at the stage they found out, like the doctor told me as well with this particular disease sometimes they don't find out until ... the forth stage ...you are really lucky...and I know God is there but I just don't want to believe like close your eyes and just believe in God. I am not doing that...

(Mrs. Murthi: Lines 208-288)

Mr. Kumar seemed more unswerving about the power of prayer and thought that the responsibility of his daughter's good outcome could be attributed both to medical treatment and a divine entity:

Mr. Kumar  ...and that belief in God has helped...my wife used to pray all day and Anjula was getting better and so that would make her believe more ... I mean I think that it was the doctors that made her better but then it can't not help praying to God ..we think that God decides...helps...it's just a different way of thinking....

(Mr. Kumar: Lines 304-307)

Faith seemed to give parents greater resilience and helped them to face and accept whatever might happen to their child. When told that Parveen faced a poor prognosis, Mr. Razak told the researcher that his immediate response was one of reasserting his faith:

Mr. Razak  And he said your daughter has Lymphoma... and the survival chances are only 30%. So I said 'ok...fine...' I don't know how...but deep in side my heart... I was sure that she was going to be ok...and I said...well I left it to Allah...If she lives she lives and if she dies then she has to go...well everybody has to go...so I just left it to fate...

(Mr. Razak: Lines 63-71)

The use of prayer was not wholly exclusive to Asian parents. Two white parents disclosed that at a time when their despair was the greatest they had briefly looked to a higher force but neither found consolation in this way. Mrs. Adam's extract highlights a qualitative difference in her approach to prayer from the above Asian perspectives:

Mrs. Adams  Well ... we got married in church but I don't go to church... of the things that happened afterwards, I actually, in my head I said, 'if you show yourself to me now God I will believe you forever' and nothing happened, nothing... no pain went... nothing happened and in a way that for me was it...sort of like and since then... I've never prayed to see me through it ...

(Mrs. Adams: Lines 654-667)

**Rejection of superstition**

Asian parents also raised the issue of superstitious beliefs. These seemed to have a cultural rather than religious basis and were raised as an aside to issues such as causation of illness or the use of alternative treatment. Parents reported that they had dismissed ideas such as the Evil Eye or the use of Holy Men as unhelpful and against the teachings of their religion. Mrs. Hussain reported that the question of why Saira had such an aggressive illness was one that she constantly struggled with but rejected any suggestion from community members that it may be due to sin:
Mrs. Hussain ... I don’t think it’s because of anything I did ... you know people say to me like ... lot of Asian people said that maybe she did something wrong and that’s why this illness has come ... or that it was something that I did wrong ... maybe I did a sin and that’s why my children are ... but you know the ... Quran doesn’t say that ...

(Mrs. Hussain: Lines 595-599)

4.5.2 Stigma

Asian parents were wary that reactions from the Asian community could include a stigma of cancer and this worry was a significant cultural difference from the experience of white parents. Asian parents reported being advised by friends and relatives not to generally disclose the child’s illness as it might affect the latter’s future in relation to marriage. Even though many of the Asian participants stated that they dismissed such negative comments it seemed to intensify their distress. Mrs. Kaur’s extract illuminates her anger and incredulity at a close relative’s insensitive suggestion:

Mrs. Kaur you will laugh at this because when Shakti was diagnosed somebody came up to me and said ‘oh don’t tell everything ... what she’s got, don’t forget she’s a girl and she’s got to get married one day.’ Do you know I really felt so hurt and I thought I am more concerned about my daughter living right now ... I don’t care if she is going to get married ... when she asked again I said ‘well if she wants to get married she will get married and if it isn’t to be it wouldn’t be regardless of her illness...’

(Mrs. Kaur: Lines 359-364)

Several Asian parents raised the issue of sterility in relation to the child’s potential for marriage. However, their need for immediate support seemed to ebb their concern about this future problem. By contrast, Mr. Patel informed the researcher that he had never discussed twelve year old Siva’s illness with him or his younger siblings and that he and his wife had not told their Asian relatives or friends or even Siva’s school of his illness. When asked why they maintained such high levels of discretion, Mr. Patel, a middle-class, well-educated and fluent English-speaker gave the following reason:

Mr. Patel Yes that’s right ... yes there’s some stigma ... and my wife she doesn’t want others to look down like ... like future ... Siva’s future ... we have wedding ... marriage proposals ... we don’t want any complications like that. That’s normal way of thinking in our culture ... and in our experience that is something that could happen that people will remember ... and then that’s an added pressure ... and yes, well it was a problem, yes ...

(Mr. Patel: Lines 96-105)
4.5.3 Cultural attitude towards medical staff

The attitude of Asian participants towards doctors and the oncology team seemed qualitatively different from that of white participants. Although all parents were generous in their praise, white parents were more likely to share with the researcher criticism, constructive or otherwise, about elements of service provision. What was different about the Asian participant's attitude was an overwhelming lack of criticism; these participants seemed to want to minimise problems or dissatisfaction and instead focus on their gratitude, respect and high esteem for the hospital. For example, during his interview Mr. Razak repeatedly applauded the oncology team and the hospital in general for his daughter's treatment. The following quote from him is one of several appreciative comments littered throughout his transcript:

Mr. Razak They, that is the hospital were wonderful, you know, I mean I don't have words to describe how they treated me, my family and Parveen...it was tremendous...
(Mr. Razak: Lines 78-80)

Several parents, including Mr. Razak, made direct comparisons with the treatment that they could have expected to receive from their country of origin. This seemed to accentuate their gratitude with remarks such as not being able to expect this quality of medical or social intervention from the health services of either India or Pakistan. Moreover, a final vindication in their mind was the argument that their child's treatment was 'free.' Mrs. Mir's comment appears loaded with hyperbole but typifies the responses of many of the Asian participants on this issue:

Mrs. Mir ... they very kindly provided me with a room as well upstairs. You know, words can't describe it how good they were ... I was speechless honestly. Especially when you look around other parts of the world, this is heaven...you can't get care like this anywhere...I don't think...even if you pay...you know you just cannot compare at all...and I don't think...I hope you don't mind me saying this...you are our own... that our own people wouldn't care like these people care for our children...
(Mrs. Mir: Lines 134-139)
5. Discussion

5.1 Introduction
A summary of the main findings for each theme is presented and then discussed in relation to existing literature on the psychological factors involved in childhood cancer. In line with recommendations for qualitative research, relevant literature is introduced to facilitate the discussion of the study’s findings (Charmaz, 1995). Methodological issues, including the challenges of undertaking research with this particular population are discussed along with the clinical implications of the study and directions for future research.

The themes that emerged from this qualitative study provide some insight into the way parents of different cultures experience a diagnosis of cancer in their child. However, what is most evident from the results was the range of experiences that were more similar than different between white and Asian parents. Indeed, excepting the super-ordinate theme of culture, they could almost be considered as one sample containing the usual breath of individual differences. Certainly, the researcher was struck by the close congruence in the twenty interviews in terms of the general process that parents described undergoing which seemed independent of factors such as socio-economic status, age of child, gender of the parent let alone a complex variable such as culture. One explanation for the lack of difference may be that it is a consequence of the particular characteristics of this population: all of these families were undergoing the experience of a severe childhood illness where there was the real possibility of the death of a child. Ostensibly, cultural influences are important and as the analysis of this study suggests can shape differences in perceptions and attitudes but arguably the quintessential issue for all parents as primary care-givers is one of the long-term health of their child. Essentially, the very fact that the family is facing a crisis of such magnitude means that cultural variables play a relatively less crucial role.

5.2 Summary of findings
5.2.1 The complexity of a severe childhood illness
A range of themes emerged from the transcripts that broadly reflected the complexity of a severe childhood illness and which have a strong congruence with the existing literature. These included discussing their experience of the diagnostic process, the emotional impact of the diagnosis and coming to accept their child’s illness once the initial feelings of shock, anger and guilt had subsided. These experiences compliment the description of the diagnostic phase as being an acute traumatic stressor proposed by Hoekstra-Weebers et al’s (2000) model and
add to it by giving a more complete account of the effects of the illness variable, that is, cancer, on the parental experience of distress.

One of the most frequent and emotive experiences that parents relayed was the perception of not being treated seriously by health professionals and the belief that this contributed to a delay in their child's diagnosis and treatment commencement. Indeed, the difficulty of the diagnostic process and its association with parental dissatisfaction has been documented in previous research for both adult and childhood cancers (for example, Ginzler, Pritchard and Mant, 1993 and Eiser, Parkyn, Havermans and McNinch, 1994). Sloper (1996) argues that a certain degree of delay is unavoidable for childhood cancers, as the symptoms are often varied and non-specific. However, the perception of what constitutes avoidable delay versus non-avoidable delay can differ between professionals and parents. Inherent in this issue is the matter of communication: parents in the present study repeatedly spoke of not being heard or taken seriously, a theme echoed in previous research (Sloper, 1996) and which has implications for parent-professional relationships.

Parental accounts of the immediate impact of the diagnosis upon them contained a plethora of emotions including shock, relief and self-blame resulting in a sense of constant tension and anxiety. Indeed the diagnosis of cancer in one's child is accepted as one of the most severe stressors that parents can experience (Kazak, Meeske, Penati, Barakat, Christakis, Meadows, Casey and Stuber, 1997). Irrespective of time since diagnosis or stage of illness all of the parents in this study appeared to demonstrate signs of residual anxiety when discussing their experiences which is congruent with existing literature that parents can remain both anxious and depressed throughout and following completion of treatment (Eiser, 1998).

White and Asian parents reported that once the diagnosis was confirmed it made clear to them that their child had a serious and potentially life-threatening illness with long-term implications. Most parents then made the follow-up point that the exigencies of cancer and its treatment meant that life for the entire family was governed by the overwhelming repercussions of a severe childhood illness. The suggestion that family life had irrevocably changed is synonymous with the findings of a Dutch study (Enskär, Carlsson, Golsaäter, Hamrin and Kreuger, 1997) where parents spoke of their personal life plans being upset, their private life as a couple diminishing and relationships with all of their children changing.

Underpinning this adaptation to an extreme life event, parents described what seemed to be the initial operation of coping mechanisms. Thus parents relayed the process leading to an
eventual acceptance of their child’s ill status in the period following the cancer diagnosis. This reconciliation to their situation confirms previous findings. For example, Sawyer, Antoniou, Toogood and Rice (1997) in a prospective study of children and parents reported that families cope well despite the stresses of childhood cancer. Other research has raised the possibility that some parents experience symptoms of post-traumatic distress as a longer-term consequence of diagnosis (for example, Kazak et al, 1997) but this issue, whether directly or indirectly, was not raised by any parent in the present study.

5.2.2 The application of knowledge

This super-ordinate theme encompasses parental ideas of the strengths and limitations of current medical knowledge, the application of medicine from a theoretical basis to the reality of intervening with their child and the wide-ranging consequences of that. Specifically, parents discussed the nature of their child’s treatment, their relationship with health professionals at all levels but particularly with respect to treatment, achieving personal expertise about their child’s cancer and as a consequence developing informed views about the future.

Parental descriptions of the slowness of the diagnostic stage can be juxtaposed with those of the immediacy of the commencement of treatment. This seemed to suggest that parents thought that once professionals had established a diagnosis it was then a relatively straightforward matter of applying their medical training to implement an appropriate treatment protocol and cure for their child. However, the application of knowledge in the form of active intervention can carry an unforeseen emotional cost aside from the obvious physical side effects. For instance, one of the most poignant themes parents raised was that of physically and psychologically handing over care of their child to professionals. Parents were aware that the ‘oncology experts’ needed to help the child but at the same time they stated that they found it difficult to cope with their child’s separation anxiety and their own considerable distress. Despite a policy of greater encouragement for parents to be involved in the course of their child’s treatment this seemed to be an enduring source of anxiety for the present two groups of parents. Their experiences emulate a finding in an early review of the childhood cancer literature (Van Dongen-Melman and Sanders-Woudstra, 1986) which reported parental experiences of feeling powerless and incompetent in seeing their child suffer.

A novel finding from this research was the parental perception of not just learning more about cancer but of perceiving themselves as relative ‘experts.’ This is not egocentricity on the part of parents. Greater communication and transparency from health professionals towards
parents were perhaps means by which this might have been facilitated. Moreover, a number of parents relayed that irrespective of the information that they received from the hospital they conducted their own research, predominantly via the internet, for further ‘up-to-date’ information about their child’s diagnosis and treatment. Clearly, one advantage of engaging in such information gathering was that it elicited a sense of empowerment, which seemed to counter-balance the absolute lack of control that parents experienced at the time of diagnosis. Moreover, in a climate where the reputations of health professionals and the NHS are no longer the subject of total trust in the public mind, for some parents this might have served to diffuse fears that information could be being withheld. Nevertheless there are also disadvantages: parents can make the erroneous assumption that the information they possess is more accurate than that of the professionals. This in turn can have negative implications for the parent-professional relationship especially if parents disagree with their consultant’s explanation for a particular treatment course, all of which essentially underlines the complexity of cancer treatment.

Within the context of becoming greater ‘experts’ and the implication that this carries of having knowledge and information, parents reported facing the uncertainty of the future. Many seemed resigned to the fact that they were likely to remain anxious about their child relapsing or even not surviving. Experiences of parents of childhood cancer survivors suggest changes of a definitive and long lasting nature in the parent as a result of the cancer in their child (Van Dongen-Melman, Van Zuuren, Verhulst, 1998). Those authors noted that in spite of the child’s survival, feelings of loss, perseveration and considerable emotional distress persisted and seemed to mark the parents for life. This type of continuing, longer-term stress is recognised in the model proposed by Hoekstraa-Weebers et al (2000). Such a sense of melancholy was present throughout the interviews of parents in the present study but, paradoxically, they also maintained hopes of living a normal life. For the majority of parents making changes to their personal and family philosophy seemed to help them cope with the day-to-day demands of having an ill child (whether the child was in active treatment or remission) and increased their perception that they were managing to achieve a more balanced life.

