LIFE AFTER STROKE:
Using Interpretative Phenomenological Analysis
To Understand How Stroke-Survivors
Make Sense Of And Manage Life After Stroke

by
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CONTENTS OF VOLUME ONE  
(ACADEMIC, RESEARCH & BRIEF CLINICAL DOSSIERS)

Introduction to Volume One  Page 1

ACADEMIC DOSSIER  Pages 2-84

Introduction to the Academic Dossier  2

Adult Mental Health Essay  4
"Would there ever be a scenario in which a psychodynamic rather than a cognitive behavioural approach might be more appropriate in the treatment of obsessive-compulsive disorder?"

People With Learning Disabilities Essay  26
"Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities"

Children And Families Essay  46
"'Early intervention works'. Critically discuss the evidence for the effectiveness of early intervention approaches for behavioural problems"

Older People Essay  65
"'Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people.' Critically discuss this statement."

CLINICAL DOSSIER  Pages 85-110

Introduction to the Clinical Dossier  86

Summaries Of Clinical Placements  87-93
Adult Mental Health placement  88
People With Learning Disabilities placement  89
Children And Families placement  90
Specialist placement in Psycho-oncology  91
Older People placement  92
Specialist placement in Addictions  93

Case Report Summaries  94-110
Adult Mental Health  95
People With Learning Disabilities  98
Children And Families  101
Specialist placement in Psycho-oncology  103
Older People  107
# RESEARCH DOSSIER

**Introduction to the Research Dossier** 112  
**Research Logbook** 113  

**Service Related Research Project:** 120-152  
"An audit of referrals for initial assessment two community mental health teams"

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>121</td>
</tr>
<tr>
<td>Abstract</td>
<td>122</td>
</tr>
<tr>
<td>Introduction</td>
<td>123</td>
</tr>
<tr>
<td>Method</td>
<td>124</td>
</tr>
<tr>
<td>Results</td>
<td>127</td>
</tr>
<tr>
<td>Discussion</td>
<td>134</td>
</tr>
<tr>
<td>Conclusions</td>
<td>136</td>
</tr>
<tr>
<td>References</td>
<td>137</td>
</tr>
<tr>
<td>Appendices</td>
<td>138 onwards</td>
</tr>
<tr>
<td>• Appendix One - Form A (Pre-assessment Data Form) &amp; Form B (Post-assessment Data Form)</td>
<td></td>
</tr>
<tr>
<td>• Appendix Two - Reminder for team</td>
<td></td>
</tr>
<tr>
<td>• Appendix Three - Qualitative coding form</td>
<td></td>
</tr>
<tr>
<td>• Appendix Four - Table of presenting problems</td>
<td></td>
</tr>
<tr>
<td>• Appendix Five - Feedback to the CMHTs</td>
<td></td>
</tr>
<tr>
<td>• Appendix Six - Audit Declaration Form</td>
<td></td>
</tr>
</tbody>
</table>

# Qualitative Research Project 153-185

"The desirability of having personal therapy during clinical psychology training: A qualitative analysis of the views of third year trainee clinical psychologists"

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acknowledgements</td>
<td>154</td>
</tr>
<tr>
<td>Introduction</td>
<td>155</td>
</tr>
<tr>
<td>Method</td>
<td>155</td>
</tr>
<tr>
<td>Analysis</td>
<td>157</td>
</tr>
<tr>
<td>Overview</td>
<td>164</td>
</tr>
<tr>
<td>References</td>
<td>167</td>
</tr>
<tr>
<td>Appendices</td>
<td>168 onwards</td>
</tr>
<tr>
<td>• Appendix One - Interview Schedule</td>
<td></td>
</tr>
<tr>
<td>• Appendix Two - Information Sheet</td>
<td></td>
</tr>
<tr>
<td>• Appendix Three - Consent Form</td>
<td></td>
</tr>
<tr>
<td>• Appendix Four - Background Information Sheet</td>
<td></td>
</tr>
<tr>
<td>• Appendix Five – Sample Transcript</td>
<td></td>
</tr>
</tbody>
</table>
Major Research Project

"Life after stroke: Using Interpretative Phenomenological Analysis to understand how stroke-survivors make sense of and manage life after stroke"

Acknowledgements 187
Abstract 188
Introduction 189
Method 202
Analysis 210
Discussion 237
References 247
Appendices 255 onwards

- Appendix One - Letters of ethical approval from (a) local NHS Trust and (b) University of Surrey
- Appendix Two - Letter of approval from local Research and Development Committee
- Appendix Three - Letters from local NHS Trust approving later protocol amendments
- Appendix Four - Invitation letter for patients
- Appendix Five - Participant Information Sheet
- Appendix Six - Tear-off response slip
- Appendix Seven - Interview Guide
- Appendix Eight - Demographic Form
- Appendix Nine - Consent Form
- Appendix Ten - Example Transcript
- Appendix Eleven - Letter to G.P. informing of patient's research participation
- Appendix Twelve - Table matching sub-themes to suggested adaptation and interventions
INTRODUCTION TO THE PORTFOLIO – VOLUME ONE

This portfolio comprises of two volumes that contain work completed as part of the PsychD in Clinical Psychology.

**Volume One**

Volume One of the PsychD in Clinical Psychology portfolio comprises of three dossiers of academic, clinical and research work.

1. **The Academic Dossier:** Four essays pertaining to each of the four core placement areas written during the course.

2. **The Clinical Dossier:** Summaries of the six clinical placements undertaken throughout the training programme and summaries of the five clinical case reports completed over the course. (Due to their confidential nature full versions are kept in the Department of Psychology at the University of Surrey, see below).

3. **The Research Dossier:** The Service Related Research Project (Year 1)  
The Qualitative Research Project (Year 2)  
The Major Research Project (Years 2 & 3)  
The Research Logbook (Years 1, 2 & 3)

**Volume Two**

Volume Two of the PsychD in Clinical Psychology portfolio comprises the full confidential clinical dossier, which details the experience gained over the course of the clinical placements. It contains the placement contracts, clinical placement evaluation forms, logbooks of clinical activity and correspondence written for the six clinical placements. Clinical case reports for the four core placements and one specialist placement are also presented in full in this volume. Volume Two is presented in two parts. Part 1 contains documentation pertaining to Adult Mental Health, People With Learning Disabilities and Children and Families placements. Part 2 contains documentation pertaining to the Older People and two specialist placements.

Due to the confidential nature of the material within this volume, Volume Two is held in the Department of Psychology of the University of Surrey. All client names and other identifying details have been changed in order to maintain client and service confidentiality.
INTRODUCTION TO THE ACADEMIC DOSSIER

The Academic Dossier contains four essays, one each from the client groups studied over the course of the training program. The essays critically examine a range of psychological theory and practice as applied to a variety of life-span issues.
ADULT MENTAL HEALTH ESSAY

“Would there ever be a scenario in which a psychodynamic rather than a cognitive behavioural approach might be more appropriate in the treatment of obsessive-compulsive disorder?”

April 2002

Year 1
INTRODUCTION
“Freud (1926), at the age of 70, concluded that the problem of obsessional neurosis, ‘unquestionably the most interesting and rewarding subject of analytic research,’ had not been mastered.” (Brandchaft, 2001, Page 253). Indeed prior to significant advances in understanding and treatment in the last thirty years, there was resignation to the poor prognosis of obsessive-compulsive disorder (OCD). Much of the recent increase in optimism has been claimed by developments in pharmacological, behavioural and later cognitive, approaches. Therefore, following an introduction to the main features of OCD, the current essay explores the relative strengths and limitations of two psychological treatment approaches for OCD: Cognitive-behavioural therapy (CBT), the current treatment of choice and, psychodynamic approaches, stemming from the oldest theoretical account. It will be examined whether there are scenarios in which psychodynamic approaches might be more appropriately used than CBT.

Definition
Classified as a neurosis and one of several anxiety disorders (de Silva, 1994a), “[o]bsessive compulsive disorder [OCD] is a chronic and disabling illness” (Matthew, Simpson & Fallon, 2000). OCD is characterised by obsessions, compulsions, or both. Obsessions are recurrent and intrusive thoughts, images or impulses that are recognised to come from within, are resisted by the individual and cause significant anxiety. Compulsions are intentional repetitive behaviours or mental acts that may occur without obsessions but are commonly performed in order to reduce the anxiety resulting from obsessions (Foa & Franklin, 2001). While many with OCD recognise the ‘senselessness’ of their obsessions and compulsions, insight lies on a continuum (Foa & Franklin, 2001) with children, for example, typically showing less insight than adults (Foa, Kozak, Goodman, Hollander, Jenike & Rasmussen 1995; cited-in Foa & Franklin, 2001). Obsessions usually reflect personally repulsive themes and a fear of future harm with an urge, and attempts, to prevent its occurrence. There is often an apparent paradox such as a caring mother having thoughts of harming her child (Salkovskis & Kirk, 1989).

Of interest is the finding that obsessions and compulsions are part of usual realm of human experience. 90% of adults are estimated to experience fleeting unwanted thoughts or have compulsions to check for example, a locked door (Rachman & de Silva, 1978). However clinical significance is determined by their intensiveness and pervasiveness - the extent to
which obsessions and/or compulsions cause severe distress, are time-consuming and interfere with life functioning (DSM-IV, 1994).

**Prevalence**

OCD is not a new phenomenon, nor one that is confined to Western cultures (Greenberg & Witztum, 1994). There are accounts as early as 563-483 B.C. of the ritualistic sweeping of Buddhist monk (de Silva, 1992) and William Shakespeare’s dramatisation of Lady MacBeth’s handwashing rituals (Salkovskis & Kirk, 1989). However many suffer secretly and with embarrassment for years before others realise the extent of the problem or treatment is sought (Rasmussen & Tsuang, 1986). This may help explain why OCD was once considered rare, with lifetime prevalence reported at 0.05% (de Silva, 1992). A recent survey of nine populations however found rates between 0.7% to 2.1%, observing a slightly higher prevalence among females than males (Bebbington, 1998). Prevalence rates of 2% to 4% are reported for children (Geller, Biederman, Jones, Park, Schwartz, Shapiro & Coffey, 1998), with OCD features described as essentially similar in children, adolescents and adults (Flament & Cohen, 2001). Psychodynamic, behavioural, cognitive, genetic and neurobiological factors may all be implicated in its etiology (Soomro, 2001). Indeed Swedo and Rapoport (1989) found a family history of OCD in twenty percent of their NIMH sample of 70 children, with father-son pairs predominating. Rasmussen and Tsuang (1984) found a 63% concordance rate in monozygotic twins, indicating the combined etiological role of genetic and environmental factors (Black, 1992).

**Age Of Onset, Course And Duration**

The average age of onset is early adolescence to young adulthood (Minichiello, Baer, Jenike & Holland, 1990; Foa & Franklin, 2001), with evidence that males develop OCD at an earlier age than females (Rasmussen & Eisen, 1990). Indeed Swedo and Rapoport (1989) observed that the earlier the age of onset, the more striking the male predominance. Emmelkamp and van Oppen (2002) write that in 10% of cases, OCD begins before the age of ten, with cases as young as two (Rapoport, Swedo & Leonard, 1992), and in 9% of cases, begins after the age of forty (Emmelkamp & van Oppen, 2002). While acute onset is observed, OCD more commonly develops gradually over several years (Emmelkamp & van Oppen, 2001), typically with a “chronic waxing and waning” course (Foa & Franklin, 2001, Page 211).

**Manifestations Of OCD**

While OCD tends to be conceptualised as a unitary phenomenon, there are a variety of presentations and subgroups (de Silva, 1992). Obsessions commonly reflect themes of
contamination, disease and illness, violence and death, and sexual, moral or religious topics (de Silva, 1994a). Compulsions can be loosely classified into categories: 'Washing and cleaning', 'Checking', 'Symmetry and ordering', 'Counting, touching and talking', 'Aggressive impulses and fantasies', 'Pure obsessionals', and 'Primary obsessional slowness' (de Silva, 1994a; Grabe, Goldschmidt, Lehmkuhl, Gansicke, Spitzer, & Freyberger, 1999). Symptoms tend to change over time, with almost all having experienced excessive washing at some time (Rapoport, Swedo & Leonard, 1992).

Co-morbidity
OCD commonly co-exists with other conditions and personality disorders (38%; Ruppert, Zaudig, Hauke, Thora and Reinecker, 2001). Co-morbid conditions include major depressive disorder (30%; Kanno, Golding, Sorensen, & Burnam, 1988; cited-in Foa & Franklin, 2001), phobia and panic (30%, 15% respectively; Rasmussen & Tsuang, 1986), tic disorders (20-30%; Pauls, 1989) and schizophrenia (Foa & Franklin, 2001). Similarly common are co-morbid personality disorders such as schizotypal (16%; Mavissakalian, Hamann & Jones, 1990), borderline and passive-aggressive disorders (39%, 61% respectively; Joffee, Swinson & Regan, 1988). The interplay between OCD and co-morbid conditions may not only increase distress, but also has implications in the selection and outcome of OCD treatment (Abramowitz, Franklin, Street, Kozak & Foa, 2000).

Differential Diagnosis
Accurate diagnosis or conceptualisation is important for the treatment of any disorder. However given high levels of co-morbidity and OCD's similarity to other disorders, this seems particularly relevant to OCD treatment. Differential diagnoses include anxiety disorders, such as phobias, Tic Disorders, schizophrenia (Swedo & Rapoport, 1989; Foa & Franklin, 2001) and dissociative identity disorder (Shusta, 1999). Indeed Jenike (1991) regarded incorrect diagnosis as constituting one of the several reasons that many cases were believed to be refractory.

Treatment Needs
In summary, OCD is a complex, chronic and debilitating condition. It impacts on both the individual and family, and effects as many as three percent of the general population. Treatment needs may range from improving symptoms, reducing their impact on social functioning and quality of life (Soomro, 2001), enhancing a sense of self, supporting life-functioning, and preventing hospitalisation (Chessick, 2001).
Historical Overview Of OCD Treatment
Psychodynamic approaches provided the first theoretical account of OCD with eloquent clinical observations (Freud, 1895, cited-in de Silva, 1992). However support, long-term hospitalisation and psychosurgery were the recommended treatments up until the 1960s (Salkovskis & Kirk, 1989), with an "almost resigned acceptance... of the poor outcome of therapy" (de Silva, 1994b). Later developments in behavioural approaches by Wolpe (1958) and Meyer (1966) (both cited-in de Silva, 1994b) brought increased treatment optimism, with these later enhanced by the addition of cognitive techniques and pharmacotherapy. Such has been their success, that cognitive-behavioural therapy (CBT) with exposure and response prevention, has become the current treatment of choice in the initial treatment of OCD (Matthew, Simpson, & Fallon, 2000). However CBT may not always be appropriate and the essay will now turn to an outline of the two treatment approaches under discussion, an evaluation of the available evidence for their appropriateness and an exploration of when each might be most appropriately used.

THE COGNITIVE-BEHAVIOURAL TREATMENT OF OCD

Outline Of The Cognitive-Behavioural Model
CBT model uses principles from classical conditioning (Pavlov, 1927), operant conditioning (Skinner, 1938) and cognitive theory (Beck, 1976) (all cited-in Atkinson, Atkinson, Smith, Bern & Hilgard, 1990) to understand OCD. It is formulated that anxiety, through learned faulty appraisals, is elicited by and becomes a conditioned response to obsessions. Further that compulsions, through their ending of the obsession and attempts to prevent feared consequences from occurring, alleviate anxiety (Salkovskis & Kirk, 1989; Shafran, 1999). Obsessions and compulsions are mediated by learned faulty appraisals that bring about an overestimation of harm and personal responsibility, and difficulty distinguishing thoughts from actions and tolerating uncertainty (Salkovskis, 1985).

Principles Of Cognitive-Behavioural Treatment
As with psychodynamic approaches, CBT requires a trusting empathic therapeutic relationship and sensitivity to the idiosyncrasies of each individual client (Salkovskis, Forrester & Richards, 1998). CBT targets the relief of symptoms (Esman, 2001). Behavioural components such as exposure and response prevention (ERP) focus on disrupting patterns of avoidance and neutralising. Exposure to feared situations (in vivo) and feared consequences (imaginal) while also refraining from neutralising behaviours allows habituation to occur, such that feared situations are easier to face and tolerate. It further helps disconfirm beliefs about the catastrophic consequences of not engaging in neutralising
behaviours. Guided discovery, cognitive techniques and behavioural experiments are used to modify appraisals of harm and personal responsibility (Shafran, 1999; Salkovskis et al., 1998). New ways of coping and managing triggers and anxiety are also encouraged (Overholser, 1999).

Effectiveness Of Cognitive-Behavioural Treatment

CBT's status as the current treatment of choice has been achieved through the accumulation of evidence ranging from uncontrolled trials (meta-analysis by van Balkom, van Oppen, Vermeulen, van Dyck, Nauta & Vorst, 1994) to randomised-controlled trials (RCTs) (all cited-in Matthew et al., 2000: Foa & Kozak, 1996; Abramowitz, Franklin & Foa, in-press; Kozak, Liebowitz & Foa, in-press). Furthermore, CBT approaches for OCD continue to be developed, adapted and researched. Investigations are extending to incorporate neuro-chemical processes, finding for example, evidence that CBT can modify metabolic activity in a clinically meaningful manner (Schwartz, 1998). Techniques have also been developed to successfully treat previously resistant sub-groups, such as 'Pure Obsessionals' (Salkovskis, 1985; Freeston, Ladouceur, Gagnon, Thibodeau, Rheumae, Letarte & Bujold, 1997) and CBT principles been applied to group-work with children and their families (Waters, Barrett & March, 2001).

Pato and Pato (1997) report that few individuals achieve cure of OCD. Indeed Abramowitz (1998) compared sixteen outcome studies with nine normative samples and concluded that while clinically significant changes were maintained for up to five-months post-treatment, those treated remained more symptomatic than normative samples. RCTs suggest a 50% mean percent reduction in obsessive-compulsive (OC) symptoms (range 26.7% to 66.7%) (Abramowitz, Franklin and Foa, in-press; cited-in Matthew et al., 2000). However Pato and Pato (1997) suggest that even a 15-25% reduction can make a significant impact.

Methodologically, there is much to recommend the supporting evidence for CBT. Through the use of RCTs with follow-up, later research has been more adequately able to account for the natural fluctuations in OC symptom-severity and accordingly attribute outcome to treatment effect (Abramowitz, 1997). Evaluations have included clinical as well as statistical significance to determine outcome success (e.g. Freeston et al., 1997), and broadened outcome measures beyond symptom-severity to include measures such as life-functioning (Freeston et al., 1997) and family functioning (Waters et al., 2001).
Limitations Of Cognitive-Behavioural Treatment

There are however some limitations in CBT's supporting evidence. The follow-up length used by existing studies vary, with no apparent consensus as to the meaningful follow-up required to evaluate the durability of treatment effects for a condition that waxes and wanes. Abramowitz (1998) points out the potential bias where studies exclude dropouts from analysis and, or, exclude participation of those with co-morbid conditions (with the exception of Abramowitz, Franklin, Street, Kozak and Foa's (2000) investigation of severe depression). Firstly, co-morbidity is known to represent a significant proportion of those with OCD, secondly, this group are frequently excluded from clinical trials (Freeston et al., 1997; Waters et al., 2001) and thirdly, have been found to respond less well to behavioural and pharmacological treatments (Ruppert et al., 2001). Exclusion of co-morbid conditions may have positively skewed evidence in favour of CBT (Abramowitz, 1998) and have also reduced the generalisability of their findings to all with OCD. One study has examined whether findings from RCTs can be generalised to routine clinical practice. Warren and Thomas (2001) concluded positively, albeit providing evidence from a private practice in N.USA, with outcome measures limited to symptom severity and assessment immediately following treatment.

The effectiveness of CBT may also be limited by its reliance on active participation, collaboration and adherence (Salkovskis & Kirk, 1989; Jenike, 1991), with there being evidence that these are currently problematic in the case of OCD. Although cognitive strategies may help prepare treatment "readiness" (Foa & Franklin, 2001; Page 259), CBT, particularly exposure-response-prevention, is not always acceptable to suitable treatment seekers. March, Frances, Carpenter and Kahn (1997) report a 25% refusal rate; Freeston et al. (1997) found 22% withdrew around assessment. Furthermore, a proportion of those who initially consent, later do not adhere or complete treatment; not all those who complete treatment respond. Three of the ten families reported by Waters et al. (2001) did not complete treatment; 21% of those in Freeston et al. (1997) study did not complete treatment, with dropout occurring during the most intensive part of exposure-response-prevention. With regards to those who complete treatment, Kozak, Liebowitz and Foa (in-press; cited-in Matthew et al., 2000) found 80% responded to CBT. Indeed it is estimated that treatment refusal, dropout and failure will mean that 50%-70% of those suitable for and seeking treatment may improve (Salkovskis, 1989, cited-in Salkovskis & Kirk, 1989; Pato & Pato, 1997).
THE PSYCHODYNAMIC TREATMENT OF OCD

Psychodynamic Accounts Of OCD

Psychodynamic theoretical accounts of OCD may be divided into Freud’s libidinal theory and subsequent elaborations (e.g. Fenichel, 1945) and, Object Relations theories (e.g. Klein, 1952; cited-in Gomez, 1998) and later incorporating interpersonal and attachment factors (e.g. Brandchaft, 2001). All approaches focus on what psychodynamic theories formulate to be the underlying cause of OCD - intrapsychic conflict originating from childhood. Obsessions and compulsions are viewed as “transitory and shifting manifestations” of this underlying conflict (Crawley, 1974, Page 268).

Freud (1895) provided the first and most well-known theoretical account of OCD, with his writings changing over time (de Silva, 1992). Freud proposed that greater ego maturity relative to libido (id) development during the Oedipal stage resulted in anxiety or conflict. In order to avoid this anxiety, libido drives are regressed to an earlier fixated stage of development – the anal-sadistic stage. Regressed drives, expressed as murderous and incestuous impulses (Fenichel, 1945), provoke anxiety and guilt by the “severe” and “unkind” superego (Esman, 2001, Page 147) and further conflict within the ego. Defence mechanisms are then used by the ego to guard against id impulses, thereby containing the id-superego conflict and anxiety with varying success (Crawley, 1974). Ego defence mechanisms include reaction formation, intellectualisation, isolation, undoing and magical thinking. Hence obsessive-compulsive symptoms reflect “the compromise between instinctual drives [obsessions] and defences against them [compulsions].” (Emmelkamp, 1982; Page 180). However stable compromise is not possible (Crawley, 1974). There is an escalation of defences, altered impulses, ego adjustments, an increasingly severe and ‘commanding’ superego and secondary defences, resulting in symptoms no longer functioning as defences but rather for gratification (Fenichel, 1945).

Whilst retaining Freudian oral, anal and Oedipal dynamics, Object Relations theories centre on the individual’s need to relate to objects rather than the need to manage libidinal conflict (Gomez, 1998). This framework also locates OCD development within the anal stage of development, in which the child learns to negotiate power and control (Gomez, 1998). Buergy (2000) describes how OCD functions as a coping response to conflict between symbiosis and separation. OC symptoms both attempt to compensate for threatened object loss, while also attempting to prevent blending with the primary object. OC symptoms reflect the severe super-ego’s confrontation with sadistic impulses so as not to jeopardise the essential object relationship.
Other frameworks incorporate the effect of interpersonal and attachment factors on the development of OCD. Brandchaft (2001) and Meares (2001) identify pre-oedipal attachment trauma as having undermined a secure external and internal setting, and thereby not made development of a mature true self, with self-other differentiation possible. Mallinger (1984; cited-in Esman, 2001) describes how the obsessive-compulsive’s preoccupation with control may reflect childhood attempts to cope with parental inconsistency and unreliability. Psychodynamic theories provide eloquent account for the dynamics observed in OCD, such as ambivalence, concerns with control, defence mechanism, omnipotence of thinking, magical thinking and doing-undoing (Chessick, 2001). While both cognitive-behavioural and psychodynamic theories recognise the role of compulsions in reducing anxiety, psychodynamic approaches consider not performing compulsions to result in displacement of underlying conflict rather than in control (Emmelkamp, 1982). Both theoretical approaches account for guilt and omnipotent and magical thinking.