5.2.3 Accessing support from different Systems
The theme of the child and family as being part of a System is essentially about support. Thus, it acknowledges that the participants in this study live in the context of their families and a wider system that have interaction patterns, rules, organising principles and general belief systems as well as those specifically regarding health (Kazak, Segal-Andrews and
Parents in this study demonstrated that they were adept at accessing support for themselves and their child from a range of sources including family and friends, health professionals, the child's school, their employers and other parents of ill children. They also highlighted areas where they perceived that support was lacking.

The role of social support in promoting well-being in crisis situations is well known (Speechley and Noh, 1992) but it cannot be presumed that such support can always be provided within existing social networks. Although relatives and friends were most often cited as sources of support, a significant number of participants noted the difficulty of providing or gaining support from their spouse, a finding consistent with the view of parents in Sloper's (1996) quantitative childhood cancer study. Indeed, Hoekstra-Weeber et al's (2000) model incorporates the robust positive correlation between marital satisfaction and psychological adjustment.

Most parents discussed the positive support that they both received from and offered to other families in the same situation as themselves but up until recently professionals were reluctant to encourage friendships between families (Eiser, 1998). One parent in this study shrewdly pointed out there are personal risks involved of getting close to families particularly if someone else's child dies, but the majority of parents talked positively of this type of support.

Support from the wider community was greatly appreciated by parents. Although parents admitted having been financially adversely affected as a result of their child's illness they reported that this was despite employers and colleagues providing practical and emotional support. These findings are commensurate with those of Sloper (1996). Absent from the literature has been the role of the school once the child is ready to return to some form of education. In the present study parents paid tribute to the caring response of school staff in actively seeking information about the illness, ensuring the child's safe and appropriate transition back to school and dealing pre-emptively with issues such as informing classroom peers about cancer and preventing bullying.

Generally speaking parents had positive experiences of the support that they received from staff at the RM; this is important as the interaction between patients and families with their health professionals is an aspect of the social nature of the cancer experience (Spencer, Carver and Price, 1998). An area where there was arguably the greatest consensus in terms of lack of support was with the issue of Shared Care. This finding is particularly relevant as it implies that these participants, that is, the Users/Clients of the health service, perceive there to be a
problem with an element of the service that they receive from the NHS. The rationale for Shared Care is ostensibly to relieve the burden of care from a specialist resource. However, as this is a relatively new system of relocating routine procedures and the general care of paediatric oncology patients to local hospitals, a process of auditing and evaluating this service may be warranted. This would be seen to address the parental anxieties raised about the quality of care that they received and also be within the remit of providing an evidence-based service.

5.2.4 The influence of Culture

Up until this point the study has presented the findings of Asian and white parents experiences of their children’s illness in a manner which indicates that there were many similarities. Notwithstanding this, there were key differences in the way in which Asian parents seemed to manage their situation and which differentiated them as a group from the white parents. Sometimes this was in positive terms of being able to draw upon additional resources to those of white parents, for example, having a strong faith and their use of prayer. However, cultural influences seemed to play a less benign role in terms of parents having to deal with stigma and prejudice from their community members about their child’s cancer and also seemed to shape their interactions with health professionals.

Arguably the clearest difference that emerged between the white and Asian parents from the moment of diagnosis was the latter’s faith in an omnipotent force and a belief in the healing power of prayer. These beliefs also seemed to act as a method of coping with their child’s illness. Furthermore, for all of the Asian parents the degree of their religiosity either remained stable or increased even at the most difficult of times of their child’s illness providing a contrast with white parents few of whom mentioned a real belief that a God would or could ease their difficulties. In the literature, the impact of religion and spiritual beliefs on coping with a crisis has very often been overlooked (Levin, 1994) but the few studies that have looked at these variables have suggested that patients report a positive benefit. For example, Baider, Russak, Perry, Kash, Gronert, Fox, Holland, and De-Nour (1999) in a cross-cultural American and Israeli study reported that there was a positive correlation between religious beliefs and an effective coping style in adult Israeli cancer patients that might have a protective function on psychological distress. This kind of finding has patently not been established in the present study but the fact that Asian parents draw on religion and prayer may provide them with a valuable resource with protective implications.
Where white parents did not report the experience of stigma, Asian parents did, and surprisingly, from within their own community. Interestingly, the stigma was not of the cancer per se, but of the future ramifications of it for their child and in particular the ‘marriage prospects’ of the child. Even the most resilient of Asian parents seemed to worry about this issue especially when discussing it in relation to sterility as being one of the long-term implications of cancer treatment.

A final and unexpected difference between the two groups of parents emerged with respect to a tendency for Asian parents to be less likely to express dissatisfaction about the service they received from the oncology centre. Not only were Asian parents loath to express any negative experience but they seemed to want to stress their positive experience. It is possible that Asian parents genuinely did not encounter difficulties but this does not explain why white parents did! Moreover, it contradicts findings from the epidemiological literature that children and young people from minority ethnic groups are more likely to receive a poorer quality of healthcare compared with the white population (Cooper, Smaje and Arber, 1998).

A number of hypotheses could usefully be considered. Firstly, that these particular Asian parents were more likely to minimise difficulties and/or were less inclined to challenge any problems that they did encounter. It may be pertinent that of the ten Asian parents, half drew direct comparisons on the quality of British treatment versus treatment that which their child might have received on the Indian sub-continent as well as making mention of ‘free’ cancer treatment from the NHS. Another hypothesis may be that this is an effect of a positive cultural attitude towards medicine with Asian parents holding health professionals in high esteem so to overtly complain about the service would be considered both disrespectful and ungrateful. A more complex hypothesis might be that is an effect of socio-economic status on culture, particularly as two professional Asian parents did voice concerns about service provision whereas parents of a lower socio-economic status were significantly more muted. Nonetheless, this finding of non-communication of dissatisfaction or criticism is difficult to explain especially given the findings of recent studies looking at consanguinity and childhood disability (Ahmad, Atkin and Chamba, 2000). These authors reported that the experiences of parents in their qualitative studies was one of overall dissatisfaction with the level of information they were given as well as an unhelpful attitude from health professionals. This resulted in parental perceptions that service professionals held racial constructions of disability and chronic illness towards them.
In conclusion, it should be emphasised that on the whole there were more similarities than differences between the experiences of white and Asian parents. Perhaps this is not so surprising given that the experience being researched is childhood cancer, a rare phenomenon, and one that has potentially devastating consequences for the child and his/her family. Conceivably, in such a context where there is the possibility of the death of a child, the impact of the diagnosis and treatment are primary and universal processes for parents and cultural issues, although important, play a relatively less significant role. Nevertheless, culture could usefully be consolidated into the model proposed by Hoekstra-Weebers et al (2000) incorporating an extra dimension to the parental experience of a complex variable having both a protective utility as well as the converse depending upon individual contexts.

5.3 Methodological issues

5.3.1 The impact of the parents experiences upon the researcher

This entire process of this study from its conceptualisation, design, interviews, analysis and writing up was a moving and humbling experience for the researcher. There were a number of reasons for this apart from the subject matter. Firstly, it seemed to the researcher that all of the parents shared their experiences both honestly and openly. As a consequence, the researcher developed an increased sensitivity to the vulnerability of these participants which sometimes resulted in her experiencing a conflict between the roles of researcher, clinician and fellow human being. This was irrespective of the culture of the participant and is probably a reflection of the researcher's private emotional reciprocation of the parent's distress.

The researcher also made the observation that in many of the interviews the parents digressed to talking about subjects that did not directly relate to the main topic. Such flexibility for free discussion was considered necessary, as it seemed to offer a short respite to the otherwise emotive material as well as demonstrating the researcher's empathy and respect for the parents. This in turn seemed to further promote engagement and offered the parents, albeit post hoc, a share in the control of the interview process.

There was an implicit need for the researcher to be aware of the role that she played in the research process as well as reflect on what was said and discussed throughout the research process. One of the most difficult issues for the researcher was the realisation that some of the participant's children might die by the completion of the study. In addition using a qualitative methodology meant that the researcher spent a great deal of time not only interviewing the participants, but listening to their interviews, transcribing them, reflecting upon them and then
re-reading and coding for themes. Thus it was difficult not to be moved by their words, experiences and their very real wishes to be useful to future generations of ill children and families and this, in turn, reinforced the determination to present as comprehensive an account as possible of the experiences relayed.

5.3.2 The impact of theory and the researcher upon the research process
The importance of the impact of theory on the research process needs to be acknowledged. At the start of the study the paediatric oncology, chronic childhood illness as well as general qualitative research served as guides when designing the interview schedule and thus acted as sensitising concepts that influenced the researcher's perspective. As a result, the structure and content of the interviews were informed by these concepts, a process that is acceptable within the framework of IPA (Smith, 1996).

However, in reality, and perhaps as a result of their experience of dealing with health professionals and complex information, it was ultimately the parents who directed the structure and content of the interview with the researcher needing to ask direct questions relatively infrequently. In this way the parent owned their contributions to the discussion and this served to emphasise their personal and individual perspective. Even so, at the analysis stage it was still necessary for the researcher to detach from any pre-conceptions from the psychological literature as well as from her personal experiences of cancer.

5.3.3 The strengths, limitations and challenges of undertaking research with parents of children with cancer

Informed consent
Given the potentially vulnerable and distressed sample of people the procedure of gaining informed consent was particularly rigorous and carefully followed for each participant. Unusually, the ethics body required written consent to be obtained both before and at the end of each interview and this was adhered to. Moreover, the researcher was conscientious of allowing ample time between the initial invitation letter and the follow-up telephone call to ensure that parents did not feel pressured to participate in the research. In addition, participants were encouraged to re-read the information sheet before the start of the interview and to clarify remaining queries about the nature of the study. In this way the researcher attempted to provide safe options for participants to decline participation at any stage; in fact no participant declined. This emphasises the high ethical stance of this study.
Confidentiality
During some of the interviews, particularly after disclosing sensitive or personal experiences, some participants' re-sought reassurances about confidentiality. Participants were then reminded that information would not be disclosed to medical staff without their prior consent and that extracts of their interview might appear in a report and/or presentation but that anonymity would be provided by the use of pseudonyms and by the removal of identifying details.

The interview
A particular challenge in conducting these interviews was of having to gauge the level of parental distress during the interview. No interview was terminated but interviews were suspended either for parents to re-gain their composure or because it seemed inappropriate to continue interviewing at a given moment. One parent however insisted that the recording continue whilst she was upset arguing that this was an aspect that the interview should be capturing.

Related to this is an ethical issue of whether such a study could potentially harm the interviewees or their families. This issue was important to consider not just because it was a concern of the ethics body but also because there was both explicit and implicit criticism about the service from some of the participants. Structures were set in place so that if participants wished to access further support and advice following their interview they would be able to do so from the hospital's Psychological Medicine department. In fact, no participant followed this through; indeed some participants informed the researcher that the interview experience had been cathartic.

Asian participants
There did not appear to the researcher any obvious difference in the quality of the Asian interviews as compared to white interviews. However, the researcher did observe that some Asian participants seemed interested in knowing about her personally, for example, whether she was from the Indian sub-continent and even whether she was married. Kauffman (1994) refers to 'getting in' as the process of gaining, building and maintaining trust with the group under study. This is arguably difficult for any researcher, but in particular, variables such as ethnicity, gender, age and class, which often differentiate the researcher and the participant, pose special problems (Becerra and Zambrana, 1985). It is therefore generally assumed that the more researchers and participants have in common, the greater the potential for understanding the subject of interest. This ethos has been formalised by the concept of
‘matching’ a term used to recognise shared identities between researchers and participants (Weiss, 1977).

In the present research the matching process was a variable that could not be controlled, as there were two culturally diverse groups of people but a sole Asian researcher. The situation might be construed as being complex as the researcher was clearly of a similar general ethnic background to the Asian group but may have been regarded as having less in common with some of the Asian families because of her western presentation. The researcher does not believe that initial engagement was an issue either with the white or Asian parents. Nevertheless, her personal knowledge of Asian social etiquette dictated that she used the relevant cultural greeting when first meeting an Asian parent. In the researcher’s opinion not only did this establish initial rapport but it helped to ease any trepidation or uncertainty on their part. This does not imply that white families were treated differently by the researcher at initial contact; conversely, it emphasises that the researcher tried to ensure that appropriate social rules were followed for both groups of people.

5.3.4 The strengths and limitations of the study

This study has a number of strengths, some of which have already been outlined. In addition, the methodology enabled rich data to be gathered, with findings derived from the participant’s own accounts. Importantly, the sufficiently large sample size allowed saturation of categories to be reached and reflected a broad range of perspectives.

The study recognised the potential vulnerability of parents of children with cancer as well as the sensitivity of the topic that parents were asked to discuss and endeavoured to protect their right to decline participation in this research through a thorough informed consent procedure. Furthermore, the researcher endeavoured to build trust and rapport with all of the parents, enabling them to share their experiences both openly and honestly. As already discussed, although there was a structure to the interview schedule, generally speaking, these participants spoke independently and articulately about the full range of their experiences from specific details of their child’s symptoms to disclosing deeply private information such as marital discord.

On balance, the attention to establishing and maintaining engagement along with the flexible interviewing style facilitated clarification of the parental perspectives and thus allowed the study to achieve its aim. Furthermore a clinical psychologist (of British white origin), who was not involved in the study and thus was not biased or primed in any way, read a sample of
the interviews. She identified similar themes to those that emerged from the researcher's analysis and considered the findings to be a valid interpretation of the parents' discourse.