**Principles Of Psychodynamic Treatment**

Psychoanalytic techniques include free association, interpretation and transference. Free association requires the individual to freely voice their thoughts with no intentional censoring, to which the therapist listens with openness to “blocks, themes, modes and trends in the patient’s words, manner and silence” (Gomez, 1998, Page 26). Resistance is reached once thoughts dry-up reflecting the super-ego’s censorship of less acceptable impulses. Much of the benefit of psychoanalysis is believed to result from the transference process (Rycroft, 1995), the process whereby earlier object relations are reproduced in the current therapeutic relationship. Approaches differ with regard to whether transference is of actual object relations or inner relationships with the internalised parents (Gomez, 1998).

In OCD, the super-ego is formulated as overly severe and the unchangeable id impulses as not recognised. Psychoanalysis therefore aims to modify the super-ego and strengthen the ego in managing conflict and anxiety arising from conflicting id, super-ego and external demands (Gomez, 1998). Hence interpretation of unconscious material elicited through free association and transference, helps to convert the incomprehensible into comprehensible problems that can be resolved (Salzman, 1980). Once underlying intrapsychic conflict has been alleviated, the individual is more able to deal constructively with anxieties and relationships, resulting lastly, in the reduction of OC symptoms (Crawley, 1974). Therapy provides a secure context where one may not have previously existed, allowing ‘templates’ for object relations developed through traumatic primary care-giving to be replicated and worked through (Brandchaft, 2001). Buergy (2000) describes the importance of OC patients...
experiencing the ability to effect action (learning self-assessment) rather than relying on others for reassurance.

**Difficulties Associated With The Psychodynamic Treatment Of OCD**

In contrast to CBT, there do not appear to be figures estimating the proportions suitable for, engaging and completing psychodynamic treatments. However Freud himself recognised that analysis could take months, even years (Freud, 1926) and also noted the particular difficulty of analysing obsessive clients (Freud, 1913/1958). Fenichel (1945) reports analysis to be even more time-consuming in cases of chronic, uninterrupted OCD with onset in latency.

Difficulties participating in free association (Fenichel, 1945), free communication (Salzman, 1980), reaching more than an intellectual understanding (Storr, 1979) and establishing a trusting therapeutic relationship have all been observed in OCD. Fenichel (1945) also points out the difficulties resulting from co-operation with one part of the “split-ego” and the other, unconscious, magical part, resisting, creating ambivalence between submission and rebellion (Page 309).

**Evidence Not Supporting The Use Of Psychodynamic Approaches**

Reviews from the last decade do not recommend psychodynamic approaches as a treatment option for OCD (Matthews et al, 2000; Greist, 1992; Black, 1992) and furthermore, many dismiss psychodynamic contribution to an integrated treatment plan (Greist, 1992; Black, 1992). Some, like Jenike (1991), consider individuals previously labelled ‘treatment resistant’, to have in fact been treated by ineffective methods such as psychodynamic psychotherapy.

However the current consensus may have been based on earlier reports studying psychodynamic approaches as a sole first-line treatment. Earlier approaches may also have reflected theoretical inadequacies in not recognising the importance of the actual care-giver relationship and environment. Such studies range from not supporting the use of psychodynamic approaches at all (Asher, 1972 and Malan, 1979 cited-in Greist, 1992; Black, 1992) to implying limited effectiveness when used alone (Eysenck, 1952; Jenike, 1991; Pato & Pato, 1997).

Johnston and March (1992) and Sherman, Ellison and Iwamoto (1996) (both cited-in Gold-Steinberg & Logan, 1999) found psychodynamic approaches ineffective in modifying thought and behaviour patterns, Jenike (1990) found no reports of effectiveness in stopping rituals.
Storr (1979) recommends behaviour-therapy where symptoms include compulsions (Page 123). CBT-advocates, Salkovskis and Kirk (1989), write that formulations of weak ego boundaries and pre-psychosis states led to the idea that behavioural treatment would undermine defence mechanisms and precipitate psychosis, therefore delaying development of these approaches.

Dolnick (1998) suggests that Freud (1909) did not provide details to support his claims of cure and even overstated outcomes, reporting that Rat Man, Freud’s most famous OC patient appears to have been killed in World War I and could not be followed-up. He, less harshly, calls for psychodynamic approaches to recognise their limits in facilitating coping rather than cure. Indeed Fenichel (1945, Page 308) calls for caution in promising cure, suggesting that improvement may be a more realistic expectation.

Methodological Limitations Of Earlier Psychodynamic Research
Crawley (1974) painstakingly reviewed studies of formal psychotherapy treatments for OCD. He concludes that the available evidence was not sufficiently valid to determine effectiveness in either direction (Page 288). Confident conclusions were difficult to draw owing to selection bias, heterogeneous participants (also noted by Emmelkamp, 1982), varied treatment approaches, settings, outcome measures, follow-up periods and biased assessment of outcomes (Crawley, 1974).

Crawley (1974) and Crits-Christoph (1992) highlight the methodological problems associated with evaluating psychodynamic approaches. These difficulties are especially striking when compared to the measurability of cognitive-behavioural treatment components and outcomes. While rich in meaning, psychodynamic concepts and treatment components do not appear to readily transfer themselves into measurable terms for empirical investigation (Crawley, 1974). Earlier studies also lack the use of control groups (Emmelkamp, 1982) making it difficult to distinguish between the effects of long-term therapy and spontaneous recovery (Rachman & Wilson, 1981; cited-in de Silva, 1994b) or symptom fluctuation (Abramowitz, 1998). Indeed Esman (2001; Page 154) concludes that “the problem of OCD brings into sharp focus some of the major issues confronting psychoanalysis as it faces its second century”.

SCENARIOS SUPPORTING THE USE OF PSYCHODYNAMIC APPROACHES
However, while there has been little development of psychodynamic thinking and treatments for OCD since Freud (Esman, 2001; Meares, 1994; PsychInfo search, 2001) there is some recent evidence to support Gold-Steinberg and Logan’s (1999; Page 496) warning against
“throw[ing] out the baby…. with the bath water”. While of lesser power and generalisability than CBT randomised-controlled trial evidence, single-case studies suggest psychodynamic contributions to the following scenarios.

As already discussed, it is unclear whether CBT is, at all or less effective for those with co-morbid conditions and personality disorders. However two case-reports flag up the potential contribution of psychodynamic approaches in this scenario. “Mr. B.” with OCD and long-standing paranoid personality disorder found psychodynamic approaches more tolerable than medication and CBT (Gabbard, 2001). Chessick (2001) demonstrates the value of long-term psychotherapeutic “holding” (Page 206) in a case of complex co-morbidity (OCD, OCDP, depression, paranoia, borderline states and schizophrenia). “Mrs A.” attended twice-weekly psychodynamic treatment (with pharmacotherapy) for thirty years. This was effective in supporting autonomous functioning amid multiple needs and in avoiding the costly and undesired alternative of managed care. When faced with fluctuating OC symptoms, Chessick (2001) emphasises understanding the meaning of underlying conflict (e.g. narcissistic rage) rather than symptom reduction.

If, as de Silva (1992) suggests, explanations of the etiology and maintenance of OCD require different theoretical approaches, then it is equally probable that treatment requires an integrated ‘stepped-care’ approach. Such that psychodynamic and CBT approaches are not mutually exclusive treatments but that the appropriateness of each is determined by the individual’s needs at any particular stage in the treatment process. There may therefore be scenarios in which it will be more appropriate to use psychodynamic adjuncts before, during or after CBT.

**Personal Preference And Insight**

Crits-Christoph (1992) speculates that those who prefer a task-oriented approach with clear steps and explanation may prefer CBT. Similarly that those who prefer exploring and understanding complex meanings and interpersonal relations might choose to work psychodynamically. Indeed Leib (2001) describes a scenario in which psychodynamic, behavioural-therapy and pharmacological treatment are successfully integrated. “Rachel” specifically requested psychoanalysis, insisting that recovery was only possible through analysis of her OCD symptoms. She was reluctant to consent to behaviour therapy and opposed to medication, regarding it to represent a dismissal of her mother’s pathogenic role. However development of a trusting therapeutic relationship, with exploration of the symbolic meaning of Rachel’s symptoms and Leib’s transferential experience of Rachel’s mother, were critical in reducing Rachel’s resistance to other forms of treatment and thereafter, symptom
reduction. Leib (2001) notes how the most significant analysis followed symptom reduction, rather than the reverse postulated by psychodynamic theory.

**Treatment Engagement**

Several authors describe how the OCD dynamics of control, ambivalence and defences can beneficially address issues of treatment engagement, barriers and adherence (Pato & Pato, 1997; Esman, 2001; Gabbard, 2001) – problems encountered by a significant proportion of those presenting for CBT.

Both Gabbard (2001) and Gold-Steinberg and Logan (1999) describe how OCD symptoms (whether of biological or psychodynamic origin) have unconscious meanings that might explain an individual's investment in maintaining the symptoms. Psychodynamic approaches help explore the anxiety evoked by changing from life-long patterns of feeling, thinking and acting (Brandchaft, 2001). They also explain the function of symptoms interpersonally (Case of “Mr A.”; Gabbard, 2001) and in the expression of psychodynamically-based conflicts (Gabbard, 2001, Page 218). Perhaps these approaches may help where beliefs about the consequences of refraining from compulsions are rigidly held, a factor often related to treatment response (Foa, Abramowitz, Franklin & Kozak, 1999) and salient to a difficult-to-treat sub-group, ‘hoarders’ (Black, Monahan, Gable, Blum, Clancy & Baker, 1998).

Gabbard’s (1992) case illustrates how psychodynamic work can address resistance to medication compliance. Piacentini (1999) notes how children often have difficulty articulating their fears, making exposure exercises problematic to construct. Children are also less present-oriented and motivated to suffer anxiety-provoking behavioural tests for a future reward. Gold-Steinberg and Logan (1999) illustrate how psychodynamic play helped address these and other issues for “Annie”, a four-year old child. Displacement, interpretation of defences, transference and counter-transference were effective in allowing Annie to express the function her OCD played for her and her worries about changing her behaviour.

**Lapse**

Gabbard (2001) suggests that psychodynamic factors may trigger OC symptoms, indicating the importance of helping the individual and family to identify and understand the meaning of psychodynamic triggers. Interpretation of transference and counter-transference helped “Mr A.” (and his family) to understand recurring relationship patterns and family dynamics maintaining the OCD (Gabbard, 2001). Psychodynamic techniques were also helpful in
understanding the function that OCD played for Annie in her family, and therefore in encouraging more adaptive family interactions (Gold-Steinberg and Logan, 1999).

Quality Of Life
Given the pervasive impact that OCD can have upon an individual’s life, psychodynamic approaches may be especially valuable in supporting broader issues of adjustment (King, Scahill, Findley & Cohen, 1999), self-esteem and relationships (March, 1995; cited-in Gold-Steinberg & Logan, 1999) and general life-functioning (Boyarsky, Perone, Lee & Goodman, 1991). Psychodynamic play therapy encouraged Annie to find more adaptive ways to express her previously intrusive thoughts and emotions. It also facilitated exploration of the OCD’s impact on Annie’s self-image and interpersonal relations (Gold-Steinberg & Logan, 1999). While Mr B’s symptoms did not disappear, psychodynamic approaches helped him adapt to his symptoms and enhance the quality of his life (Gabbard, 2001).

These issues may be more salient where OCD is of early onset and long-standing duration, with OCD having a wider-reaching impact on personal and interpersonal development. Indeed OCD of earlier onset and longer duration is associated with a higher frequency of symptoms (do Rosario-Campos, Leckman, Mercadente, Gedanke Shavitt, da Silva Prado, Sada, Zamignani, & Miguel, 2001) and worse behavioural and pharmacological treatment outcomes (Skoog & Skoog, 1999; Soomro, 2001).

The majority of the aforementioned case-studies examined psychodynamic approaches integrated with behaviour-therapy or pharmacological treatment and it is therefore difficult to judge whether these findings may be generalisable to scenarios that incorporate cognitive components of CBT. However since cognitive techniques are believed to overcome these issues and CBT continues to suffer from engagement and adherence, it may be cautiously assumed that these findings are indeed generalisable. With these caveats and the limitations of single-case studies in mind, it is suggested that there are indeed scenarios in which psychodynamic approaches may be a more appropriate treatment than CBT. However scenarios more frequently arise as part of an overall treatment plan rather than as a sole line of treatment.

SUMMARY AND CONCLUSIONS
While the rigorous methodological evidence base for CBT supports its current use as a first line treatment for OCD, there are limitations. CBT trials have not yet reflected the common occurrence of co-morbidity or personality disorders. CBT’s primary focus on symptom
Reduction may be insufficient or inappropriate for cases requiring re-adjustment or on-going support, particularly OCD of early onset and chronic duration. The durability of CBT's effectiveness is not yet known. Furthermore, a proportion (of unknown characteristics) are not suitable, refuse, dropout or do not respond to CBT. Future cognitive-behavioural developments may be anticipated to overcome these current limitations.

However while the existing empirical base for psychodynamic approaches does not compare with that of CBT, single-case studies suggest treatment stages in which psychodynamic approaches may be more appropriately used than CBT. Such scenarios might include where CBT is not initially acceptable or tolerable, where OCD co-exists with one or multiple co-morbid personality disorder(s), where the individual, such as a young child, cannot directly describe OCD cognitions, where personal preference indicates and where support with individual and interpersonal adjustment is required. Psychodynamic approaches may also work well alongside CBT.

In the words of Watson (2000) – "not every client... will respond to the treatment of choice.” (Page 259). Hence selection of an ‘appropriate’ treatment requires consideration of evidence-based effectiveness, speed and durability of effects (March et al., 1997) and consideration of treatment acceptability and tolerability for the individual.
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PEOPLE WITH LEARNING DISABILITIES ESSAY

Critically review the current status of the assessment and treatment of dementia in adults with learning disabilities

October 2002

Year 1
INTRODUCTION
People with learning disabilities are living longer and since age is the strongest predictor of developing dementia, dementia has prompted increased interest by researchers and clinicians alike (Aylward, Burt, Thorpe, Lai & Dalton, 1997). Interest has turned to developing methods to accurately identify dementia and thereby facilitate effective program-planning and clinical-care (Aylward et al., 1997). Following a general introduction, the essay continues to review the current status of assessment and treatment of dementia in adults with learning disabilities. While the essay reflects the focus of published literature in its attention on Dementia of the Alzheimer's Type [DAT] in adults with Down's syndrome [DS], adults of aetiology other than DS and dementia of static and reversible causes are occasionally referred to. ‘Assessment’ is taken in its broadest form as relating to diagnostic criteria, assessment strategies and tools. The term ‘care-management’ is used in preference of ‘treatment’ to reflect the literature and the absence of means to prevent dementia progression.

Definition Of Dementia
Cognitive decline of such severity that everyday functioning is affected is characteristic of all types of dementia. A diagnosis of dementia does not imply a specific aetiology or determine a specific prognosis (American Psychiatric Association, 1994, cited in Burt & Aylward, 1999), such that progressive or static courses, and irreversible or reversible causes may be described. Most prevalent is a dementia of insidious onset and progressive deteriorating course - Dementia of the Alzheimer's Type [DAT]. It is a diagnosis of exclusion that further requires presence of characteristic neuropathology (Zigman, Schupf, Haveman & Silverman, 1995).

Type, Prevalence, Age Of Onset And Duration Of Dementia In Adults With Learning Disabilities
Risks of dementia and age of onset vary according to aetiology of learning disability and dementia type. There are very few studies investigating adults of aetiologies other than Down syndrome [DS] (Zigman et al., 1995; Database searches 2002). Existing studies show discrepancies regarding comparative risk with adults in the general population. Some suggest similar risks and age of onset for each types of dementia (cited in Burt & Aylward, 1999: Barcikowska, Silverman, Zigman, Kozlowski, Kujawa, Rudelli & Wisniewski, 1989; Janicki & Dalton, 1993). Others suggest adults with learning disabilities other than DS have a four-times higher risk than adults in the general population (Alzheimer's Society, 2000). Approximately 50% of cases are accounted for by DAT, 25% by vascular dementia, with the
remaining 20% resulting from less common causes such as Lewy-Body dementia and Creutzfeldt-Jacob disease. Average age of onset of DAT is 65-years (Janicki & Dalton, 1993, cited in Aylward et al., 1997).

Many more studies have investigated adults with DS. However methodological variations create difficulty in indicating accurate prevalence rates, with overall and age-specific prevalence rates of DAT varying across different studies (Zigman et al., 1995). Studies have, for example, varied with regard to diagnostic criteria, assessment tools and consideration of differential diagnoses (Burt, Loveland, Primeaux-Hart, Chen, Breen-Phillips, Cleveland, Lewis, Lesser and Cummings, 1998; Zigman et al., 1995). Adults with DS are however, consistently found to be at increased risk of developing DAT than adults of other aetiologies of learning disabilities and adults in the general population. Interestingly the substantial proportion who, after the age of 40, develop clinical signs of DAT is lower than that showing DAT-neuropathology (Zigman, et al., 1995).

Adults with DS show an earlier average age of onset (Aylward et al., 1997) and more aggressive course than other adults (Zigman et al., 1995). Prasher and Krishnan (1993) found an average onset of 51.7 years (ranging from 31 to 68 years), with a mean duration of five years (Lai, 1992; cited in Zigman et al., 1995). This compares with two to twenty years duration estimated for the general population (US Department of Health & Human Services, 1984, cited in Zigman et al., 1995). However it may be that early subtle symptoms remain unrecognised resulting in later detection (Zigman et al., 1995), suggesting even younger onset.

Effects Of Dementia Of The Alzheimer’s Type
The course of DAT varies between individuals with learning disabilities, resulting in individual differences in areas of functioning affected, speed of decline (Burt et al., 1998) and expression of changes (Janicki et al., 1995). Furthermore changes may vary from day-to-day and within-a-day, with tiredness, stress, anxiety and physical illness likely to accentuate decline (Cairns & Kerr, 1994). Despite such variations, DAT is commonly conceptualised as progressing through early-, mid- and later-stages with characteristic behaviours and symptoms assumed for each stage (Janicki et al., 1995). Early signs may include uncharacteristic irritability, disorientation, forgetfulness and apathy, with decline becoming more marked over time to result in eventual loss of everyday abilities, incontinence and finally death from causes such as pneumonia and congestive heart failure.
ASSESSMENT

Early and accurate diagnosis is generally considered essential for planning and guiding appropriate social- and health-care provision (Aylward et al., 1997). Diagnosis may help reduce uncertainty and help cope and plan for the future (Staff, 1994a; cited in Lavoie & Herlihy, 1999). However concerns have been raised regarding false positives where no effective treatment for DAT is available, and where a diagnosis of dementia may overshadow treatment of symptoms (Zigman et al., 1995).

Current Status Of Assessment Strategy

New literature over the last decade has enhanced knowledge of assessment difficulties and brought an apparent consensus regarding assessment strategies. All recent literature strongly advocates longitudinal establishment of decline from a baseline level of functioning using standardised assessments (Aylward et al., 1997). Heterogeneity in pre-morbid levels of cognitive functioning and adaptive abilities (Janicki & Dalton, 1999) and range of behaviour problems (Harper, 1992, cited in Oliver, 1999), render meaningless any assumption of change from ‘normal’ as used in the general population.

Authors advocate for establishment of a baseline profile when presumed healthy. Earlier baseline is recommended for adults with DS (i.e. before the age of 40) than adults of all other aetiologies (i.e. before 50) (Burt & Aylward, 2000). Assessment should be repeated every 1-5 years depending on age and risk of dementia (Burt & Aylward, 2000) and, as soon as dementia is suspected (Aylward et al., 1997). While resource intensive, Oliver (1999) raises ethical concerns of not using a prospective strategy for adults with DS. Documentation is essential to this process, ensuring that data are not lost with staff turnover and are readily accessible to those involved in care (Burt & Aylward, 2000).

However a prospective strategy from healthy baseline may not be possible for currently ageing cohorts. In such cases change may only be established longitudinally from time of suspicion (Oliver, 1999). Consequences of a retrospective strategy may include delayed diagnosis, difficulty detecting decline on available instruments due to ‘floor’ and ‘ceiling’ effects and reliance on retrospective, usually informant-based information. Evenhuis, Kengen & Eurlings (Page 2 of questionnaire, 1990) specified that informants be “familiar with the observed person”. However there are often difficulties finding informants with past and present knowledge of an individual (Burt et al., 1999), a problem accentuated by frequent staff turnover (Janicki & Dalton, 1999). This may particularly affect detection of earlier subtler signs of decline (Oliver, 1999). Perception of decline is influenced by the nature of
interaction an informant may have or the demands placed on an individual (Harper, 1993). Others may not have the skills to rate conditions (Oliver, 1999). Furthermore, declines acquired over time often become absorbed into the service and remain unnoticed (Oliver, 1999). Reliability may be partially overcome through the use of multiple informants (both family and non-family) across multiple settings (Aylward et al., 1997; Burt, Primeaux-Hart, Phillips, Greene, Loveland, Cummings, Lewis, Lesser, Cleveland & Chen, 1999).

Current Status Of Diagnostic Criteria

International Classification of Diseases [ICD-10] diagnostic criteria (World Health Organisation, 1992) are recommended over Diagnostic and Statistical Manual of Mental Disorders [DSM-IV] (American Psychiatric Association, 1994) for determining dementia in people with learning disabilities (Aylward et al., 1997). This is further supported by the lack of systematic data to support whether dementia can be accurately assessed using DSM-IV criteria in the “presence of intellectual disabilities” (Page 136, Oliver, 1999).

ICD-10 gives greater emphasis to behavioural and emotional changes over cognitive changes than does DSM-IV (Aylward et al., 1997). Such changes most frequently trigger concern in those around the individual. However the recommendation to use ICD-10 criteria may cause difficulties where cognitive decline is masked by more easily recognisable changes (Holland, Karlinsky & Berg, 1993) or not evident until at quite a severe level. Application of diagnostic criteria developed for the general population implicitly assumes comparable profiles of decline (Oliver, 1999). While preliminary evidence supports this idea (Oliver & Holland, 1986, cited in Oliver, 1999), greater investigation is needed (Oliver, 1999). The ICD-10 confers additional advantage by its two-step process, whereby decline is determined, then cause differentiated (Aylward et al., 1997).

Current Status Of Assessment Tools

Currently available are recommendations for tools to be used as part of a comprehensive test battery (published in Aylward et al., 1997; Burt and Aylward, 2000). These have been compiled through a consensus approach based on the shared expertise of Working Groups such as the American Association on Mental Retardation [AAMR], International Association for the Scientific Study of Intellectual Disability [IASSID]. Tools are based around ICD-10 diagnostic criteria (Burt and Aylward, 2000) with areas for assessment shown in Figure 1 below.
FIGURE 1: Areas For Assessment

On the basis of ICD-10 criteria, an assessment tool or test battery must demonstrate the following:

- Decline in memory (both verbal and non-verbal)
- Decline in other cognitive abilities (e.g. judgement, thinking, planning, organisation, general processing of information)
- Decline in control of motivation, emotion and social behaviours
- Decline in memory and other cognitive functions of at least six months duration
- Decline that is sufficient to significantly interfere with everyday functioning
- Decline that is greater than that related to normal ageing in adults with learning disabilities
- Awareness of the environment


The following sections use examples to illustrate some advantages and limitations of existing tools recommended by the Working Group.