As with all research there were limitations. In line with most qualitative research it was based on a smaller sample compared to that, which would have been required, using more empirical research methods. The fact that the Asian sample was heterogeneous with respect to the non-differentiation of Pakistanis and Indians does pose a problem in that there are many ways in which they can be considered culturally distinct but this would have necessitated a much larger sample and longer time-frame. It is acknowledged that there was a significant difference between the white and Asian samples as the former was more likely to consist of marital couples. Logistically, it was more difficult to recruit Asian families given that there were significantly less sick Asian children compared to white children. However, the researcher encountered a problem in that Asian participants tended to agree to only one interview within the family stating that their spouses' view and experience was congruent with theirs. Hence, it is theoretically possible that this may have had an impact on the breadth of themes that emerged. Finally, there were no single parents in this study and, for instance, their perception of support might have been different to the present samples' where all of the parents were married.

Despite these shortcomings it is stressed that this study was designed to be of an exploratory nature and to this end it has more that adequately served its purpose of providing a reference point for future research.

5.3.5 Clinical implications and directions for future research

In spite of the heterogeneity both between and within these two samples of parents it was clear that the participants expressed more similar experiences to each other than differences and that relevant experiences appeared commensurate with the existing literature. Given the small sample size, the particular characteristics of these parents and the nature of their experiences the ability to generalise these findings cannot be assumed. Nevertheless, a number of important findings emerged that may be of relevance to professionals working in paediatric oncology as well as general paediatrics.

A complexity of psychosocial concerns emerged, which emphasise the importance of addressing these in service provision. Clearly, the item that raised the most criticism from participants was the issue of Shared Care; it is pertinent because it indirectly resulted in parents feeling unsupported by the 'hospital system.' There is a need to disseminate
information regarding the specific vulnerability of these families to secondary care systems as well as to ensure that the basic medical requirements of a child with cancer are met. Knowledge of the concurrent stresses faced by families is well established and it has been suggested that there is a more pro-active role for GPs during the stage of hospital treatment in continuing involvement with the family, particularly to monitor distress (Halliday, 1990).

An interesting alternative research approach for investigating the impact of the family dynamics would be to adopt a stronger systemic approach through interviewing family members simultaneously. The resulting discourse could subsequently be analysed. Future research may usefully seek to explore the perspectives of the ill child (dependant on age) as well as siblings. Moreover, future work would ensure that Asian groups would be homogeneously represented and indeed that the experiences of parents of other ethnic groups, such as those from the African-Caribbean or South East Asian communities would also be investigated. Refinement of the present study would also ensure that non-white participants were differentiated in terms of whether they were first, second or even third generation immigrants.

As this is an exploratory study the use of quantitative research may become more relevant in future research. Using the themes that emerged from the present work there may be a need to develop and refine outcome measures with known psychometric properties so that the issue of generalisation and representativeness is addressed by the use of larger samples.

5.3.6 Conclusions

This exploratory study highlighted the range of experiences of parents when their child is diagnosed with cancer as well as demonstrating the wide-ranging effects of childhood cancer on families post-diagnosis. There were some key differences between the experiences of white and Asian parents, particularly with respect to cultural beliefs and values but the similarities in terms of the diagnostic and treatment process and the utility of support were more marked.

The findings have practical implications for service provision: in a busy paediatric-oncology department it is important for professionals to keep sight of the concerns and needs of the individual child and family. Moreover, there should be some recognition that cultural influences may play a key but subtle role in how some families might present. Suggestions were also made as to how the views of these individuals might usefully and reliably be accessed in future work.
6 References


Bhopal, R.S. (1986) The inter-relationship of folk, traditional and western medicine within an Asian community in Britain. Social Science and Medicine, 22(1), 99-105.


Levin, J.S. (1994) Religion and health: is there an association, is it valid and is it causal? Social Science and Medicine, 24, 589-600.


Appendices
Appendix I
Letter confirming ethical approval from RM NHS Trust
Ref: CF/Ethics/PROTOCOL No. 1822

22nd September 2000

Dr Lesley Edwards
Child & Adolescent Clinical Psychologist
Department of Psychological Medicine
Royal Marsden NHS Trust
Sutton

Dear Dr Edwards,

Re: Protocol No.1822 The experience of care-givers in the diagnosis of cancer of their child: towards a cross-cultural understanding using Interpretative Phenomenological Analysis (IPA) (Prof. C R Pinkerton, Dr L Edwards, Dr A Hashemi, Dr L Dowdney, and Nina Patel)

I am writing to acknowledge receipt of the letter dated 31st August 2000 from yourself and Dr Hashemi enclosing a revised protocol and patient information sheet for the above study, as requested by the REC. I confirm that these meet the REC's requirements and that final approval is given for the study to go ahead.

Yours sincerely

Christine A Ferguson
Secretary to the REC

Cc Professor Ross Pinkerton
Dr A Hashemi
R&D Office
Appendix II  Interview schedule
Interview Schedule

The main purpose of the study will be reiterated at the actual start of the interview to ensure that the participant is still clear about why we wish to conduct this research. At all times the family member will be spoken to in a sensitive and empathic manner using appropriate and non-technical language. Furthermore, throughout the duration of the interview, the interviewer will endeavour to check that the participant fully understands each question.

Semi-structured interview protocol:

The actual questions that will be asked are in bold, italic font.

1. Knowledge and beliefs about child’s illness

a) The interview will endeavour to start with gaining an account of the child’s development and any medical history. The main function of this particular line of questioning is to set the child within his/her developmental framework and to establish rapport before moving onto more stressful material. However, parents will also be encouraged to discuss this topic to elucidate an understanding of if and how they evaluate and attribute their child’s current illness state to previous health.

I believe that your child is x years old – before talking specifically about his/her present illness, could you please tell me a little about the following:

The immediate family (i.e. how many adults and children there are, how long parents have been together, etc),
Adam/Jane’s previous medical history
Could you also briefly talk about Adam/Jane’s developmental milestones, such as when he/she first started walking, talking, eating, development at school, etc.

Could you now tell me about how your child came to be diagnosed with cancer and how you knew or suspected that anything was wrong?

Prompt questions to be used throughout the interview:
Can you tell me a little more about that?
Then what happened?
How did you feel about that?
What were your thoughts at the time?
b) The family’s prior and current knowledge and beliefs about the aetiology and prognosis of the illness.

What do you and your family believe may have caused the illness?
Do you have any ideas about this?
Do you think these beliefs have changed since your child’s diagnosis and treatment?
How do you think your child will do in terms of his/her treatment?

2. Effects of illness and coping strategies
a) The parental perceptions of the events that occurred following the onset of the illness and during the assessment of their child’s illness.

What happened during the time that your child’s illness was being investigated and also after the initial diagnosis?

b) If, when and under what circumstances they informed their child that he/she had cancer.

Did you tell your child about the nature of his/her illness?
How did you come to make the decision to tell/not tell your child about their illness?
If you did decide to tell your child how did you do this and who was present?
What do you call this illness within your family?

c) A description of the general effect on both the immediate and extended family.

Could you tell me how the diagnosis affected and impacted on your family members (both immediate and extended family)?

d) Perceived changes in their parenting behaviours since diagnosis, perhaps, as a consequence of changing coping strategies.

Do you think you have changed as a parent/person since your child’s diagnosis?
Do you think your behaviour towards your child and your other children has changed at all? How has it changed?
Are you satisfied with the way that you now manage matters with the children?
e) With hindsight, was there anything that helped them, or did not help them, get through the experience?

*With the benefit of hindsight, do you think there were things that were helpful to get through this experience / to get through this time? Do you think there were things that were not so helpful?*

f) The family’s attempt to cope with the condition, for example, the use of spiritual/religious resources or searching for and identifying ‘front line’ experimental interventions.

*How do you as a family cope?*

3. **Treatment and service provision**

a) How they were told about their child’s illness and what has happened since then.

*How were you told about your child’s illness by the hospital staff? What has happened since the time that you were told by the diagnosis? Could anything have been done differently? How?*

b) Their understanding of the initial, current and future medical therapy.

*Do you feel/believe that you understand well the course of your child’s treatment and future therapy?*

c) Their experience with health professionals and service provision.

*What has been your overall experience of the medical staff that you have been involved with, e.g. Doctors, nurses, radiotherapists, O.T.’s, dietitians, etc? What has been your experience of the RM Hospital itself and the service that it provides to patients and their families?*

d) Could anything have been done differently to best suit their needs.

*Could anything have been done differently to better suit your specific needs?*

e) Their identification and use of ‘alternative’ therapies.

*Have you considered the use of therapies other than medical treatment options? What made you consider this? How did you find out about them?*
4. **Hopes and fears for the future**

a) Future orientated plans.

*What are your plans for the future?*

Is there anything else that you would like to discuss or that you feel that we have not yet touched upon?
Appendix III  Letter to participants
Dear Mr & Mrs.

We would like to invite you to take part in a study to try and understand the experience of a parent when their child has been diagnosed with cancer. We are particularly interested in the influence of cultural background. We are aware that in the Children's Unit that there are many aspects of treatment and care. These may be experienced differently depending upon a number of factors. For example, your family's experiences and cultural beliefs about cancer and illness, the way you and your family have coped with ....... illness and what you believe has helped you at this time.

We are keen to learn more from families themselves so that we can provide a service that is suitable to all those who attend the RM Hospital.

This study will involve one interview with you for a maximum of 2½ hours with myself. With your permission the interview will be audio-taped to ensure that all the information is collected as accurately as possible. All the information that you provide will be kept confidential and neither your nor .......s name will appear in any paperwork, in accordance with normal standards of medical confidentiality and the Data Protection Act. All tapes will be destroyed after the study is completed.

Your participation is totally voluntary. If you agree to participate you can stop the interview at any time if you no longer wish to proceed. Taking or not taking part will not affect the treatment of ......... here in any way. I will be taking the liberty of telephoning you in a few days to discuss the matter further with you.

If you need any further information or if you have any questions you can contact me at the above number in the Department of Psychological Medicine.

Yours sincerely

Dr. Amtul Habib Hashemi
Psychologist in Clinical Training

Dr. Lesley Edwards
Child and Adolescent Clinical Psychologist
<table>
<thead>
<tr>
<th>Appendix IV</th>
<th>Information sheet</th>
</tr>
</thead>
</table>

237
Information Sheet for parents

The experience and cultural understanding of the parent when your child is diagnosed with cancer

We would like to invite you to take part in a study to try and understand more clearly the experience of a parent when their child has been diagnosed with cancer. We are particularly interested in the influence of cultural background. We are aware in the Children's Unit that there are many aspects of treatment and care. These may be experienced differently by parents depending upon a number of factors. For example, your family's experiences and cultural beliefs about cancer and illness, the way you and your family have coped with your child's illness and what you believe has helped you at this time.

We are keen to learn more from families themselves, so that we can provide a service that is culturally suitable to all those who attend the RM Hospital.

This study will involve an interview with you for a maximum of 2½ hours with myself. With your permission the interview will be taped. The tapes will then be typed out, so that I can listen again to what you said during the interview, but the transcription will not contain any information that can identify you, your child or any member of your family. All the information that you provide will be kept confidential and neither your own nor your child's name will appear in any paperwork, in accordance with normal standards of medical confidentiality and the Data Protection Act. In line with normal medical practice your GP will be informed that you are taking part in a research study concerning your child's illness.

Your participation in the project is totally voluntary. If you agree to participate you can stop the interview at any time if you no longer wish to proceed. Taking, or not taking part in the study, will not affect the treatment of your child here in any way.

If you need further information or if you have any questions, please contact:

Dr. Amtul H. Hashemi  Dr. Lesley Edwards
Psychologist in Clinical Training  Child and Adolescent Clinical Psychologist

Date given to patient: ________________________________
Title of study:

The experience and cultural understanding of the parent when your child is diagnosed with cancer.

Section 1 - TO BE SIGNED BY THE PARTICIPANT

I .................. consent to participate in the above research study. The purpose and nature of this study has been fully explained to me by Dr. Amtul Hashemi (Psychologist in Clinical Training).

I understand that my participation in this study is entirely voluntary and that I may withdraw from it at any time without giving a reason, and without jeopardy to my child’s future care.

I also understand that if I withdraw from this study, my child will continue to receive the best conventional treatment that is available.

If I have further questions regarding the study at any time I should contact Dr. Amtul Hashemi (Department of Psychological Medicine).

Signature of participant ......................... Date .....................

Section 2 - TO BE SIGNED BY THE DOCTOR/PSYCHOLOGIST

I .................. declare that the purpose and nature of the above research study has been explained to the above person in writing and verbally. This explanation included a description of the procedures involved, possible benefits to the participant, potential risks or side effects and the expected duration of the participant’s participation.

Signature of Doctor/Psychologist ..................... Date ..................

Section 3 - TO BE SIGNED BY AN INDEPENDENT WITNESS

I .................. declare that in my opinion the participant has understood the nature and the purpose of the above study. He/She was given the opportunity to ask relevant questions and his/her consent was given freely.

Signature of witness .................. Date ..................

240
Section 4 - TO BE SIGNED BY THE PARTICIPANT

This section will be completed after the interview has taken place and been recorded.

I .................................. have given my consent for the interview to be tape recorded. I understand that the tapes will be typed out and the tape recordings will then be destroyed.

Signature of participant ......................... Date .........................
<table>
<thead>
<tr>
<th>Appendix VI</th>
<th>GP letter</th>
</tr>
</thead>
</table>


Dear Dr

I am currently conducting doctoral research for The University of Surrey, at the School of Clinical Psychology under the supervision of Dr Linda Dowdney and Dr Lesley Edwards. This involves a cross-cultural study on the way families respond when their child has been diagnosed with cancer. This study has received ethical approval from the RM Hospital NHS Trust/Institute of Cancer Research.

I am writing to inform you that I intend to contact the parents/carers of (name of patient) who I understand to be a patient of yours, to request their participation in this project. This will involve a single interview lasting approximately 2 hours, which will be analysed using a qualitative form of data analysis.

I trust this information is acceptable. If for any reason you wish to contact me for any further information you can contact me at the above address/telephone number.

Yours sincerely

Dr Amtul H Hashemi
Psychologist in Clinical Training
School of Psychology; University of Surrey.
Appendix VII  Examples of English and Asian transcripts
First of all we'll just start of with some basic questions – could you just remind me how old Mat is?
Six
Six years old- ok and who's in the immediate family? Yourself...
My husband, Mat and Chloe

And how old is Chloe?
She'll be four in March

So there's a two year difference
Yeah

What was Mat's early medical history. I don't know when he was diagnosed, if you can talk me through when he was born and his developmental milestones and what your conceptions of him were, was he a well child?
Had a normal pregnancy, normal labour – everything as far as I was concerned was normal, , when he was a baby he was fine he didn't have much apart from the coughs and cold—normal illnesses

Developmental milestones... where they all fine??-.....
At 13 months he walked really well- just over a year, urm. Teething, feeding, everything was fine...

So when did he come to be diagnosed- how did you know or suspect something?
He was diagnosed a year ago this week so – but from the previous September. He’d been under Mr. Roberts care, repeatedly because he was having very bad nosebleeds in the summer and urm....

And has he got Leukaemia?
No, he's got a rare bone...rhabdo myosarcoma..... and urm he was under Mr. Roberts for his nose but and then in the January of last year urm I was getting him ready for school and just noticed what I thought was like a boil type thing in his ear... urm which I took him to the doctors about that day and they gave him some antibiotics , that was on the Wednesday, but by the Saturday it was actually out, it was coming out of his ear- it really was...

Was it painful for him?
No, no he didn’t know it was there

Right ....
And then it was just a course of going back and forward to different hospitals and then come the 11th of February he had urm his nose cauterized and at the same time they did a biopsy on what they thought was a pollack and we were told two weeks later cos we were away and we came back the next week and we were told that it had formed a cancer.

and did St Peters tell you that
Yeah,

And you know the nose bleed which you were under Mr. Roberts for, were they related...
They don't think it was related- it was just in /the case ... unfortunately he had that as well.

Right ok...that period from January and February when you were going in and out of hospitals , doctors or whatever, what were the medical staff like then at that point?
Urm not particularly helpful ,urm...The GP was fine... we went on the like the Wednesday and I was concerned and went back on the Saturday emergency appointment and they sent me straight over to
The Royal Surrey in Guilford, um... who weren’t particularly helpful when I look back now... um... they only had... um... sort like I don’t know skeleton staff on the Saturday when we were there...

So you went to casualty?
Well no we went up to I can’t remember the department – I presume it was the pediatrics, um and they asked us to come back on the Monday when the senior registrar would be there and you know so she told us that it wasn’t anything serious and then...

He wasn’t kept in...?
No and then because we were already under Mr. Roberts and had an appointment to see him that was on the Monday we weren’t there then on the Tuesday he had to go um St. Peters to see Mr. Roberts... and then it was like Wednesday, Thursday Friday we were in to see different people different.....

Urm
then you know we... well nobody thought it was worse than a pollock and we really didn’t think anything of it, really. I was worried... I just thought he’d perhaps scratched his ear and that it had got infected...

It got infected
Yeah that way, I just didn’t know anything. We’ll you don’t think....Apart from one thing I really was annoyed about when I look back when were at the royal infirmary one of the Registrar’s there turned around to us and said don’t worry its not cancer or anything. And when I look back now I feel like in one way, writing but I have no idea what the bloke’s name was or anything... and to him it was just some kind of throw away comment. But when I look back now I think he had no idea what that

He didn’t did he?
He didn’t yeah... And it was... I didn’t even think, that anything of cancer... I didn’t know what it was for a start really. So when I look back now its quite hurtful,

How did you feel at the time?
Just patronised... then I thought what did he mean and I hadn’t even thought of it... hadn’t even thought it was a cancer... but St Peters were brilliant Mr. Roberts who he was under... he couldn’t do anymore for us...

When he came back from holiday or wherever you went was there a message left or letter or...?
No we had an appointment because he wanted to see him because of his nose... um... we had to keep the ear clean... cause he’d had the biopsy done on his ear to take the pollock out... out um and he was going to wait they wanted to see us back to make sure that the ear was still clean, and um... we had an appointment made and we were told there. And then it was the case....

What do you remember about that day?
I remember going and when we checked in at St Peters one of the nurses came out and when I was actually checked him in when I was in the queue behind some people and she came out and she when Mr. and Mrs. Hampton come in there’s to be no interruptions... and then my stomach went, I thought there was something wrong.

She didn’t realise it was you?
No she didn’t realise it was me... and my stomach just went there’s something wrong here and then we were called in...

And was it Mr. Roberts?
Yes. Mat was with me he was in the room and then Mat was taken out, um... don’t really remember much else. For a few minutes...

But you and Mark were together?
Yeah I don’t really remember much else... anyway... then he made appointments for us to come straight up to here... That same day... Yes um I didn’t know where Sutton was or anything and directions...
Did you drive over there?
Yes...just didn’t know just stunned, it was like hitting a brick wall...we just didn’t know what to do...umr very tearful, very emotional, umr... but when we got here you know it was another ball game, I just didn’t know anything about this hospital... I didn’t know anything about what Mat had...

How did it feel when you got here? I know it was a matter of hours of being told...
yeah a couple of hours ... I didn’t know looking back I didn’t know what was happening... trying to not be to emotional in that you frightened your child... umr and yet you want answers ...but I couldn’t take it in. Whatever Cathy said to me that day I don’t know...it didn’t go in...because it was to much of a shock...

What was Mark like?
He was quite calm... he was definitely better off that day... umr I think it hit him hard later on and even during the treatment. Whereas I was coping with the treatment because I was here, I was seeing things... Mark in one way was trying to keep a normal working life cause didn’t know how long the treatment would go on... at first he had a lot of time off, hospital visits, the first two lots of chemo...he was here everyday... and as the treatment went on he felt well his got to keep his side of work going. And come and visit Mat, after work... I think in one way he was affected later on...

that day did you ring anyone?
Yeah family...My mom... fortunately both parents live within five minutes walking so we’re very close. No actually I didn’t ring my mom, cause my mom was on holiday, so she rang that night that night when we got home to find out how he’d got home, thinking that he’d got treated for his pollock.... They were in Spain, so I said fine, I thought I can’t tell her over the phone and umr...but she said later on they were home on Friday and... she... looking back now she knows something was wrong because I wasn’t chatty... my normal self ...she thought...something at the time

Do you have siblings?
No, Mark’s got a brother and a sister...They were very good... I think it affected them differently because obviously we were going through it with Mat, and they were wanting information and we weren’t always able to tell them you know ...we were trying to understand it ourselves in the early days and what was going on...

What do you understand about all this?
That it’s a very rare condition... I think it was 1 in 650,000 ...this form of cancer... unfortunately it was Mat, other than that I don’t really know, I just haven’t read through it ...because I just couldn’t...at the time I couldn’t ...but as the years go on I might like want to find out a bit more but this year it’s just...

So you’ve not been... have you done your own research?
Friends kept saying to me why don’t you contact so and so... and I just couldn’t, I had to put my trust in one person and that was a way of coping...sorry...(cry’s)... (STOP TAPE)

Can I just take you back there a second about the statistics being incredible...
you wonder... sort of why...why him... I don’t know with how it came out... I sort of thought did fall down, did he bump his head... in the playground ...did I not know...every child falls down and bumps their head you know... you just sort of think you know I should have seen it earlier ...

And what did Cathy say about it?
No...she said that nothing you could have done differently, that would have caused it and not caused it, it just one of those things ...

Have you told Mat about it?
Urm... Tried to tell him... he knew there was something nasty in his ear which had to come out, but umr we tried to be open with him ...but we tell him as much as we feel he can cope with...
In terms of being in that first day being in hospital... what did he think was going on then?
We just said it was all to do with his ear... the doctor wanted to look at his ear and that there was something that wasn’t quite right in his ear, and that they were going to make it better you know we didn’t know ourselves, we just had no idea...
Going back to that difficult time... was Mat admitted straight away
No... I think it was a week of various tests... of different things and then he had his line inserted...
Can I just take you back to St Peters did they know that it was rhabdo sarcoma... did they know that or did they know it just as a malignancy?
I don't know whether they knew... I can't remember whether they told us or whether it was here who told us,

Don't worry it's not important... and then he had his line put in...?
Yeah... and then they started the treatment in March... he had nine courses, three weekly intervals... and yes, he had radiotherapy in the middle of it, five weeks intensive... so a course of radiotherapy as well...

No surgery?
No... they were thinking about doing surgery... we had to go over to St George's during the treatment to see somebody over there... but we felt we couldn't make the decision... we were told that if went the surgical route he would be disfigured and the hearing loss would be definitely greater than if we went chemo and radiotherapy... we just felt we couldn't make that decision and we didn't know enough... and so we'd actually decided... we had until one course of chemo to decide... and we felt we couldn't make that decision... so the choice was taken away from us because Cathy & St George's discussed it, I think, with Mr. Roberts. And it was decided that it was the radiotherapy that was the way to go... and so far Mat's hearing is a little bit down... but its fine. And they obviously didn't know how far the tumor had got, so they couldn't tell us exactly how much... how big it was...

It sounds like even the medics, the experts weren't quite sure... didn't know ???
Yes... They did ask us to do a study, and we actually opted out we just felt... we just felt that we couldn't put Mat through anymore although I know the treatment was exactly the same... we just... It was an extra level of stress... We just couldn't do it at the time... but then you feel bad in one way because if nobody had taken that choice and done it... with the chemo or with anything... then lots of children with things like that probably wouldn't be here today... and a lot of medicine... people have got to do these studies to help...

I think you need to think about in terms of that you taking part in that research but in that particular time it was such an early and difficult time for you.
Yes... because we were having to cope with something that was brand new and its giving a lot of oneself... but in one way... you know you feel... but then it's a choice and we had to make that choice then... yeah...

You said in terms of causation that it's just one of those things that happens... but do you still believe that...?
I think in one way you want to know why... now I want to know why... why in Mat was it, you know I want to meet that other 650,000'th person... you know... like what similarity... they've got between them... and things like that

Is there a group or associates?
Not particularly for this cancer... there's variant forms of it... there was one little girl in the unit... she had lumps all over her body he just had it in his ear, just one lump in his ear... it's so rare...

Were you encouraged to talk to other parents families with different kinds of cancer?
I talked to a lot of people in the unit... you listen to them... and you understand what they're going through... but each child each family have got their own specific worry... we were fortunate that R only had a short time in his course of treatment and some children spend years... and that's quite hard to take on board but we were only here for six months and some families have been here years...

And what stage is Mat at now?
He's been given the all clear... and just regular check ups and follow-up...

Will that be for five years?
Be definitely for the next two years and then it'll be yearly...
**So how have they said he has done?**

Yes, they were very pleased with him and he coped really well... The first two times of chemo he didn’t really understand what was going on... towards the end of the treatment... half way up he was physically sick every time,

**So he developed an aversion?**

Yes... he didn’t know why he was going through this or... didn’t know what was going to happen... but he’s been really brilliant throughout, he managed to get to school... the school I must admit have been brilliant, he went through a difficult stage, when he was losing his hair. And that came out very, very quickly and within three days, it was nearly gone... but we managed to keep him going to school, and the school talked to the rest of the school and he did have a little bit of bullying and that was dealt with very very quickly at the school. He never actually said that he didn’t wanted to go to school, but he cried a few times when I actually took him to school but he probably didn’t want to separate from me... but once he was at school, he was fine... his teacher was amazed at how he kept up... certain things help like reading and things like that... we felt we couldn’t push him to do things in that way, so things like that he was low on...

**Plus he is very young, What about implications of the radiotherapy?**

That... in one way... the actual radiotherapy was fine, we didn’t like the way it was dealt with, by the radiotherapy unit... that upset us. When we knew he had to go to radiotherapy we were bought in... the doctors came in, unfortunately Cathy was unable to come in with us, and the nurse that was looking after us that day was called away suddenly... we were really on our own with the two doctors... and they looked at Mat... and when ever we’d spoken to Cathy she talked to Mat at his level... and things like that and then said... do you want to go and play and he’s gone off and he’s quite happy... these two doctors unfortunately spoke to us but with Mat in the room... and used words that he would understand, that his growth might be affected... face might be affected might change...

**Very technical information in front of him?**

His face might change... they were like touching him and saying things and he got a bit edgy said... I want to go to the toilet, and when I got him outside the room he just burst into tears. And he said mum I don’t want my face to change... it was just like that...

**How did you feel about that?**

I refused to go back into the room, because it upset him and then I was upset. Mark came out and said what’s wrong... I said they’ve spoken to us in language Mat would understand and now he’s confused and doesn’t know what’s happening... and...

**Up to that point it feels like Mat took on board what you told him and their was a strong bond and he trusted you and... then suddenly... is that right?**

Yes

**He became confused what were you doing?**

I felt that I couldn’t help him (cry’s) I didn’t know what was going to happen I had not idea... I didn’t know anyone who had ever had radiotherapy... I didn’t know anything and I felt like I couldn’t help him

**Did you make any complaints about that?**

Cathy did speak to them,

**So you went to Cathy?**

Yes

**And you discussed it with her?**

We weren’t getting at the doctors we just felt but Mat didn’t need to know what they said and the way that they said it... he didn’t need to know certain things... a child doesn’t understand that he might not grow properly... or that his face might change... that sort of thing we just felt very strongly about... and they said afterwards that there’d be redness... you know on his face and things like that and scarring but at the time I didn’t know what they meant... and then the actual... when he was having the radiotherapy at the RM... it was all fine... in fact, the play therapist that was done brilliantly... you know they brought
out the doll and it was fine...and he went down to radiotherapy room everyday...once he was there he
was fine, he just lay very still and they had no trouble with him at all...while he was having it...he was
lucky he only had 31 minute sessions...so...

**Can you just tell me what he was like when he had his hickman line put in...?**
Again they did it through play...showed him where it would go...erm...but he was very, very
protective over it...erm...when they would come to change the plaster he would just scream, he didn’t
like it...he got better...but he was ever so protective over it.