'Dementia Scales'

'Dementia scales' target all areas specified by ICD-10 diagnostic criteria. The Dementia Questionnaire for Mentally Retarded Persons [DMR] (Evenhuis, Kengen, & Eurlings, 1990) has status as the only informant-scale for assessing orientation (Burt & Aylward, 2000) and only instrument with cut-offs indicative of dementia at a single assessment and varying by level of learning disabilities (Evenhuis et al., 1990). It is further designed for adults of all levels and aetiologies of learning disabilities (Burt and Aylward, 2000) although Oliver (1999) would not recommend use with people with profound learning disabilities. However there are problems generalising findings from an institutionalised population in the Netherlands where internationally recognised criteria were not used (Prasher, 1997). Furthermore scores may be inflated by some items' rating of verbal reactions (Evenhuis et al., 1990).

There are clear specifications regarding administration of the Dementia Scale for Down Syndrome [DSDS] (Gedye, 1995): Namely yearly administration to two informants by a chartered psychologist. It is useful in its inclusion of changes commonly observed in adults with DS, such as seizures. Importantly typical and atypical behaviours are differentiated, thereby overcoming difficulties of heterogeneous abilities and behaviours common to adults with learning disabilities. It is further possible to establish duration of changes (Aylward et
al., 1997) and a differential diagnosis scale is included (Burt & Aylward, 2000). Service-planning may be helped by its measurement of early, mid and late-stages of dementia.

Of the two informant scales, the DSDS appears more useful for assessing adults with DS than the DMR. When compared with clinician diagnosis, the DSDS better identified dementia over general disability than did the DMR (Deb & Braganza, 1999). Even using modified cut-offs, Prasher (1997) found the DMR to yield an unacceptable level of false positives in adults with DS. False positives reflected behaviour problems and declines in adaptive behaviour. Prasher (1997) further described how ceiling effects on the DMR prevented changes in scores with the progression of dementia.

The Test for Severe Impairment [TSI] (Albert & Cohen, 1992; reviewed-by Cosgrave, McCarron, Anderson, Tyrrell, Gill & Lawlor, 1998) is the only recommended direct assessment tool. It is brief, easy to administer and may be more accessible to individuals with lower verbal skills since 16 items do not require verbal response. Adults with moderate to severe learning disabilities showed a wide range of scores on the TSI, suggesting its use for this ability range (unless already at the advanced stage of dementia). It may further be useful for monitoring the progression of dementia. However the TSI is likely to need supplementing with other scales since change was not observed on four (unspecified) items until the later stages of dementia. Furthermore those with mild learning disabilities or high language skills may show ‘ceiling’ effects, such that additional Mental Status exams are suggested (Wisniewski & Hill, 1985, cited in Burt & Aylward, 2000). No cut-off scores for dementia and annual rates of change scores are yet available (Cosgrave et al., 1998)

Scales To Measure Specific Deficits
Also available are tests not specifically relating to dementia but that may be applied to assess abilities in each diagnostic area. Selection of such tests are determined by time and resources and the specific characteristics of the individual (e.g. level of learning disability and verbal skills) (Burt & Aylward, 2000). As with the dementia scales, all tests of specific deficits require measurement of change from a baseline level. Hence choice of test will be also determined by which instruments have been previously administered and can be used as a baseline (Burt & Aylward, 2000).

Difficulties associated with the assessment of adults with severe and profound learning disabilities (Zigman et al., 1995) are apparent when identifying appropriate standardised cognitive tests. Valid measurement of change (‘floor’ effects) may not be possible using the
tests such as the Wechsler Adult Intelligence Scale, Version III [WAIS-III] (Wechsler, 1997; cited in Oliver, 1999). Other tests may not be accessible for those with pre-existing visual impairments (e.g. Developmental Test of Visual Motor Integration, Beery & Buktenica, 1997) or low verbal skills (e.g. test of cognitive decline such as Boston Naming Test, Kaplan, Goodglass & Weubtraub, 1978; all cited in Burt & Aylward, 2000). Such limitations will necessitate reliance on more informal tests, dementia scales, careful history-taking and observation.

Choice of mental status examinations is also limited. While recommended by the National Institute for Clinical Excellence [NICE] to determine need for dementia-medication, the Mini-Mental Status Examination [MMSE] (Folstein, Folstein & McHugh, 1975; cited in Deb & Braganza, 1999) cannot be used reliably by adults with learning disabilities. Deb & Braganza (1999) could only administer the MMSE to 55% of their sample; Stewart (2001) indicates that scores are strongly affected by education, cultural differences and where English is not the first language. While a more viable option for adults with DS, Tyrell et al. (1996) found that those with severe learning disabilities frequently score zero on the Down Syndrome Mental Status Examination [DSMSE] (Haxby, 1989; cited in Tyrell et al., 1996). Cosgrave et al. (1998) found similar limitations.

Many informant-report scales of adaptive behaviour are available. However while it may be possible to establish decline from a baseline level of functioning (for example, using the Adaptive Behaviour Scale-Residential & Community [ABS], Nihira, Leland & Lambert, 1993), it is not possible to distinguish the effects of normal ageing from that of DAT (Deb & Braganza, 1999). However this may rather reflect lack of knowledge regarding these differences than limitations of the assessment tools. Prasher (1999) for example, points out the need for longitudinal studies of age-related decline in adaptive skills of adults older than 50 years and of adults other than those with DS. Furthermore, while cognitive decline must diagnostically be significant enough to affect everyday functioning, further research is needed of the relationships between such changes (Prasher, 1999).

**Measurement Of Differential Diagnosis**

Exclusion of other causes is especially critical for adults with learning disabilities, since potentially treatable conditions are likely to result in behaviour changes also seen in the early stages of dementia. Appropriate investigations should be carried out to address conditions such as depression, thyroid disease, sensory impairments, pharmacotoxic reactions (Tuinier & Verhoeven, 1994; cited in Aylward et al., 1997), acute confusional states, bereavement and
changes in environment (Aylward et al., 1997; Oliver, 1999; Trumble, 1999).

In addition to medical investigations, some scales are available. For example, the DSDS boasts a differential diagnosis scale (Burt & Aylward, 2000) and tools exist to screen for psychiatric disorders and measure life events. The Reiss Screen for Maladaptive Behaviour (Reiss, 1987; cited in Burt & Aylward, 2000) appears the most promising tool for psychiatric disorders. It is appropriate for all levels of learning disability and determines typicality of problem behaviours. The Stress Index (Seltzer, 1997; cited in Burt & Aylward, 2000) is useful in its availability of both informant and self-report forms. However no existing scale validated for use allows clinical differentiation among various types of dementia (Deb & Braganza, 1999).

**Summary**

Difficulties continue to exist for the detection of change in adults with profound learning disabilities. Although both informant-report and direct assessment are recommended (Burt & Aylward, 2000; Aylward et al., 1997; Burt et al., 1999), few scales incorporate both versions. All scales require comparison of baseline and change scores in conjunction with clinical examination. It is not yet possible to determine dementia at a single administration, nor the cut-off point or number of “points” that must be lost over a specific time period to warrant a diagnosis of dementia” (Page 159, Aylward et al., 1997). Existing tools may not yet adequately measure decline interfering with everyday functioning or decline greater than expected from normal ageing (Prasher, 1999). Available research suggests that such cut-offs may vary according to the level or aetiology of learning-disability. Furthermore differential diagnoses is not sufficiently considered by tools (McCallion, 1999).

**TREATMENT – ‘CARE MANAGEMENT’**

The results of database searches (e.g. PsychLit, MedLine, 2002) confirm findings by the Edinburgh Working Group on Dementia Care Practices [EWGPCP] (2002): A lack of literature relating to “specific services or support practices or principles” (Page 281, Wilkinson & Janicki, 2002) for adults with learning disabilities diagnosed with dementia. This applies to both descriptive accounts and evidence-based research. Hence those looking for an overview of dementia-care for adults with learning disabilities, or more personally, Clinical Psychologists looking to provide psychological input, may need to synthesise existing literature with that available for the non-learning disability population.

Literature specifically relating to adults with learning disabilities consists of the summaries of
People With Learning Disabilities Essay

Clinical expertise resulting from consensus approaches (e.g. Working Groups) and several descriptive accounts of caring for adults with DS and dementia (e.g. DayBreak, cited in Janicki & Dalton, 1999; Newroth & Newroth, 1980; Lavoie & Herlihy, 1999). Common themes regarding an appropriate philosophy of care are apparent. These emphasise a person-centred approach (EWGPCP, 2002), ‘ageing-in-place’ (Janicki & Dalton, 1999), preservation of skills (Janicki et al., 1995) and maximising quality of life (Janicki et al., 1995) with the involvement of family and close supports (EWGPCP, 2002). Also emphasised is on-going physical and health monitoring and treatment (Holland, Karlinsky & Berg, 1993), “using interventions and supports that are appropriate to the stage of the disease” (Page 9, Janicki, Heller, Seltzer & Hogg, 1995) and “proactive strategic planning across all relevant policy, provider and advocacy groups” (Page 280, EWGPCP, 2002). The importance of on-going coordination and clear documentation is recognised (Janicki & Dalton, 1999), especially in an area where high staff turnover is experienced (Janicki et al., 1995).

Critical review of the current status of treatment for adults with learning disabilities and dementia is hampered by the scarcity of descriptive accounts and particularly, absence of evaluative accounts. This limits evaluation of the extent to which approaches are used and found effective. While less rigorous, a review of the literature relating to people without learning disabilities may help suggest useful approaches for use with those with learning disabilities. Unfortunately, the current essay has not sufficiently investigated this strategy. With the aforementioned in mind, the following sections endeavour to describe and where possible, review therapeutic approaches outlined by the Working Group (Janicki et al., 1995) and others.

Educational And Emotional Care

All authors highlight the need to provide educational and emotional support to caregivers (e.g. Holland et al., 1993; Janicki et al., 1995). The content and emphasis of such support will vary over the course of the disease and as a function of any person’s relationship with the individual affected – individuals themselves, family members, professional caregivers, housemate and peers.

Initial education may focus on diagnosis and prognosis. Lavoie and Herlihy (1999) describe the successful application of a technique by Antonangeli (1995a) using a toy train set with dimmer switches to explain dementia-related changes in concrete terms. More able adults may benefit from one-to-one counselling in the early stages of dementia (Holland et al., 1993). They will benefit from sensitive responses to frustrations and behaviour changes.
People With Learning Disabilities Essay

(Holland et al., 1993). Indeed the attitude of caregivers is critical in the management of dementia for those without learning disabilities (Holden and Woods, 1982; cited in Holland et al., 1993). This view is emphasised by Kitwood and Bredin (1992) in their person-centred model of care. Caregiver distress and negative interpretations may be reduced, and helping behaviour increased, through preparation of expected behavioural or personality changes (Holland et al., 1993; Whitehouse, Chamberlain & Tunna, 2000).

Preservation of abilities is a core theme of dementia-care and caregivers may benefit from education regarding appropriate strategies and environmental adaptations. Janicki et al. (1995) recommend a supportive management style for professional care-givers. Newroth and Newroth (1980; cited in Holland et al., 1993) identified the need for appropriate training, educational staff counselling, and where needed, personal counselling. They further recommended shared responsibility for care to overcome the potential for caregiver staff 'burn-out'.

Authors also warn against the risk of neglecting the emotional and practical needs of fellow housemates (Newroth & Newroth, 1980; Lavoie & Herlihy, 1999). They may for example, benefit from understanding the effects of dementia (Janicki & Dalton, 1999), and involvement in caring and reminiscence activities (Lavoie & Herlihy, 1999).

There is recognition that discussions with family caregivers of respite and home-help options should be sensitive (Janicki et al., 1995) and respectful of cultural differences regarding accepting outside help (Hogg, Lucchino, Wang & Janicki, 2001). Practical support must be tailored to the individual case (Hogg et al., 2001) and may be especially pertinent for ageing parental caregivers (Oliver, 1999).