**Can I ask you a difficult question...how do you think he’ll do with his treatment?**
As he’s going at the moment...brilliantly I think...but obviously you don’t know...in one way from
the onset when you’re 1st diagnosed it’s all emotional and then you go through the treatment and then
its all taken out of your hands really...every 3 weeks you’re up here or whatever and then there’s that
tense feeling like we had when we wanted the all clear and we had to wait over a week...so it’s a bit
stressful cos you think oh I hope he’s chest x-ray is going to be all clear...and then that’s it and you
start again...We try not to tell him that we’re coming up too soon...erm...we just feel that he’s 6 and
he doesn’t understand and he’ll say ‘well what am I going up for?’ and we say ‘oh just for a chest x-
ray.’ So he knows that there’s thing that he’s been through...in 1 way I suppose it’s taken his
innocence away a bit...I mean he’s had to deal with a lot of things that most adults will never have to
deal with hopefully...but I think it’s made him stronger...

**We haven’t talked about Chloe...how has she been?**
Well she was 2½ when Mat was diagnosed and she’s now 4...I don’t think she’s felt left
out...erm...she again was quite funny because she used to ask Mat if his line was alright...and don’t
get it wet...they knew that they had to be careful in the bath...and she was quite protective. And when
Mat had his line out she told everybody that he had his line out and things like that...and in that way
I don’t think it’s affected her at all. In 1 way she’s so young and she used to come up most days and I
would see her and my mum used to bring her up or whatever...I didn’t have her here with us...I think
she was ...I didn’t think it was fair to the other children and also it wasn’t fair to her or to Mat...and
she was fine with my mum I think...

**How do you think this has changed you as a parent...?**
Yes...I think coughs, colds, things like that they’re at the Drs...erm...I take them quick...especially
Mat... but my Dr understands you know given what I’ve been through...

**Have you changed as a person?**
Erm...probably more philosophical, especially last year...err...like planning wise...I used to plan
goods to do...holidays...but now when Mat’s well enough to do something we do it...I rely on my
mum and Mark...we didn’t want Mark’s work to suffer just because of days like this when we’ve come
up here...at least then he can ask for the time off cos he has to come to the hospital without it becoming
an issue...I mean they’ve been very supportive, especially right at the beginning...it was more Mark
not wanting to take the time off...just for the sake of it because he might need it later on or he might
need 3 days off...and he was able to take that time as compassionate leave. But he didn’t want it to get
to the stage where the other men might think ‘oh! He’s always off ’...I mean they knew and they
understood and things like that...and my work, fortunately I worked as a temp...a company I worked
for years and so if I didn’t go in I didn’t get paid...and in that it was ideal....

**Was that ok...financially...?**
I think so...I think in 1 way we knew that this was going to go on but we didn’t know how long it
would go on...you know everybody has children that are ill...but it’s not just 1 worry...it’s all the other
mundane worries...and I think friends and things like that...they wanted in 1 way to know more but
then didn’t feel that they could ask...

**TAPE STOPPED**

I think in 1 way we would have liked to know more about the different departments...you know like
what can that department help with you know like with psychological medicine...a leaflet or something
that you could read and get an idea about different things...I know like from my mum that they felt like
they couldn’t keep asking erm…certain things, perhaps, I mean I don’t know but perhaps a consultation with like the family or something like that that the hospital could have arranged…

Ok, so we’ve started talking about general service provision apart from the treatment aspect… I mean with the benefit of hindsight do you think that there were some things that were helpful about the way the hospital is set up and other things that weren’t so helpful?

Yes… social services approached us straight away and they were fine… very helpful… loads of information… but just generally they were really fine, they were very approachable… encouraged you to fill the forms in…I mean it’s just so hard… even coming up here… its wear and tear on your car, different costs that you wouldn’t necessarily have... I mean I was fortunate I didn’t have to pay anyone to have Chloe… you know and things like that… I mean some people have to find childcare 24hrs a day… so err… The play therapists they were really good… brilliant… the nurses always are approachable… even not just Mat, maybe there’s something you’re worried about… they always seem to be able to put in the time… you know had the time to speak to you… it wasn’t just their job… they were definitely caring. And the Dr’s… we were quite lucky in that during Mat’s time the people that came in Feb were here near enough until he went, the SHO’s… and they gave us everything at the right level… I think they gave us information in bits and that was the right way to do it and then nearer the end… they were talking about the scans and things at the end and things like that… booking them in…

My next question is how do you as a family and you personally cope?

Just live day by day as it comes… I think in 1 way you know that you’re not alone when you come up here and seeing Mat and how he was and then seeing children that were next to him erm… you know… he was just unbelievable… I know the 1st time that we came for Mat’s chemo and I didn’t even see the little boy next to us… he was always covered… it turned out that he wasn’t very well… so in 1 way that worries you… you know you think ‘oh is that going to be Mat?’ but he was never that ill. So I think you… you know just feel very sorry for these children and their parent and you think that’s not Mat… in a selfish sort of way… and on a different sort of thing my dad hadn’t come up the hospital… my mum had and we made my dad come up to the hospital just to see how Mat was in hospital and how he was coping and my dad’s in his 70’s and you know… he was just amazed… you know he’d got these horrible visions of him lying there with tubes and things like that… and I made him walk around with me and see… you know ‘look at that child, that’s not Mat’… look how well Mat is…” and he was a lot better after doing that… it did help him… I just felt personally that Dad had heard… known… seen people with cancer and I just felt that he’d got the wrong impression of how Mat was…

Did you and Mark have any other experience of cancer?

No… err… well my mum’s mum died of cancer before I was born so it was a word I knew… and Mark’s granddad had it but we didn’t have any experience of young people having it…

Do you feel that you understand better the course of Mat’s treatment…?

Yeah… initially you’re given this big folder full of information and I just couldn’t read any of it… D did… he went home and read it straight away… I couldn’t deal with it in that way… so I sort of picked things up as I went along… I just found I couldn’t read it… I needed to do it bit by bit… And yes… I think I do understand… now…

What’s your overall experience of this hospital?

I think it’s absolutely brilliant… you know people were saying you should get this opinion or that opinion but I just didn’t want it. I just put all my trust rightly or wrongly in the Marsden and that’s how I felt I would deal with it…

So, sorry, were people talking about alternative therapies…?

Yes, I think so… some people said put this crystal near him, but… I didn’t want to… erm…

And is that because the RM had a treatment plan?

Yes… and we just felt happy with Cathy (consultant)… but also the other people that we’ve seen they’ve been fine… and it’s been a success… I mean I can’t say that if Mat’s treatment had been totally different what I would have done then… but… Mr. Roberts knew… knew Cathy… I think they were at university together… so there was that relationship… that people were working together… in one way it felt like no-body would pull the wool over our eyes… they would tell us what we wanted to know… and
it always felt like we could ask and get a straight answer...I know the information was going backwards and forwards but the nurse and Dr. Roberts wanted to know what was happening with him and they wanted us to tell them...things like that...which was nice...which was helpful...and showed that he cared...well Mr. Roberts said he'd never had to tell anybody that kind of news before...and he's a father...and it seemed to touch everyone at a really personal level...and then I don't know how people do it in a hospital...even your job listening to us...I just couldn't...I'd get too attached...I think to the children...but I suppose you get used to it?

Well you do and you don't...my last question is well...what are your plans for the future...?

Just to live...to make Mat live...and for us and Mat to do all the things that we want to do...anything he wants to do...we can only guide him...we can only presume...he's very arty...not academic (laughs) but he's still young...! Definitely arty...he loves drawing and things like that...sporty...typical boy! And I'm not going to stop him doing anything...but then from a mother's point of view I want him to be academic but...it's what's right for him...with what he's been through...it's just about enjoying life...

END OF INTERVIEW
Example of transcript from Asian parent

Italic = Researcher

Asian 10

Reflecting a little bit on what Fatima was like as a child before she became ill before so before you noticed anything wrong with her in term of; is it Leukaemia she has?
Yes she did

Um really, would you describe her to me, her personality what was she like?
She was a very content baby, never had any problem like winging and crying, very happy going very forward and I would say a little chatter box. We just did not have one minute of break to be honest. She was just like, oh we were on the train and she probably make friends with any of any age does not matter as long as she could get their attention, when I took her in a gathering she still didn't she was a wonderful child, I never had any problems apart from one little problem was her eating habits.

Right
I was never ever happy the way she ate and I kept on going back to the health visitor saying that the child is never happy in eating she goes "no you're a first time mum your overprotective and stuff like that, to be honest now I realise I wasn't at that time I thought ok maybe I'm a first time mum I haven't seen a brother or sister in my house neither niece or nephew cause I was the only child so maybe I am overprotective. But when I think now Fatima always had this problem.

What kind of, what was it like? was she fussy about what she wanted or afraid?
She really took very very little portions, very little portions and if you ever ever tried to talk to her and force fed her not force fed her like really put a spoon in her mouth like talk her into it she would throw up, she would throw up definitely.

Did she have any problems with reflux or gastro-intestinal problems?
No, no problem at all. I've been to...I've forgotten the doctors name now...paediatric consultant in Shirley Hospital because we were with BUPA at that time and she said there was nothing wrong with her but...

So she had investigations done?
Not to the extent where maybe a blood test could have done, maybe given me more satisfaction and I always said to her, the health visitor and the doctor,' being an Asian girl we are not very fair, why is Fatima always so pale?' and she goes 'no that is her, just the constitution that is her skin' but if you look at her now she definitely hasn't got that colour on her she is more like me now, but before if she obviously didn't have black hair or brown eyes people assume she is a white girl, she was that white.

Did she have anything like a Barium Test? She didn't have any of those kind of things?
Nothing

But did it sound like, did it feel like you weren't being taken seriously or were you not that concerned at that point?
The first year I wasn't that concerned because she was, well the health visitor said, she growing beautifully, she's gaining weight, she's taller than her age, so obviously that did compensate my fear inside but between, I would say 18 months to 2 years, no I was not very happy with what I was told at all.

So was she still, even between 18 months and 2 years was she still maintaining her centiles?
Yes, she was still growing,
She was quite robust.
Absolutely, I mean, the Doctor said I can't see any problem the girl talks like a 4 year old even at the age of 2 and there's no problem with her speech, there's no problem with her height..... Weight on and off but she was never an underweight baby so that meant anyone would have made so hold on a minute.

So when she was born her birth weight was a good weight?
Eight and a half

Oh right, a very good weight...OK
She did have a traumatic birth but obviously she recovered quite well

What was traumatic?
Her heartbeat was dropping and I couldn't push they tried to take her out with there? that exploded on the Doctor and they gave me an episiotomy and I still could not push her out they then forceped her out which obviously marked her skin quite badly .......You probably would not believe it they didn't tell me to feed her so I left the poor baby all night, the next day I was told she is jaundiced, which may be could have, I mean not 100% prevented but maybe if she had some liquid it might have helped but I actually know

No midwife told you?
Nobody told me, after the birth it was about 11 o clock at night, they took me to the ward they said to my husband you can't come in the ward because its all ladies, they put Fatima in the cot and obviously because I was so sedated I fell asleep, 10 O Clock in the morning the baby's crying her eyes out and I said what do I do now, even then no one told me to feed her, its only when another midwife came to see me she goes 'has the baby been fed?' I said no

So there was a cock up there?
I didn't really appreciate that at all but...there was still a sense of insecurity because the paediatrician came to see her and they kept on looking at her eyes and ? but not telling me what exactly is wrong and they were talking between them and I said 'is everything ok' and they said 'we're not sure' so that was the only experience at birth I think...

Did they rectify the Jaundice?
Yes, she was in the incubator for about 24hrs, which I did mention categorically to Dr Cathy Pritchard when Fatima was diagnosed, that was ultra violet light as well, could that have anything to do with M diagnosis? and the second thing that I was very concerned was that I had 2 X-rays done while I was expecting, could that have done anything to Fatima? But obviously its all a big question mark nobody knows.

How come you had to have X-rays when you were pregnant?
I just get rid of my pirexia, they did all the tests, blood tests on me nothing was coming up but my chest would not clear.

What's pirexia?
Temperature, just carrying on.

While you were pregnant?
Yes. They did protect my tummy but they took a chest x-ray twice and I did mention that at the time of diagnosis as well

Ok we'll talk about that a bit more later. And in terms of her milestone you know between sitting up unsupported smiling walking properly?
Absolutely fine, she was a late walker like her mum I didn't walk until I was...........mum tells me 18 months, Fatima was.....

Eighteen Months?
Yeah I was too big, the doctor said my legs could not take the body weight I was a 12 pounder so I used to do bum shuffling then I found it, it was easier than making the effort. M was 16 months when she
started taking her first steps and then after that she was absolutely fine. But she was never like, you know like little children run, Fatima could never do that she was always hesitant in running.

*Why was that do you think? What was her body shape like?*

Absolutely fine

*She wasn’t plump or....*  
Not at all, no. Fatima was never like that. I mean, I was, I wish Fatima you would run but she wouldn’t she would just walk so carefully, so carefully that it was amazing.

*She had no knocks or falls when she was little?*

No

*Ok ... lets go on a bit. How old was she when she got diagnosed exactly?*

Exactly 2 years.

So talk me through when you notice something was wrong.

Right ... we were all planning to go to Pakistan, we had booked our holiday when Fatima developed this viral infection which just wouldn’t go and the Dr gave her Amoxicillin, Paracetamol obviously to keep the temperature down the temperature would go down but her runny nose and cough wouldn’t stop so I was a bit unsure should I book the plane or not? At the time she developed a limp if I am not mistaken it was her left ankle she would tell me categorically it hurts I mean a 2 year old would not tell you but she would tell but she told me it hurts she wouldn’t put her foot on the ground. I took her to the Doctor and she said ‘it could be because, because they play around toys Fatima stepped on a toy, see if it doesn’t settle within a week and then we will do an x-ray and obviously it settled in a week after that Fatima didn’t complain, her temperatures had gone down her runny nose then I said to the doctor, I remember Dr Eileen O’Brien should I go or not. She goes ‘I think its just viral she’s just got out of hand I think you should go’ I took Fatima’s water, Fatima’s milk powder because I didn’t want to give her milk there Fatima was quite used to Pasta so we took all the tinned stuff anything that you could name in order to avoid giving food and water there because I know I come from there that Fatima would not be able to cope with the infections.

So you took bottled water over?

Bottled water, ah yes I took 100 bottles there

Wow

I mean at the airport the lady laughed at me and I said no I am sorry I am not, I am not making her drink because there was a big hooaha about, I can’t remember if there was an epidemic there at that time

*Cholera or something*

Something more severe than that hepatitis and it was coming through water and I said no I am not. We went there and Fatima obviously was not a very good eater, she was not even eating half the amount she would eat back home. So everybody said oh no she’s probably the language is different, its different in one land doesn’t matter she’s probably home sick and I took the view as a parent ah yeah but every day went past.

How long did you go for?

We went for a month but I was back with her in 2 weeks. Obviously she was not getting an ounce of water from anywhere her food was cooked in the mineral water that we took from here. She then developed a mild diarrhoea so I kept on giving her diorahite that was helping her and umm... But her food intake was reducing every day like instead of 3 meals she went down to 2 meals instead of 2 meals she went to 1 meal that all happened within a weeks time and anybody who saw Fatima there said she was too pale and something was not right. Now them saying it and me already been noticing it I did realise that her hands, like we’ve got red specks, she had nothing I’d squeezed it like this and it was all white and they said why don’t you go for a blood test and I said no I’ll take her back and I remember I requested my cousin to book my ticket and within 2 days Fatima stopped talking completely.
What suddenly?
Suddenly, she was just tired in any way but then suddenly one day she got up and she just fell on the bed and she goes 'I can't walk' and I thought something is not right. Those 2 days that I spent in Pakistan were unlike her cause she stopped walking then she stopped talking, which was not Fatima at all. She was not eating in any way, so I think those were the worst 2 nights I had there.

Then you had to wait it out to get the flight back?
Until I could get the flight.

And you didn't see any Drs over there?
No, my fear was that they might just send me on a wild goose chase I would rather sit it out, yeah, in Diarrhoea she did develop a little bit of blood in there as well, I remember I did book a call to the GP to say 'if you don't mind this is what is happening, Fatima is very pale, could you book me an appointment with a specialist and she said to me 'Mrs Bashir, don't worry, it is highly unlikely children that age are anaemic' as soon as....

So this was in Britain?
No I rang from Pakistan.

Oh right
Just to make, like as soon as I get there, there's already an appointment and she goes 'its very unlikely that children at this age will be anaemic so don't worry as soon as you come we'll sort it out.

And did that reassure you at the time?
It just made me think there's nothing wrong. I thought maybe she's picked, because she was chewing shoes at that time and she was teething as well and I thought maybe she's picked up some kind of nasty bug because she kept on chewing her shoe and I said Fatima don't do it and she just wouldn't stop. And umm the flight to be honest was like eternity; she just wouldn't stop going to the toilet. She was nappy trained I put a nappy on she wouldn't do it so like I was running to the toilet every 15 minutes and all she drank was water.

Were you by yourself for the journey back?
Yes, my husband had already come back he already had a week, week and a half holiday so he came back couple of days before me because he had no choice. So there was a week apart between me and him. I remember when I saw Zaid from where I was standing and I said, I said can you ring the emergency number? He goes 'why?' I said well that's what's happening but Fatimas not talking and he put her there and she goes 'don't let go I will fall' and he goes alright lets go straight to emergency in MayDay hosp.

Croydon?
Yeah, no I beg your pardon, we went to Croydoc first, which is in MayDay hosp but it is an emergency service. The doctor saw Fatima there and looked at me and she goes 'how long as she been like that?' I said 'well its only been 2 weeks that I've been away so within 2 weeks doctor' didn't you show her to the doctor I said 'No' and he obviously was not very happy with this he, he just wrapped her in the blanket and said I'm ringing the emergency service, take her in the emergency service. I had to wait 5 hours, I mean I just came off the plane I was, I have to be honest, totally gone Fatima was obviously kicking up a fuss because she was not eating, she was tired and probably her illness was playing up as well. Five hours later 2 doctors assessed Fatima and they took a blood sample immediately I mean without failing time because she said she could see definitely she needs blood but we need to know exactly how much and then they kept on looking for bruises but Fatima did not have any bruise.

Oh right she didn't cause that's a symptom
No, no bruising she's only had one birthmark there and they kept on saying 'and there' its like a little brown mark 'has she developed it now?' I said 'no it's from birth'.

So they suspected straight away then.
Yeah but obviously ER has not idea of the illness and we did not want her to think that far that Fatima's got something that nasty, I just to be honest thought that she would probably need blood transfusion end
of story and go home...2 hours later there were 3 doctors and a consultant from MayDay hosp who really informed us of the news.

_T hey told you in 3 hours_  
Yeah

_Really, gosh I have never heard that before._  
By 4 O clock in the morning I knew in MayDay hosp Hospital that Fatima had Leukaemia and...

_Did you know what Leukaemia was at that stage?_  
The minute she said it I just looked at her face, to be honest as if I had just gone dumbfounded and I said I don't know that it means and the next minute I said to her 'I know what it means' so it obviously must be the shock that did it to me. I knew it very superficially not in detail as much as I know now but at that time all I knew is that it was Cancer end of story. I really thought she was going to die and basically there is no cure for it.

_That's what you thought?_  
Yeah, because my mum died of cancer and some other cousins died of cancer, so obviously my very little knowledge just led to death and that was it

_So there was a family history of cancer?_  
Yes, there is. About 5 in the morning we were transferred to the RM....

_So three in the morning you were told five in the morning you were transferred and in those two hours it must have been a real blur and stuff but can you just, what did your husband and you talk about?_  
We didn't talk about anything apart from just crying to be honest because we were shocked, I just said to her if she dies we have to go with her and I tell you there was nothing else coming to my mind. I remember I came out to ring my friend in Pakistan and she kept on saying there is cure for it calm down and I said to her no there isn't and basically I was not registering or listening to anybody.

_And the medics at Croydon at MayDay hosp apart from giving you the diagnosis did they give you anything in terms of treatment? Were they able to reassure you in any way?_  
Well to be honest the consultant all she did was tell me what she had and that was it end of story but the junior doctors, god give them long life, they were absolutely gems, they were like hugging and really holding my hand and said 'believe you me' and reassuring that once they know exactly they know what stage she's at and what Fatima exactly needs, what protocol, you'll find its not that difficult there will be difficult patches but there is a cure for it, but the consultant was like, done her big job and gone. The junior doctors were absolutely wonderful,

_They were really supportive._  
Very supportive, very very supportive

_So you hadn't even gone back home at this stage, you'd got off the plane from Heathrow or whatever_  
Yes, straight we rang, you know you ring the doctor and the doctor then has an emergency number that number is actually Croydoc in MayDay hosp it's a special unit so you don't have to wait in emergency for 5 hours, if the doctor can help you there it actually stops them having a long

_A long waiting list_  
But he's obviously said it's an emergency case and we should have been there and from MayDay hosp I went to Marsden

_So gosh just like this_  
Yeah within hours

_So you got to the Marsden_  
Yes,
Before we get to the Marsden she's only 2 so what did you tell her? Did you tell her anything?
She was too ill to be told anything, she was very lethargic its like she had no strength in her, she was
now without food for near enough 3 days solid food. She was only drinking water because Fatima as a
child has never drunk anything but water because I have never offered her any juices like other mums
and never did and up to this day she has never drunk anything but water, the good thing was she was
still drinking her HB level was shocking and I was told in MayDay hosp her HB level was 4.6 and I still
remember the young doctor who was there said ' put it this way how positive it is if Fatima can breath
at high altitude with only 4.6 haemoglobin it must be a reason she's made it, obviously to be cured'
because there is no way somebody can breath with such low haemoglobin she had very low platelets,
low HB and obviously they found Leukaemia as well.

Thank you. So what happened in terms of treatment? How long does it last?
The treatment near enough took 2 and a half years.

Did she cope well with it?
I think what I hear and what I've seen with my own eyes she has coped very well. We never were in
a situation where the doctor has said oh she's very critical. Even though she had a critical illness but even
then in that span she was not that critical. Her Leukaemia was, her abnormal cells were only 22000.
Something like that so she was not in the higher risk factor and her age was with her and being a girl
they said was in her favour as well for some reason boys don't have such as good chance as much as
the girls have.
So everything that could protect her although the illness was very critical were in her
favour she did have very tough 4 weeks initially cause where they gave her lots of blood transfusions
platelets, obviously the canula was painful it she was very little going with out food because she,
coming from a 3rd world country did not help because she had to be in isolation just in case she had
cought another bug from there but she was bleeding through stools, she had enlarged liver so things
were very critical but still very much in her favour. The consultant we got in Marsden was absolutely
wonderful was Dr James who was a consultant himself somewhere, very good doctor Dr Allison, only part time now in out patients.

I actually don't know very many of the Doctors
They all took care of Fatima, I mean as much as they could

Did you and your husband stay?
Yes we stayed at Marsden for 3 weeks initially.

Did Zaid get that time off?
Yes he just rang his company and told them and they were quite understanding I mean at this stage if
they said sorry he will lose his job earning was not our priority we need to get over this shock that we
had actually confronted with.

What about family members you said your mother had died from cancer so who was around for you in
London?
In London I don't have any relatives at all apart from an aunt and she doesn't live very close by it was
Zaid's family, Zaid's mum and dad Zaid's bother Zaid's sister their children

They live locally do they?
The sister lives in Swindon; brother lives in Reading parents live with us. I would say my father in law
was sensible in everything in understanding giving us the room that we needed at that time and not
asking question unnecessary as much as my mother in law, but then again there is a big educational
difference between them. Right now I can sympathise with her but at that time I felt I am going to kick
you if you don't leave me alone cause I myself was so shocked and asking question like that I just
couldn't handle because a. I didn't know the answer and if I did I didn't want to share it with her cause I
didn't want her sympathy at that time.

Just wanted to deal with what you've got.
Yes I think firstly once you've come over the shock then it's the acceptance part that you really accept
what is there and once you have accepted it then the time comes but when you in yourself are in shock
nothing means anything its just like I thought just leave me alone.
So you just needed that time just to be yourself?
Yeah, just with Fatima because it was just not coming to terms with what had happened

You weren't or she wasn't?
She was too ill to understand I think and plus I think she was too little she kept on saying I want to go back to Pakistan I don't like it here but obviously that was her way of telling me that I don't like it but I don't think she could understand what had really happened.

At some point did you ever tell her look your poorly that's why you're here?
Once she had come over the initial hurdle her diarrhoea settled down her liver was back to the normal size and we were told exactly what her protocol was going to be and when does the treatment really start we did tell her that not that she did really care because once she got her energy back, she still didn't walk she didn't walk for a good 3 months because she had a fenbury line in her groin area and once they took it out she was very sore so she just basically refused to walk. She had 3 major blocks of treatment when we learnt she can lose her hair she can be very sick she can have diarrhoea because any fast growing cells obviously would be killed with the chemo and they don't know how to identify whether it is a good fast growing cell or a bad fast growing cell so that was a tough time because she would eat the food and it would come out the other end. She could not even digest water. She lost about 2 and a half kilos. But then again really thinking logically and remembering what I saw in the ward, outpatients, she still wasn't that critical she was still well enough in comparison to the other children.

All right what about her chattering?
It came back, I mean it was amazing, I remember Dr James saying 'I can't believe you can talk not even my 2 year old can even say anything but goo ga' Fatima said to him don't touch my potty I don't like you. Talking came back the minute she had some blood transfusion and platelets and they stuck her on a very high dosage of steroids immediately so steroids side effects she was eating like a horse I can't explain how much she was eating, like 6 eggs in a day and Fatima has never eaten an egg in her life. A whole Easter Egg and she never touched chocolate she was asking for all the stuff she had never asked for.

Did they give her steroids to boost her weight then?
No, it was basically for liver enlargement if I remember and plus the initial chemo they gave her they had to give the steroids along with it... it was not to boost her weight at all no.

It was a secondary effect then?
Yes she would get very puffy very big...and then...hair... Losing hair was not a problem at all because she had long hair up to there when she was diagnosed and I said to her because you are going to be in hospital it going to be very difficult to wash can she have her hair cut? So her hairdressers really convinced her to have her hair cut and we kept it virtually short so when she loses it its not very long she gets a shock. When she lost it completely it still I don't think it affected her at all because I kept on saying it will come back again. She was not in school at that time and plus everybody here was in very much in a similar environment so it didn't make a lot of difference

All her peers in the hospital bays they had no hair or very little
So obviously as far Fatima was concerned it was something very normal

Did she like long hair?
Oh yes.

So persuading her to cut it was that difficult?
I wouldn't say it was that difficult because she probably knew within herself that she was not 100% and plus any doctor and anybody who explained anything Fatima did understand Fatima was never a difficult child. I never honestly had a scene like I have seen here, children kicking on the floor, Fatima never did that she probably would be very reluctant at first and then forgiven within minutes

So quite placid made it easier for you?
Yes and probably made it easier for her to be honest.
Can we talk a little bit about what you and your family were experiencing your first response?

My first question was to the doctor was we're first cousins does it have anything to do with that? And he said no, then I did mention the 2 things that I said that I was x-rayed during my pregnancy and Fatima was under ultra violet light just after birth could it be anything to do with that or were some things really not right from day one and was just may be found when she was 2 I think no body had the answers to all of this because again her growth was fine she was tall, she was not skinny she was not underweight her speech was absolutely fine.

How much do you think it might have been anything to do with the x-rays or the UV light don't you know or are they meaningless questions?