Current knowledge of the progression of dementia allows some planning ahead for later stages. This relates to issues such as guardianship, advanced directives (Janicki et al., 1995), aids and adaptations (Janicki & Dalton, 1999) and personal-care training (Janicki et al. (1995). Caregiving strain is likely to peak during the later-stages (Janicki et al., 1995), with all involved faced with preparing for bereavement. Lavoie & Herlihy (1999) use a composite case to eloquently describe the impact of dementia on family, caregivers and housemates. While little is written about loss, death and grieving for this specific client group and disease, they describe the successful application of Kubler-Ross’ five-stage model of grief (1969; cited in Lavoie & Herlihy, 1999) and Fox’s four-task process of grief management (1988; cited in Lavoie & Herlihy, 1999).
The Health Psychology literature provides support for the benefit of support for dementia caregivers (albeit in the general population). For example, Kiecolt-Glaser, Dura, Speicher, Trask & Glaser (1991) established the negative impact of caregiver stress on immune functioning and illness, and the benefit of social support for coping, mental and physical health. Other research, although unrelated to dementia, indicates increased satisfaction with services, reduced distress and enhanced coping associated with educational care (reviewed by Nichols, 1984).

**Approaches For The Individual**

Care-management moves away from the assessment deficit model to emphasis of strengths (McCallion, 1999). Janicki et al. (1995) and McCallion (1999) emphasise the importance of continued routines, activity and social involvement in maintaining quality of life and preserving functioning. Indeed lack of stimulation may accelerate deterioration and social withdrawal (Bourgeois, 1991, cited in McCallion, 1999). Several approaches are suggested for enhancing activity, however as already stated, there is little or no literature describing their use and success in adults with learning disabilities and dementia.

One such approach is environmental modification. Here safety, familiarity and ease of access are facilitated through reducing extraneous stimulation and distractions, use of bright lighting without glare, special markings and important stimuli highlighted. It may also mean level floor surfaces, aids and adaptations and décor rooted in the individual’s long-term memory (Bawley, 2001; The Dementia Services Development Centre, 1997). Evidence suggests its benefit in reducing confusion, sustaining participation in daily activities and creating a safe environment for wandering for adults with dementia in the general population (Bawley, 2001; Dementia Services Development Centre, 1997).

Participation may also be sustained through using principles from behavioural therapy such as providing structure and supports to daily routines that maximise retained abilities and compensate for those lost. This will involve using explicit short instructions, cues and modelling (Janicki et al., 1995). Functional analysis may assist in managing less desirable behaviours. Memory Aids may help where these can be appropriately tailored to the individual’s cognitive ability. While not referred to in the learning-disability and dementia literature, evidence from the general elderly population suggests the potential of sustained and carefully individualised Reality Orientation cues for helping temporal and spatial orientation (Woods, 1994).
The importance of maintaining existing social networks for as long as possible is highlighted by all literature relating to dementia in adults with learning disabilities (Janicki et al., 1995, Janicki & Dalton, 1999). However declines in memory and pragmatic communication often create frustration for individuals (and others) and lead to social withdrawal (McCallion, 1999). Support is likely to be of value. As well as simplification of language and greater use of prompts, cues and structure, McCallion (1999) recommends use of aids such as a ‘personal memory album’, ‘memory chart’ and ‘memory audiotape’. These reflect meaningful people and events in the person’s past and present life, things the person likes to talk about and information usually forgotten but important to conversations. McCallion (1999) recommends their on-going use with reference to the appropriate place. These have been effective in persons with dementia without learning disabilities (Bourgeois, 1994, cited in McCallion, 1999).

Such aids may be used as part of reminiscence. While not valued by all older adults (Scrubton, 1989), Reminiscence Therapy has been found beneficial for well-being in the general elderly population with dementia (Brooker & Duce, 2000). Scrubton (1989) anecdotally describes how reminiscence can enhance feelings of self-worth, be enjoyable and stimulating and increase animation between carers and individuals. Lavoie and Herlihy (1999) report its benefit with housemates affected by the deterioration of a fellow housemate - further investigation may prove fruitful.

Principles of validation are recommended during the mid- to later-stages when loss of memory and language skills become more pronounced and paranoia and delusions increase (Page 11, Janicki et al., 1995). Cairns and Kerr (1994) emphasise consideration of the individual’s reality and that logic lies behind all behaviour even when disorientated. They suggest that aggressive behaviour may be more understandable if a stranger was perceived as approaching to undress you. Logic may have its root in long-term memory, which for adults with learning disabilities may hold a higher proportion of abusive incidents. Literature relating to the general elderly population considers that such principles are easily used by caregivers (Benjamin, 1999) and enhance communication (Toseland, Diehl, Freeman, Manzanarea, Naleppa, McCallion, 1997).

Stimulation is beneficial throughout the course of dementia (Janicki & Dalton, 1999). During the later-stages, options include passive exercises, companionship, massage with scented lotions and physical affection. Sensory techniques, such as snoezelen, may be of value in reducing agitation (Janicki & Dalton, 1999), enhancing quality of life and social interaction.
Implications For National Systems

Increased dementia prevalence has implications for governmental policies, service commissioners and education/training strategies. Authors advocate the development of a register with a minimum data-set for, at best, all adults with learning disabilities, and at least, those at high risk of developing dementia (Zigman et al., 1995; Turk, Dodd & Christmas, 2001; Hogg et al., 2001). Such developments may inform service planning and facilitate appropriate physical and health surveillance (Hogg et al., 2001).

Current expertise supports ‘ageing-in-place’. This requires anticipation of future needs when changes in home are considered (Hogg et al., 2001). It further requires increased responsiveness by funding bodies and service commissioners with regard to access to funding, appropriately trained and supported staffing, environmental aids and adaptations (Turk, Dodd & Christmas, 2001). This is especially pertinent to adults with DS in whom dementia is observed to have more aggressive course. A national commitment is needed to disseminate current knowledge and raise the profile of dementia in the field of learning disabilities, increasing the awareness of families, caregivers and professionals (Hogg et al., 2001). This may address issues such as recognition of dementia and its differential diagnoses (Whitehouse, Chamberlain & Tunna, 2000), help-seeking, appropriate procedures and investigations, and care management.

OVERALL SUMMARY AND CONCLUSIONS

Dementia is a developing area in the field of learning disabilities. However both assessment and treatment literature fail to sufficiently consider adults with aetiologies other than DS (Zigman et al., 1995); The majority within the learning disability population. There appears to be consensus regarding an appropriate strategy for assessment but limitations with current assessment tools. There is not yet a ‘gold standard’ tool or test battery. It may therefore be concluded that the current status of assessment tools continues to be “provisional until longitudinal research is able to establish their usefulness” (Page 161, Aylward et al., 1997).

The current status of therapeutic approaches appears both uncertain yet promising. It remains an under-disseminated area, in terms of both descriptive and evaluative literature. However the few accounts available suggest the great potential for positively enhancing quality of life for individuals and their caregivers. Dementia-care may be further developed through application of techniques from the general population.

National bodies such as NICE (Arshad, Sridharan & Brown, 2001) and National Service
Frameworks (Internet Searches, 2002) appear to have overlooked the salience of dementia in adults with learning disabilities. Furthermore without appropriate auditing or literature, it is difficult to determine whether Working Group guidelines have filtered down to local systems. In the absence of a national standard, are local health trusts or individual clinicians responsible for determining assessment protocols and care-management? Greater publication and dissemination of case-reports and descriptive accounts are needed to stimulate evaluative research. There are broader implications for dissemination and education, with a need to increase awareness of normal ageing, dementia-related changes and differential diagnoses for this client-group. Clinical services require development of co-ordinated practices for the assessment, evaluation and care-management of dementia.
REFERENCES


CHILDREN AND FAMILIES ESSAY

‘Early intervention works.’ Critically discuss the evidence for the effectiveness of early intervention approaches for behavioural problems

December 2002

Year Two
INTRODUCTION

For the purposes of this essay, early interventions have been classified according to whether they are parent-, child- or multi-focused. After an introduction to behaviour problems and early intervention, evidence for the effectiveness of each approach will be reviewed in turn, followed by an overall summary.

Behaviour Problems

Oppositional defiant disorder (ODD), conduct disorder (CD) and attention-deficit hyperactivity disorder (ADHD) are collectively referred to as ‘externalising behaviour problems’ (Diagnostic and Statistical Manual of Mental Disorders, 4th edition, [DSM-IV]; cited in Webster-Stratton, 1997). ODD is characterised by “negativistic, hostile and defiant behaviour” (Page 430), CD by behaviour that violates others’ basic rights “or major age-appropriate societal norms or rules” (Page 430) and ADHD by “developmentally inappropriate ... inattention, impulsiveness and hyperactivity” (Page 430; Webster-Stratton, 1997). Diagnosis requires that behaviours have persisted for at least six months. CD is rarely diagnosed before the age of six such that much preschool behaviour problems fit diagnostic criteria for ODD, ADHD or a combination of both (Webster-Stratton, 1997).

Prevalence rates from North America estimate 3-5% of school-age children to have ADHD, 2-16% to have ODD and, 2-9% of girls, 6-16% of boys to have CD (Sampers, Anderson, Hartung & Scambler, 2001). Rates of conduct disorders are thought to be increasing (Webster-Stratton & Hammond, 1997). Behaviour problems account for a substantial proportion of referrals to child mental health services (Audit Commission, 1999; cited in Scott, Spender, Doolan, Jacobs & Aspland, 2001; Webster-Stratton, 1999).

Behaviour problems such as non-compliance, poor self-control, aggressive behaviours, attention-seeking are commonly reported by the parents of pre-schoolers (Webster-Stratton, 1997). However while many children ‘grow out’ of such behaviours, longitudinal studies estimate problems to continue in approximately 50% of children (Webster-Stratton, 1997), with severe childhood behaviour problems setting in motion a persistent, long-term pattern of behaviours (Sampers et al., 2001; Bennett, Lipman, Racine & Offord, 1998). Childhood behavioural problems strongly predict adolescent and adulthood delinquency, substance-misuse, violence and criminality (Campbell, 1995, cited in Sampers et al., 2001; Farrington, 1994b, cited-in Fonagy, Target, Cottrell, Phillips & Kurtz, 2000).
Risk factors for childhood behaviour problems are thought to interact in a synergistic manner, increasingly compromising child functioning over time (Webster-Stratton & Taylor, 2001) and bringing about increasingly entrenched patterns of behaviour in the child and their systems (Nixon, 2002). Risk factors relate to the child (e.g. impulsivity, hyperactivity, quickness to anger, deficits in social skills), family (e.g. harsh, inconsistent parenting, high family stress), context (e.g. poverty) and school/peers (e.g. school exclusion, deviant peer-group) (Webster-Stratton & Taylor, 2001).

There is a compelling case for intervening early in the development of childhood behaviour problems. The beginnings of difficulties are seen before the age of five (Sampers et al., 2001). However only a small proportion of children with clinically significant problems receive help (Bennett & Offord, 2001), with rates of help lowest among the neediest (Cunningham, Bremner & Boyle, 1995). Furthermore it is suggested that “crisis intervention” approaches are likely to be “more difficult, lengthier, ....more costly.... With less likelihood of success” (Golding, 2000; Page 368). Indeed treatment is less successful in “chronically dysfunctional adolescent groups” (Fonagy et al., 2000; Page 445).

Definition Of Early Intervention
The theory of early intervention for behaviour problems postulates that early prevention or minimisation of risk factors or, indeed strengthening of protective factors, will interrupt a life-long trajectory of antisocial behaviour (Fonagy et al., 2000; Sampers et al., 2001). The term ‘early intervention’ encompasses a diversity of services (medical, psychological, academic), settings (clinic, school, community), approaches (child-, parent-, school-, multi-focused) and strategies (universal, selected or indicated) (McCollum, 2002; Fonagy et al., 2000).

Definition Of Effectiveness
In critically reviewing evidence for effectiveness, it becomes necessary to unpack the term ‘effectiveness’ itself. Evidence for effectiveness should allow conclusions to be drawn about whether the concept of early intervention works at all, how well it works (extent and duration of changes), how it may be optimally offered (timing in child development, duration, content and delivery) and for whom early intervention works. Evidence should allow consideration of issues such as cost-effectiveness, acceptability and accessibility. Evidence should further address whether particular approaches work better than others, or work better for certain populations or behaviour problems. Comparison of early intervention to no intervention and to other approaches that may target behaviour problems or their risk factors is necessary. Such questions are underpinned by methodological quality.
EVIDENCE BASE

Parent-Focused Interventions

Evidence of a strong association between child behaviour problems and harsh, inconsistent parenting (Patterson, 1982; Farrington, 1995; cited in Scott et al., 2001) helped develop parent-focused interventions. There are varied approaches for supporting parents and enhancing parenting styles. Interventions may be offered during pregnancy, infancy, or preschool and school years; be individually-, family- or group-based; be offered at family homes, child and family mental health clinics or community-settings. Groups vary from peer-support to more structured parent training courses.