No they are not to be honest because they do say it could be a possibility if only that 'could be' would be answered, I am sure there are surveys carrying on one day or another they will find the answer and its like 10 years somebody having Leukaemia they probably wouldn't have as much of a chance as Fatima has today now so probably 10 years from now I am sure this 'could be' will be answered definitely

And why did you think that concenuous relationships might have a baring?

Because we do have a family history of where some retarded children have been born because with the very close relationship, my aunt's son got married to, I'm sorry my great aunt got married to one of my uncles then their children got married again and their children and eventually they had children who were either deaf and dumb or totally retarded and we always have this fear in our mind that we are first cousins but this was the first this was the first question we did put.

And are you confident now, of course you're expecting again, but are you confident now?

Yes I am fully confident that it has nothing to do with being first cousins.

Sometimes people ... think all kinds of things ... about someone might have done? On them or something like that. how much do you believe in that? Or does it not even cross your mind?

It didn't cross my mind as much as when people mentioned it, you are already living in fear anyway because she was so forward for her age and she was always talking maybe something had happened nobody has to do anything anyway, it could be by your own parent. Yes it did cross my mind but to be honest it came out very quickly as well because if things like that happen god knows what would happen.

I just asked.

No it's ok, you laughed at this because when Fatima was diagnosed somebody came up to me and said 'oh tell don't everything, what she's got, don't forget she's a girl and she's got to get married one day. Do you know I really felt so hurt and I thought I am more concerned about my daughter living right now I don't care if she is going to get married, maybe at that time I didn't asked but when she asked again I said well if she wants to get married she will get married and if it wasn't to be it wouldn't be regardless of her illness.

Was it a close like a relative?

It was a close relative of my husband, but I thought what a cheek to tell me that because it was no way I thought it was something to had because the more you hide the more difficult it becomes for everybody to understand and cope with the situation. Once I understood what Fatima had we were both over the shock and accepted what she had regardless of whether she was going to make it or not, anybody who asked me I told them the truth, I said that's what's happening its 2 years long things can go up and down we will just have to see

Did you have a dad in Pakistan?

My dad has died. My dad died during December.

Sorry

No it's ok

So when you went to Pakistan your dad was alive then?

Yes, yes.
When Fatima was diagnosed did you tell your dad and whoever else was in Pakistan? Did you tell those people?
Yes, I did. Eventually when I really realised what she had although we were still in hospital cause they kept on ringing and saying 'why is nobody answering the phone at, did she reach safely?' Cause she hasn't given us a call. So obviously everyone was saying 'oh yeah they're ok but they're in hospital. So it was like a little knowledge coming out from here and there but its not the truth so we said its not fair with anybody you have to tell them.

What did it feel like your mum died of cancer and your little girl has got some kind of cancer, what did that feel like? Or did you not relate to that?
A mum is a, I don't know how to put it, because mum never saw me and always wanted me to have a child and at that time I was too stubborn or maybe too young to decide if I wanted to be a mum or not I kept on saying no I don't want to, I felt very guilty when she died and I didn't have a child. And when Fatima was born I was happy and sad at the same time and again everybody kept saying only if she could have seen it.

People are cruel
They don't seem to realise the pain they are giving because she was alive forget what my mum has been through but then again at first I took it then I said 'if only god had formed it in a way that she was going to see it she would have seen it nothing would have stopped it forget the planning' things go wrong don't they people don't want a child and they still get pregnant so if you really have faith in everything is an act of god then maybe it was not for her to see. Obviously it takes a lot of courage to say that because first you are very........ I think Fatima herself has given the strength, I would things that I have taken twice and probably answered somebody back with Fatima's confidence and her strength I told them straight away to their face that and sometimes it amazes me that its really her that has brought that change in me.

So you have changed then?
Definitely!

I have a question about change ... its almost like you changed as a, you know you had Fatima two years and she was ill, but you changed as a parent yes... But it also sounds like you've changed as a person in the way you deal with people and the way you deal with criticism maybe?
Absolutely

Can you talk me through that. That is a nice example you gave me but
When I got married I was only twenty, it was a big culture shock when I came here.

Were you brought up in Pakistan?
Yes! I have been educated in Pakistan, I was brought up in Pakistan. Always wanted to see England and see what it was about but when I came here it was totally different story. I know I should not mention it but my family was, I think was more educated in comparison to Zaid's family, not Zaid's dad, because Zaid's dad is my family as well, he's my first uncle.

Is he your mum's brother?
Yes, yes. So when I came here my expectations were very good daughter in law, cook clean and sit at home unfortunately I did not do that. I did clean I did cook, not with pride I just did it and out of the house. I joined Croydon College I was doing work so obviously it was something they never expected for me to do and I was a Pakistani girl, what am I going? But my mum was assistant director of technical education at home, of course I saw my mum was working ordering people so I just could just couldn't take that order on me. Although my mum in law herself was running a business with her husband but she just wanted me to sit at home.

Did she just want you to take care of the house?
Yes, and I don't think ? is very capable of doing that because even mum was like ironing cooking and everyone for me and she kept on warning me that 'you should take this responsibility'.

But you are only child as well?
I was adopted by her.
But you were an only child ... very loved and indulged
Absolutely and centre of attraction and suddenly there was all this criticism that you are not able to all you speak is English and you don't intentionally speak any Punjabi but it wasn't that my husband wouldn't speak anything else but English and I'm here to obviously live a life with him not with everybody else so it was very, and why am I wearing jeans when I never wore them in Pakistan?

But if you have an opportunity why not wear it?
So it was...

So their expectations were different because of what they thought they were going to get as a daughter in law but got disappointed.
And at that I was very naïve I wouldn't answer back I would end up in tears and cry and then just not talk to, well I didn't have any friends here I didn't have any relatives and plus my mum did warn me not to trust a lot of people because probably on your face they will say yes and then go back and snitch behind your back so I was very careful so they would all say 'she's very quiet' but obviously I just kept on listening to what they had to say. So obviously I think that built up a lot of bitterness and resentment and

Were you all right with your husband?
Absolutely wonderful, no problem at all, no problem at all.

Was it, for you, were you not particularly happy about living with your in-laws?
I hated every bit of it but I was very scared that if I walk out on them and they are not able to cope with the situation I might be punished by God so I just kept on saying to myself no you just have to make them realise they are wrong. So I think that I took a lot of stick for a good 3, 4 years then I started answering them back and I said its not how you see it, this is the way and you have to accept it. You left home 35 years ago and values have changed.... I mean what the confusion is, one is that we are always getting our religion confused with the culture and we are always thinking that culture is the best thing but is not that we have to really leave the culture behind and really follow the religion.

What about Zaid's sister ...
Well yes they are very advanced when it comes to their children but very backward when it came to a sister in law, it probably sounds horrible saying that but if she is good to me today it is because I have never ever exercised anything nasty on her children and if I kept on taking a lot from her one day, somebody has to break down you know there is only so much you can take.

Sounds like you had a very rough time for the first few years?
I had a very rough time the only person who kept on trying to be nice to me was Zaid's brother's wife but then again it only seemed she was nice but she wasn't.

Were they all relatives?
Yes, Zaid's sister is married to.....whoever, then his sister is married to Zaid's brother so they have interchanged the families, so I was a real........

 Outsider?
Yes I was the outsider although I was part of the family....Yes, I mean they would all sit together and I would just end up in a skirt and they would say it's not right but then again if I am wearing tights and not showing any flesh what my religion does not allow me I understand you can tell me off but as far as the culture is concerned it was just made for man's convenience.

You mean man as in man?
Absolutely!

As in male?
Absolutely
But it is amazing now that her children have grown up it doesn't matter if they wear a short top all because they wouldn't listen so I find this very hypocritical but things will change that generation is going to be totally different they don't even want to go back to Pakistan as far as they are concerned what have they got there? Grandparents who they only see every 5 years so they are not going to be attached. …I mean I think love only grows when you live together. You give trust, you respect each other and that is how love is created, that's how families are made but if half your family is in Pakistan you have to get on with your life.

Sounds like you are a practical, hands on type of person
It doesn't make sense. I mean I would love Fatima to go back to my mum's grave but I can't expect Fatima to do it. I mean the poor child won't have time and I will just have to accept it and not put any pressure on her.

Has she been or have you been since the diagnosis?
No, we just did not want to risk anything, we did not book any holiday in this past few two and a half years apart from twice to Euro Disney and that was only when she had a very good blood result no maintenance so we knew if she was without blood test for a week things would not go wrong and even then we were only

You were only a train away,
Absolutely

An hour away.
No we didn't take her anywhere, she is going now in December
Is she? Pakistan?
She is really looking forward to it, I don't know what she is expecting really, where am I

Are you looking forward to it as well?
Yes, cause obviously no matter what I have said I am still attached to my friends and lots of other little things that are just, go there and look at the little things that remind me of my childhood, my college life.

How long have you been here now then?
I have been here 14 years.

So you are 34?
Yes,

You have been here a long time then.
Yes, but I want to live here for my daughter now not for anybody else. Before I didn't have Fatima I kept on saying said we must move to Pakistan I don't think I can cope but the day I had Fatima, I said 'No Fatima will not be able to cope my country is too much for her.'

Was Zaid happy about moving back? Did you make plans?
Zaid, I tell you Zaid is, Zaid was I would say not is Zaid was such a vulnerable person, anything to make me happy he would make an effort for it but really really thinking very deeply I knew he did not know the language he couldn't read any signposts so where would he get a job from.

What does he do here?
He is a network engineer, he works in the coms room at Gatwick Airport whenever the network goes down

He is an IT kind of person. And I wanted to ask you, what your highest educational qualification?
Just a Degree.

So we are talking about the cause of the illness that's how we got into this discussion about cultural.... Some people have mentioned it but then it is not that I didn't pray for her ...name 1 prayer that haven't done for her... one thing that I do believe that you carry on with the medication but prayers do change
your life in that way that any person who prayed for Fatima somebody's prayer must have been heard. But obviously you can't say you just pray and not give the medication because that is not going to work because even Allah says you have to do whatever is necessary.

So we were talking about whether you think it's increased your faith or strengthened it or reinforced it or hasn't it changed cause you talk about the power of prayer. I was very religious even before Zaid's illness, I actually lost a little bit.

Right
Saying well if I was praying to you so many times and I don't tell lies and I am honest and I haven't done this why my daughter but within days I corrected myself and thought maybe if he has given me this exam the reward is there as well whether it is in Fatima's getting better or Fatima is going to be rewarded something for suffering so much at such a young age I actually came to terms very quickly that really whatever is happening to us I mean apart from if I am going to get drunk It is my own fault, but apart from that if anything happens to me as long as I am doing what I should be doing as a right person there must be a reason for it.

How, in the last 2 - 2 1/2 years, how has she done in her treatment? How has she coped with it?
Apart from her major blocks when she became very ill

When she was having intensive?
Yes, I think she's coped very well, she thought hospital was fun she made friends in M hosp Hospital and in Marsden so she was always, so every time she had a temperature she said ' lets go to MayDay hosp' I mean we hadn't even decided yet whether we were going to MayDay hosp or not so she never said no. I think the credit really goes to members of staff in MayDay hosp and in Marsden cause if they did not make it nice for her she probably would have said no.

So the hospital had made it nice but to me it sounds like she has a good resilient personality
She has, she has...She can be made happy very quickly, Fatima is one of those people. She can be

So you can distract her?
Very quickly yes

Does she, she is now 5?
Four and a half.

Four and half does she have any more of a sophisticated understanding of her illness now compared to 2 years ago?
Oh yes definitely, I think in comparison to her age her friends say I've got the runs and she says you mean diarrhoea and they say what is diarrhoea she says when you've got the runs. It was amazing when her teacher told me that Fatima's awareness of medical knowledge is amazing, I said she has no choice. I mean she knew all the names of her medicines when to take them when not to take them. She hated septrine which she had to take every week twice a day, she said I don't like it eerrr it's horrible but on the contrary the chemo that I gave her through her mouth she had no problem with it.

She didn't?
No she took it down. She is missing her porta cap though.

She had a port then?
Yes she had a port which nearly got blocked twice, out of the totally ignorance of the nurse at M hosp.

Where was it done? Where was it put in?
It was put in here, it was put in at RM and taken out here as well but it nearly got blocked by a nurse in MayDay hosp.

How do they get blocked?
Fatima was having a blood transfusion and suddenly the blood was not going in so instead calling a consultant and shutting it the right way. She took the blood from the, well there is a needle and you attach it to the blood transfusion tube she took if off there and the blood started clotting so she put it
back again and I said her what did you do that for? And she said it was getting clotted so I said what do you think it is going to do now? The next minute the blood did not go up at all, the consultant at MayDay hosp spent two and a half hours of struggling and I said to her in the end not being funny but if only they were a bit more educated she couldn’t multiply 4 by 8 so how is she a nurse, you know you have to calculate the doses to give exactly, because not every child can take, I said how did she get her job?, I really want to know and every time I saw her face I said ‘I am not having this nurse for my child’

Did you feel confident enough to say that?
Oh yes, absolutely. I think when it comes to your child it is a totally different thing, you just tell them not to do it. It is like the junior doctors are not that obviously aware of what they have to and what not to do when a child is nutrapenic and stuff like that the consultants are, but obviously when you are in MayDay hosp you are more in the hands of junior doctors but it is amazing how they are always willing to listen to a parent. Some of them will put an instrument on the bed and I will say if she is nutrapenic can you just allo wipe for me and say yeah no problem they will really asked how much dosage of heparin are we giving her so it doesn’t block her port.

Sounds like you are the expert a bit of a role reversal.
It is just really to be honest we had to be aware of what was happening to Fatima, I mean I am not trying to be funny if we left it all to the doctors, I am talking about the share care not about the specialists the doctors in Marsden I have no doubt about whatever they did we had to take it cause they are the ones who taught us all about that, but when you go to a shared care hospital when you are not aware of what is happening I think the sticks come out.