Since parent management training [PT] are the most commonly used and well-evaluated of parent-focused interventions for externalising behaviours (Kazdin & Weisz, 1998; cited in Nixon, 2002), only PT is discussed. Programs are largely based on social learning principles, teaching parents to manage children's behaviour through behaviour modification (Nixon, 2000). Parents' use of behaviour change strategies is hypothesised to lead to improved parent-child interactions and enhanced child social and emotional adjustment (Webster-Stratton, 1999).

Does PT work?

The effectiveness of individual-, family- and group-based PT has been established through randomised-controlled trials [RCT] (Wolpert, Fuggle, Fonagy, Cottrell, Phillips, Pilling, Stein, & Target, 2002). An RCT showed the effectiveness of Forehand and McMahon's (1981) Helping the Noncompliant Child in reducing behaviour problems in children aged 3-8 (Long, Forehand, Wierson & Morgan, 1994; cited in Webster-Stratton & Taylor, 2001). Parent-Child Interaction Therapy [PCIT] (developed for children aged 2-6) showed sustained improvements in child conduct problems and positive interactions with parents at 1-2 year follow-up (Eyberg, Funderburk, Hembree-Kigin, McNeil, Querido & Hood, 2000; cited in Webster & Taylor, 2001). RCTs have demonstrated the efficacy (e.g. Webster-Stratton, 1981a, 1981b, 1982b, 1984; cited in Webster-Stratton, 1997) and effectiveness (Scott et al., 2001) of Webster-Stratton's BASIC program. Indeed PT has been assigned treatment of choice for children aged under 8 years with CD and ODD (Fonagy et al., 2000). Behaviourally-oriented parenting programs are shown to be particularly effective (Barlow, 1997; cited in Day & Davis, 1999).

However, many evaluations are compromised by the use of a waiting-list control group (Nixon, 2002). While this design overcomes ethical problems of not treating at-risk children,
intervention and control groups cannot be compared at follow-up. Furthermore, it cannot be assessed whether long-term changes were due to maturation or treatment.

There has been less evaluation of PT compared with alternative treatments for behaviour problems (Golding, 2000). One such available study by Patterson, Chamberlain and Reid (1982; cited in Webster-Stratton, 1997) found individual-PT to be superior to family-based psychotherapy. Another found group-PT equally effective as individual ‘bug-in-the-ear’ approaches, with groups being more cost-effective (Webster-Stratton, Kolpacoff & Hollinsworth, 1988; cited in Webster-Stratton, 1997).

*How has effectiveness been measured?*

Multiple sources and measures have been used to assess outcome thereby increasing confidence in findings and enhancing knowledge of factors effected by interventions. Well-designed studies use both parent and teacher reports of child behaviour and child observations by coders blind to treatment conditions. Outcomes have also been described in terms of clinical and statistical significance, and movement out of diagnostic classifications or to within peer-compared normal levels (Golding, 2000). Satisfaction is commonly measured.

*Do benefits generalise?*

Lack of generalisation from home to school settings may impact on later psycho-social adjustment through continued school and peer-group risk factors (Webster-Stratton, 1990a, cited in Webster-Stratton & Taylor, 2001). However studies draw inconsistent findings and further research is necessary (Golding, 2000). For example, Webster-Stratton (1990b; cited in Webster-Stratton & Taylor, 2001) found a lack of generalisation to peer interactions and classroom behaviour following BASIC parent training, while Funderburk, Eyberg, Newcombe, McNeil, Hembree-Kigin and Capage (1998; cited in Webster-Stratton & Taylor, 2001) found improvements associated with PCIT to generalise to school.

Better behaviour generalisation and maintenance results when fathers (or other family members) as well as mothers are involved in PT (Webster-Stratton, 1985b; Webster-Stratton, Kolpacoff & Hollinsworth, 1988; both cited in Webster-Stratton, 1997). However further work is needed to identify factors associated with good or poor generalisation (Golding, 2000). Beneficially, generalisation to non-targeted sibling behaviours (Kazdin, 1997a, 1997b, cited in Golding, 2000) and positive impacts on family risk factors such as maternal depression (Kazdin, 1997a, 1997b, cited in Golding, 2000) have been observed.
How long are benefits maintained?
The effects of PT have been found to last up to four years following intervention (Webster-Stratton & Hammond, 1997).

When should PTs be offered?
The preschool years are considered a “critical window” for intervention (McMahon, 1994, cited in Nixon, 2002). Indeed Webster-Stratton (1997) writes that parenting programs targeted at pre-school children are more effective than those targeted at older children. However there is a lack of well-designed outcome studies for pre-schoolers (Nixon, 2002) and toddlers (Sampers et al., 2001); most studies evaluate children aged 6-11 (Kazdin, Bass, Ayers & Rodgers, 1990, cited in Nixon, 2002). Furthermore, few studies separate outcomes of preschool from school-age children (Webster-Stratton, 1997).

How much intervention is effective? Webster-Stratton (1997) writes that PT often ranges from 20-40 hours. Longer programs of up to 50-60 hours are more effective than programs of less than 10 hours (Kazdin, 1997a, cited in Golding, 2000) and families attending more than 50% of sessions show more successful outcomes (Strain, Steele, Ellis & Timm, 1982, cited in Webster-Stratton, 1997). However therapy factors, such as number of sessions attended by families (dose) and duration of training (length) have rarely been evaluated as an independent treatment variable.

How should PT be delivered?
Group/Individual
While of equal effectiveness for those who engage, group-based PT are more cost-effective than individually-based programs (Golding, 2000; Cunningham, Bremner & Boyle, 1995). However less is known about who benefits most from which format. Groups may offer protection against risk factors such as parental social isolation (Davis & Spurr, 1998), yet may not address individual needs or be accessible for more chaotic and disorganised families who find it difficult to make designated times and places (Golding, 2000).

Delivery methods
While parents reported greater satisfaction with combined therapist-led discussion and video-tape modeling than with individually administered video-tape modeling and group discussion, they were equally clinically effective (Webster-Stratton, Hollinsworth & Kolpacoff, 1989). There is also promising, although less rigorous evidence (small sample size, parent report only, no satisfaction measure) to support the use of telephone-delivered PT (e.g. Sutton, 1992;
Children And Families Essay

Connell, Sanders & Markie-Dadds, 1997; both cited in Nixon, 2002). Such developments may be useful where face-to-face contact is not possible (Nixon, 2002).

Who benefits?

Although parents that engage with parent training programs report high ‘consumer satisfaction’ (Webster-Stratton, 1997), PT are not accessible, acceptable or helpful for all parents of at-risk children (Boyle, Cunningham, Heale & Hundert, 1999). Thirty to 40% of parents continued to report clinically significant child behaviour problems after participation (Webster-Stratton & Hammond, 1997). Families least likely to participate or benefit from traditional forms of PT are often characterised by low socio-economic status, social isolation, single-parent status, maternal depression (Nixon, 2002), high parental discord, parents showing anti-social behaviour, younger children with less co-morbidity and less severe conduct problems (Wolpert et al., 2002) and families with high levels of child abuse (Golding, 2000). Programs have begun to explore the impact of different settings and PT content on overcoming these barriers.

Setting is an important factor in engaging at-risk but hard-to-engage families. While there are concerns relating, respectively, to response rates and a quasi-experimental design, community-based group programs (Cunningham, Bremner & Boyle, 1995) and individually-based home-visitation programs (Day & Davis, 1999) may reduce the stigma associated with attending services in traditional mental health clinics.

The content of PT has been adapted to broaden the range of parent-risk factors targeted (Webster-Stratton, 1994a; Sanders, Markie-Dadds, Tuly & Bor, 2000; both cited in Nixon, 2002), with varying degrees of success. Parents in the ADVANCE group program (anger management, depression, marital distress, communication skills, problem solving skills) showed superior communication and problem-solving skills to those in the BASIC group (Webster-Stratton, 1994a). Benefits did not generalise to superior child behaviour problem outcomes. However parents did not necessarily have the targeted risk factors (Nixon, 2002).

Another study recruited families with risk factors (singe-parent status, marital conflict, maternal conflict) to a RCT to evaluate the effectiveness of individually-based PT with added partner support and coping skills training (enhanced condition) (Sanders et al., 2000). The superiority of the enhanced condition was largely restricted to child behaviour improvements, with no effect on parental, personal and marital adjustment at one-year follow-up. It was questioned whether the adjuncts were appropriate for the multiple risk factors (Nixon, 2002).
Overall it seems that more work is needed to increase engagement and match PT setting, format and adjuncts to family or parental risk factors. Although Webster-Stratton (1997) refers to “booster shot” training (Page 442), little is known about how to help families maintain improvements.

How cost-effective is PT?

Aside from the greater cost-effectiveness of group- over individually-based PT (Cunningham et al., 1995), there is an absence of evidence-base relating to cost-effectiveness. However, this is consistent with the overall lack of comparison studies.

Child-Focused Training

The theory underlying child-focused early interventions [CT] is the minimisation of child risk factors for behaviour problems, such as cognitive, social and behaviour skills impairments (Webster-Stratton, Ried & Hammond, 2001). The two main approaches focus on enhancing social behaviours or cognitive processes (problem-solving, self-control, self-statements) (Webster-Stratton, 1997). CT have been delivered on an individual, group or class basis and offered in school or clinic settings.

Does CT work?

The lack of promising results from earlier studies may be accounted for by the limitations of programs and evaluations (Webster-Stratton & Hammond, 1997). Many programs developed for older adolescents were applied to younger age-groups, using age-inappropriate methods and contents (Webster-Stratton & Hammond, 1997). Often children with conduct disorders were not specifically targeted but rather grouped together with socially-isolated and withdrawn children. Studies often used small sample sizes, relied on short-term measures of improved social skills and failed to demonstrate whether improvements in socio-cognitive measures resulted in improved behaviour or outcomes generalised across situations (Bierman, 1989; cited in Webster-Stratton & Taylor, 2001). Those that studied children with conduct disorders mostly focused on pre-adolescents (aged 8 and over) and adolescents (Webster-Stratton, 1997).

More recent work such as evaluations of the clinic-based Incredible Years Dinosaur Social Skills and Problem-Solving Curriculum (Webster-Stratton, 1996c) and school-based Tri-Ministry Study (Boyle et al., 1999; Hundert, Boyle, Cunningham, Duku & Heale, 1999) has produced more methodologically-sound and positive outcomes. While Dinosaur School used an indicated strategy to target children at risk, the Tri-Ministry Study used a universal strategy
that was school-based, time-limited and curriculum-based. Pre-school or school-based programs may overcome problems with parents being unwilling or unable to attend PT.

**What has CT been compared with?**

CT has been compared with waiting-list control groups (Webster-Stratton, Reid & Hammond, 2001) and with PT and combined PT+CT (Webster-Stratton & Hammond, 1997). The Tri-Ministry Study compared social skills training (SS), partner reading (PR), combined SS and PR with a control group (Boyle et al., 1999; Hundert et al., 1999). Schools were randomised to one of the three class-wide conditions and were evaluated according to the intervention provided rather than assigned condition.

**What are the benefits?**

Multiple measures (report and independent observations) have been used, including clinical significance. Evaluations by Webster-Stratton and Hammond (1997) and Webster-Stratton, Reid and Hammond (2001) found improvements in similar proportions of children (two-thirds; 70.5% respectively). Improvements were shown as behaviour being brought into the normal range on the Child Behaviour Checklist and Eyberg Child Behaviour Inventory or, as clinically significant reductions in aggressive and non-compliant behaviour. It is not possible to determine the proportions of children showing improvements from the Tri-Ministry Study. However modest effects were found, with children in the social skills training and combined social skills and partner reading group demonstrating increased school pro-social behaviour (interpersonal competence) and reduced externalising behaviours (Hundert et al., 1999).