So you had to be on the ball?
Well you have to, even when they came in the middle of the night to give Fatima the medicine, I honestly made myself go up and look what he was doing. I mean a doctor who has been in an emergency ward for 24hrs how do you expect that doctor to really sometimes have that brain and strength...and whatever ...whatever I leant from Marsden whatever the Drs said to me and the nurses did I was always, my eyes were always open. If things were not done in the same fashion, I can understand they were not disastrously going to kill Fatima but they might have caused her some discomfort and I just did not want that to happen in any fashion to avoid anything.

What was your experience of shared care at Croydon?
Problems... Yes, on a number of occasions. We had this trouble every time Fatima's port was to be accessed at MayDay hosp the person whoever was to do it, would not get it right once and they kept taking the needle off and putting it in taking it off putting it in by this time the child was totally out of hand. They don’t want to be poked with needles all the time. I remembered still, I refused on a number of not a number of occasions but a couple times I said if the port is not accessed in RMI refuse to go to MayDay hosp and obviously that cause a big hooha why should we do it we have got enough things to do on our hands. But the thing is from parent's point of view why should my child be the learning background for MayDay hosp. I am sure they can put ports in little dollies and let them.....accessing the port was a nightmare in shared care but if you go now at the end of Fatima's treatment nearly every nurse is was an expert. We kept on shouting and shouting and I am sure most of the other parents must have done and somebody must have said ‘hold on a minute things are not right’. I mean I said I would pay a duty nurse you know you have a weekly blood test, the community nurse does that the nurses don't come from hospital it's a specially trained nurse who comes out and does it, I said I would even pay that if you could do that, cause Fatima was losing her confidence in getting her port accessed.

Yes...
And then they wanted, they asked me if a junior doctor to do it, I said of course I do mind, and A would say to me don’t be so, and I would say I am sorry I have to, there is no way, I mean I can understand they have to learn but they can be a different way of learning. I mean once you have expert it I don’t mind.

so you were making it clear what you were prepared to put up with and what you were prepared to put your child through?
Absolutely. It was like we were hearing one thing from RM. I mean they used to use heparin solution at one point and then suddenly one day I came and they said we are not using it we are using hapsul or
maybe I have forgotten the name which is slightly more concentrated than the heparin and will help in
not to block the ports they gave me the literature they said the letters were sent out to shared cared
hospital but when I went to MayDay hosp they were using the old one. I know it would not have made
a big deal but if something has been introduced then why use it? We haven't got it I said haven't you got
a pharmacy at the hospital? Oh well..... I said hold on a minute I only live 20 minutes away I will
drive and get it from the fridge. So I gave it them and said next time can you make sure you have a
stock as well. I mean everything that I could help to make life easy for the hospital as I don't mind but
they have got to really make and effort understand that a) your child has an illness which is very
critical, that every time you come to the hospital its nearly once a month twice a month because they
become nutrapenic they get some kind of infection they could be there for a week life has a bit more
comfortable especially when you see a specialist hospital which offers you everything

And once you had that and then to go back
It's very difficult to look down there... Why should we put up with that kind of quality or lack of quality
when we have had it? I mean I have been into MayDay hosp hospital, without exaggeration I have
picked up an alco wipe and dusted the whole room and I have used up the whole box.

I have heard that before.
And I thought hold on a minute you have a nutrapenic child with god knows what infection, who is
doing the cleaning? Nobody will come and clean the floor I am down on my hands and knees doing
exactly what I do at home. Fine I can do it but not everybody can do this...I mean the reason you have
to have shared care is when a child goes down with an infection a normal hospital can take of it but I
think they just don't have the facilities to offer for such a sick child...And also lack of Drs ... if only
they knew they probably wouldn't, they wouldn't give me, they wouldn't change the bed everyday so I
said where do you keep your stock she said over there so every morning after I had given Fatima her
breakfast I change the whole room and she said well not all mums do it and I thought in my heart well
why should they? Well I can understand that nurses don’t have the time I totally understand and
sympathise but then the hospital should have some other source to help the mums who go there with
children like this.

What about here? What was it like here in terms of cleanliness?
Absolutely totally different, it's actually clean and spotless.

So they have a real understanding how children can become vulnerable?
And plus if they all are nutrapenic there is hardly any chance of passing anything to each other apart
from your own body bacteria.

What about your behaviour towards Fatima do you think that has changed at all?
No I am not soft at all she gets little telling off, not little a lot of telling off. She gets now and then
beating on her bottom she goes' ow its sore'. People have stopped me why do you do that I say I am not
going to make her think that I am the only person you have to sympathise with me I says she has to live
a normal life. She was diagnosed at 2 and exactly 2 1/2 we stuck her in the nursery but we told the
school categorically what her needs were and they were absolutely wonderful and understanding that
they do not give Fatima any water but the water that was filtered from home they do not give her any
tap water they knew that Fatima was not confident in running, they have never forced her into running
sport she was not very confident coming and going up the stairs so the teacher held her hand all the
time.

Did you get any of the community nurses going from here to the school?
No the School was very understanding everybody said to me why are you sticking her so early? She
could do without it I said no why should she miss it if has the potential of learning, she should be with
children she should be laughing if not learning at least. She went to lower nursery she to went upper
nursery and now she's in to reception and I think I am more firm with her now, I mean she's just
finished her treatment a month ago but nobody could tell, I mean teachers have this thing oh I know
she's very special and your being very overprotective but maybe overprotective in some other areas
which were unavoidable like with her food and her cleanliness not otherwise but she got her
punishments she did anything wrong we had a silly step at the house and she had to sit on it regardless
and she would say well I have realised and I said well you have and you keep sitting there.
How is she with the news?
She is very very excited.

How far are you?
Five months, I've got a long way to go I feel like ten months...Everybody says I'm huge cause I'm very tiny otherwise, I'm only size ten and I'm size fourteen now.

Heavens
I say yes but there's a reason...

With the benefit of hindsight do you think that there are some things that were done here that should not have happened we have talked about the conflict with parents and professionals but was there anything else that they could have done which might have been a bit more helpful with the way they done things here
I think, as I probably have mentioned before, when you are under a shock even though somebody has not doing anything wrong you think they are doing wrong and I have had personality clashes with 2 people one was the receptionist Shirley which after that I thought was an absolutely wonderful person and one was a nurse called Sally. With Shirley I could understand she was just firm and that was her way of dealing with things and I understood immediately once we had come over our shock. It's like I still remember Fatima came back and she said I want to see my room where I was diagnosed so I said come on then and she said I'm afraid you're an outpatient your not supposed to go there, and I just thought what difference would it make if she does have a look its not going to make a big deal is it it's just around the corridor so I just completely ignored her, took Fatima there and came back, but then I thought, wicked woman but then as time went passed no she was doing her job if every parent started doing that its not possible is it?

So do you think it was the way she said it then do you think she could have said it slightly different?
Yes it was the way she said it. obviously when you are not completely well you are under the weather everything just seems to be aimed at you and the same when Fatima was playing in the ward play room and the play worker came and said 'excuse me you're an out patient you can't play here' and I said why? and she said well you can play there I said no but she wants to play here and she said but this if from my boss and I said come on call your boss I'll speak to her. She goes have I upset you? I said no you haven't upset me you've been sent by your boss but why I feel upset is this child has just left the ward 2 days ago she doesn't know any better because she was in for four weeks so you've have got to give her a chance really to understand your rules and regulations you try explaining to her that you are an out patient now not an in patient. She said 'I can understand' I said no you cannot understand otherwise your boss would not have sent you.

So did her boss come and talk to you?
No she never did so I just carried on playing and eventually Fatima understood that whenever she is in outpatient she cannot... Its like little things, I know hospitals have to be run with some kind of rules but I think little things can be ignored in a situation like this, it was not absolute necessary that oh she's an outpatient now can you ask her to move out now cause I thought it was totally unnecessary.

Yes that sounds fair ....what about the consultant you talked about C being great?
Absolutely wonderful person she, if C was not there I have always refused to see a consultant, only on the basis that they do not know the history of my child they don't know Fatima as a person so what's the point of wasting my time and their time which I am sure that the hospital does not appreciate that.

You don't feel they appreciate it?
No because they said to me why? I said well purely because Fatima was diagnosed in the hands of CP she knows inside out without opening her file so why should I go and see somebody who is going to look at the file struggle with what is Fatima all about and then tell me some technical point which I can read a book and find out.

So have you always seem C then?
I've always seen Cathy P.
And have you ever felt that to be a problem?
Never never, even if I have left a message with the secretary, she might not be able to come back to me straight away, but maybe next day or day after tomorrow as long as she is within the station she has rung back.

Ok that's good. You've got a consultant who understands you and your child's needs. What about just a general question as to how you and Zaid have coped you sound like you know everything that is going on with Fatima's treatment and who to contact and you are not very timid about standing back you will say it if you feel it.

Yes

Would you agree?
Absolutely.

So I have a good understanding of what you're like what about Zaid? You said something just before about Zaid said oh don't say that.

Yes we did have our arguments a lot of arguments

About the way you approach things?
Not just approaching things, I think because we were not having enough time with each other and whatever time we had we were in hospital or with Fatima because, it was interrupting everything because the initial six months were very crucial, I think we were taking it out on each other, that was our outlet. So the Doctor gave Zaid an anti-depressant.

Really? Zaid?
I was on anti-depressants already because

Did you see a Psychologist here then?
No, no in the doctors surgery, he, no it was a she I think said it was quite a deep rooted depression because it is post natal its probably before my mums death then my mums death made it worse and then having a child a hormone imbalance made it even worse so she stuck me on antidepressants, which helped me I was laughing I didn't see everyone was targeting at me, when Fatima was diagnosed I thought Zaid was snapping at me so I just being a stronger person in comparison to him and I think we were just taking it out on each other so when he was on anti depressants it helped both of us.

Was he happy about being on the anti depressants? Did he feel the need to have something?
Yes, I think at that time he said yes I need something because things are not right.

It sound like you weren't coping just immediately after Fatima was diagnosed you realised you weren't coping effectively.
We probably were but inside we weren't.

Are you both off now?
Yes, we are both fighting again. Well I had no choice because I was pregnant, he I don't know for what reason I still cannot understand up till this day he said 'I'm not having it'. We have this kind of disagreement in Fatima's room he was playing with a clip and he stuck it in his nose and I said how would you feel if Fatima did it to you and he goes he wouldn't think much of it and I said well I would tell her off because a its not a toy and it could hurt me and he said your always a perfectionist doesn't matter you have to play and I said 'no you don't, if Fatima did it to some other child the mother might just be at our door step play with her with things that if she did it to another child it doesn't matter' so we always have these kind of little disagreements where we both don't shout now we just go off in different rooms.

He thinks he's all right now though, Zaid?
I personally think he needs help but he doesn't think he does.

Do you think it's to do with Fatima then?
I don't think its any thing to do with that, could be because he said to me so many times at least your outlet is you cry when your on your own you're not scared and ashamed to talk to anybody but I can't
talk to anybody about my daughter's illness, so yes it could be Fatima's illness but I think that it is only a portion of it.

What about talking to friends?
He had college friends they were all all right when he went out with them, he ate with them and went to a disco but when suddenly he settled down with his wife they left him they don't want to know. When Fatima got diagnosed they all gave a call to say well I feel sorry but nobody actually made an effort to come and see so we thought hold on... All sorts Indians, Pakistanis, Kenyans so but a whole bunch of Asians I don't whether it was just...

Sometimes when you are at university you have little cliques don't you? Do you understand this, well you seem to understand very well the course of your child illness and treatments, I do

What do you think her future therapy I mean she's off chemo now isn't she?
She's off everything.

What about risks and prognosis?
Twenty percent of children relapse, Fatima could be one of them Fatima could be not one of them there is no real answer yes or no, I would love to hear that from Kathy's mouth, no Fatima is totally clear but there again there is no hard and fast rule that Fatima would get it or Fatima wouldn't get it.

It that something that makes you nervous?
Yes it does, it does give me shivers down my spine to be honest I think god forbid if Fatima was to relapse what would happen then another drag of two and a half years and then if we don't find a bone marrow match but then your don't want to think about that.

Now did they test for bone marrow the first time around?
M didn't need a transplant.

I know she didn't, I know she didn't but did they do those checks anyway?
I actually could not tell you.

Ok don't worry.
But my main fear when it comes to a transplant that not many Asians come forward to give it, its some kind of pain involved in giving marrow so they would rather avoid it. I mean my hat is off to all these English people who come forward and give it at least.

I remember this child who had leukaemia and they did this broadcast on the local television for an Indian family and I remember thinking I haven't donated blood never mind bone marrow.
Because it is such ... our people don't exactly know what leukaemia is , at least other people do and if you do tell them they make up such horrific stories in their minds.

They blow it out of proportion come out with things that really aren't helpful at all.
Well she's got another 3 years and if 3 years she doesn't relapse and things goes smoothly she should be given the all clear for life but then again she will always have this higher risk of relapse then anyone else or me.

What about plans for the future?
Well its just really getting to be honest just getting together after a very long time and this baby really to be honest is for Fatima never wanted another baby never felt the need for it but Fatima kept imposing this question my friends got a sister when am I going to have one, mum please can we buy a baby. I'll be very honest with you I am only having this baby for Fatima. I know probably as a mother sounds very nasty but it is something that Fatima can depend on.

What about Zaid is he happy about it?
He didn't believe me, I went to see shara khan, he just said no I'm lying I said no all right then, it came as a shock to him.
So it wasn't planned, I mean it must have been planned.  
It was planned but he thought it wouldn't happen that quick so he just didn't believe it.

There was nine years in your marriage before you had Fatima, so you didn't want a baby or it just didn't happen?  
I was too... I was too scared of pregnancy and childbirth I was too, too scared and then I never thought I was fit as a mother at the time. Too much involved in outer life going to college it was like, either you, you cant do everything when you become a mother you have to give up a few things and at that time I don't think I was ready to give up those things. I was like exploring a new role for myself don't forget I've come from Pakistan with very limited resources there and suddenly you come here and everything is there.

END OF INTERVIEW