**Do benefits generalise?**

Studies have investigated and found evidence to support the generalisation of behaviour improvements from clinic to home and school settings (Webster-Stratton, Reid & Hammond (2001; Webster-Stratton & Hammond, 1997), and from school to home settings (Hundert et al., 1999). Home generalisation may have been assisted through the Tri-Ministry’s use of school-to-home notes and family reading packages or placebo effect (Hundert et al., 1999). The Tri-Ministry’s lack of success in recruiting parents for PT (Boyle et al., 1999) perhaps indicated that parents were representative of typically hard-to-engage parents. Nonetheless this school curriculum-based program did find some positive effects at both home and school.

**How long are benefits maintained?**

Evaluations of Webster-Stratton’s child-focused interventions show that post-treatment improvements are maintained at one-year follow-up (Webster-Stratton, Reid & Hammond,
2001; Webster-Stratton & Hammond, 1997). However no control group was available for comparison at follow-up. Similarly in the Tri-Ministry schools not allocated to conditions served as comparison groups until allocation, thereby not allowing a control group at follow-up.

**How much intervention is effective?**

Little has been written about how much intervention is enough for positive change. Webster-Stratton et al., (2001) found that two-thirds of children showed clinically significant improvements. All but one of the children attended 13 or more of the 22-24 sessions. Following a minimum of two terms implementation, Hundert et al., (1999) reported “modest effects” that they considered insufficient to have positively impacted on child’s behaviour trajectory.

**How should CT be delivered?**

As yet the Dinosaur School has only been evaluated in a group clinic-setting. A classroom, curriculum-based implementation may help broaden and maintain positive changes and an evaluation is underway (Webster-Stratton & Taylor, 2001). Hundert et al., (1999) described the pitfalls of implementing and evaluating school-based interventions.

**Who benefits?**

When CT, PT and CT+PT were compared, Webster-Stratton and Hammond (1997) found the effects on risk factors reflected the type of intervention received. PT was superior to CT in terms of child behaviour improvements, parent behaviours and consumer satisfaction. CT was superior to PT in terms of child social problem-solving and conflict management skills. However the small sample size did not allow analysis of the characteristics of those who benefited.

Other work by Webster-Stratton, Reid and Hammond (2001) investigated whether child-focused interventions buffered against risk factors such as harsh parenting, poverty, marital distress, or, whether treatment response differed according to the type of risk factors present. ADHD classification, hyperactivity and family stress (low socio-economic status, depression, marital discord) risk factors did not impact on outcomes at follow-up. However negative parenting, as measured by critical behaviours or physical punishment, exerted a significant negative impact on child outcome. CT alone was insufficient for the children of parents who showed harsh, inconsistent parenting. However more work might be needed to add weight to Webster-Stratton et al.,’s (2001) conclusions since these were drawn from the combined data-
sets of two earlier studies (Webster-Stratton & Hammond, 1997; Webster-Stratton & Reid, 1999) to obtain sufficient power to predict outcome.

Hundert et al., (1999) speculated that the modest effects from the school-based, time-limited, curriculum-based intervention may have been attributable to selection bias – that more motivated and prevention-oriented schools were more likely to participate. This raised questions about the effectiveness of such interventions in less motivated schools.

**Multi-Focused Approaches**

The theory describing the development of behaviour problems identifies the need for early interventions to target multiple risk and protective factors (i.e. affective, behavioural, cognitive, social components) across multiple contexts (i.e. involving home, school and clinic) (Webster-Stratton & Hammond, 1997). It is also suggested that if risk is cumulative over development then high-risk children might required sustained intervention across childhood and adolescence (Conduct Problems Prevention Research Group [CPPRG], 1999).

The multi-focused programs reviewed here range from a two-component intervention (e.g. Webster-Stratton’s Parents and Children Series, [PACS], 1981a; cited in Taylor, Schmidt, Pepler & Hodgins, 1998) to, multi-site, multi-focused, multi-component preventive interventions (e.g. Fast Track Prevention Trial for Conduct Problems, CPPRG, 1999, 2002).

**Do they work?**

Evidence regarding the efficacy and effectiveness of combined parent-child-training for children aged 4-8 and 3-8 is reported by Webster-Stratton and Hammond (1997) and Taylor et al., (1998) respectively. Both have methodological strengths and weaknesses that suggest promising findings but also the value of further evaluation. Webster-Stratton and Hammond (1997) also demonstrated the superiority of combined parent and child training over parent-only and child-only training – also concluded by a review by Pellham and Gnargy (1999; cited in Webster-Stratton & Taylor, 2001).

The Fast Track Prevention Trial for Conduct Problems demonstrated support for a universal-level classroom program taught by teachers and indicated-level program for children identified at high-risk for antisocial behaviour during kindergarten. The intervention program included social skills training, academic-tutoring, parent-training, home visiting, parent-child relationship enhancement (CPPRG, 1999, 2002).
How has effectiveness been measured?

RCTs have been used to draw comparisons between parent-only, child-only, parent-child training and waiting-list control groups (Webster-Stratton & Hammond (1997), and between PACS and individual eclectic treatment conducted in everyday clinical settings (Taylor et al., 1998). RCT-evidence has also been used to compare the Fast Track’s multi-component intervention with high-risk and normative control groups followed longitudinally (CCPRG, 1999, 2002). Schools were selected on basis of crime and poverty statistics and from four ethnically diverse populations.

While multiple measures and clinical significance have generally been used, Taylor et al.,’s (1998) effectiveness study is an exception in omitting independent observations and having a poor response rate from teachers. Parent reports may show “attitudinal lags” (McMahon & Forehand, 1984; cited in CPPRG, 1999). Adding to knowledge about mediating factors, Webster-Stratton and Hammond (1997) measured risk factors such as parenting behaviour, child problem-solving and conflict management skills. Mechanisms of change were however not analysed.

What are the benefits?

Taylor et al.,’s (1998) ‘effectiveness study’ found greater improvements for the PACS group than eclectic-treatment and wait-list control groups. However 41% and 74% of mothers, respectively, continued to report clinically significant problems on the ECBI. An ‘efficacy study’ found 70% of mothers reported clinically significant improvements into the normal range (Child Behaviour Checklist [CBCL]; Webster-Stratton & Hammond, 1997).

The CPPRG (1999, 2002) reported positive effects on critical risk and protective factors at both follow-up times. There were no intervention/control-group differences in the proportions of children in the ‘non-clinical’ range on the CBCL (CPPRG, 1999). Parents reported high satisfaction, although payment for participation ($15 for every 2-hours) may have introduced bias. Furthermore it seems probable that analysis of the relative effectiveness of individual components will be complicated.

How long are benefits maintained?

Taylor et al., (1998) relied on short-term measures, but Webster-Stratton and Hammond (1997) reported sustained post-treatment improvements at one-year. Longer follow-up is needed. However positive support has been found for multi-focused early interventions by the Fast Track’s 3-year follow-up (CPPRG, 2002) and Perry Preschool Project Program.

**Do benefits generalise?**
Both reviewed evaluations of PACS did not observe generalisation to school settings (Webster-Stratton & Hammond, 1997; Taylor et al., 1998). However Taylor et al., (1998) suffered poor power to detect significant effects from teacher-reports; Webster-Stratton and Hammond (1997) explained that 60% of the sample did not show clinically significant school problems. It may be fruitful to investigate the impact of teacher involvement where school behaviour problems are present.

**Who benefits?**
Neither Webster-Stratton & Hammond (1997) or Taylor et al., (1998) explored the characteristics of children who failed to benefit from the interventions, with analysis perhaps limited by small sample sizes. Fast Track demonstrated benefits for European/African American families with low SES and multiple-problems, many of single-parent status (CPPRG, 1999).

**How much intervention is effective and cost-effective?**
The programs reviewed here vary enormously in terms of investment of finances, time, resources and systems. Direct comparison therefore seems meaningless. Longitudinal and cost-effectiveness studies of the PACS may, however help determine how much intervention is enough to make a positive impact on long-term behaviour. Fast Track on the other hand represents one of the most comprehensive and costly early interventions available (CPPRG, 1999, 2002). Indeed Bierman and Greenberg (1996, cited in Hundert et al., 1999) described a direct relationship between 'dosage' and outcome for high-risk students. Valuable information will be provided about the costs of intervening and not intervening.

**SUMMARY OF EVIDENCE BASE**

**Overview**
Despite the raised profile of early intervention strategies in the UK (Day & Davis, 1999), the number of programs currently appears to exceed the number of good quality evaluations (database searches). Much of the existing research appears to originate from North America (database searches), such that differences in societal values, cultural characteristics (Wolpert et al. 2002), service systems, research instruments and so on, may reduce the confidence with
which the findings of USA-evaluations may be generalised to UK populations. While one of
the few existing UK controlled trials supported the trans-Atlantic generalisation of the
Webster-Stratton’s BASIC program (Scott et al., 2001), further research is needed in this
area.

There is also a need for more “effectiveness” studies that evaluate whether programs
supported by “efficacy studies” are generalisable to everyday clinical settings. While a
couple of such studies exist (Scott et al., 2001; Taylor et al., 1998), an earlier review by
Weisz, Weiss and Donenberg (1992; cited in Scott et al., 2001) found evidence that findings
from university trials did not generalise to regular service clinics.

It can be difficult to draw comparisons between studies as the disorder with which children
have been treated is often unclear, with terms such as ‘behavioural problems’, ‘externalising
behaviours’, ‘conduct disorders’, ‘anti-social behaviour’ sometimes used interchangeably. A
related issue is the lack of disorder-specific studies (Kendall & Morris, 1991, cited in Nixon,
2002). While children may rarely present with a neat diagnostic label (Wolpert et al., 2002),
findings based on heterogeneous samples may not generalise to all sub-groups of
externalising behaviours.

There are also questions about the usefulness of DSM-IV criteria in pre-schoolers (Webster-
Stratton, 1997) and the accuracy of externalising behaviours to identify at-risk girls (Bennett
et al., 1998). Bennett et al., (1998), suggested that at-risk girls may not be accurately
identified, which may limit conclusions about effectiveness of early intervention for at-risk
girls. Indeed the child’s gender has received little research attention (Webster-Stratton, 1997).

Evaluation studies commonly use multiple measures to detect changes and report clinical
significance. However it is difficult to draw comparisons between studies when different
measurement tools are used and there is no consensus about what constitutes a clinically
significant change (Kazdin, 1999; cited in Nixon, 2002).

**Unanswered Questions**

Aside from methodological limitations, knowledge gaps and unanswered questions remain.
Thus far, both in the USA and UK, PMT for conduct disorders have received the most
extensive research attention. Less is known about early interventions for ADHD, and child-
and multi-focused interventions.
Existing evidence does not allow us to draw conclusions about or tell us how the format, setting and content of parent-training be modified to enhance access, engagement and benefit among typically 'hard-to-engage' families. Further work is needed to develop parent- and child-focused interventions that sufficiently buffer against wider risk factors. While there is less convincing evidence for stand-alone social skills and cognitive interventions than for parent and family interventions (Webster-Stratton & Taylor, 2001), positive findings exist. However less well known is how CT may be optimally delivered, the characteristics of children who do not engage or benefit, long-term effectiveness and cost-effectiveness. While intensive multi-focused interventions may be more effective than child-or parent-focused alone (Bennett & Offord, 2001), as yet little is known about which components are the 'key ingredients'. A related issue is the lack of attention to mediating variables, and whether interventions also affect the primary predictors of behaviour problems as well as the problem behaviour itself (Webster-Stratton & Taylor, 2001). Such data will add to the theory base and contribute to the development of more effective interventions.

Existing research has paid little attention to co-morbidity (Nixon, 2002), cultural factors (Golding, 2000), therapist variables (Golding, 2000) and how these influence effectiveness. Evaluations are commonly limited by a lack of control group at follow-up. Furthermore, little is known about the impact of parent-, child- and multi-focused interventions on the long-term trajectory of behaviour (Golding, 2000). The cost-effectiveness of early intervention, both compared against other interventions and no intervention, has received little attention. More needs to be known about how to maximise the benefits of any one intervention through generalisation across settings and impact on multiple risk factors (Golding, 2000).

Such questions are likely to limit clinical decision-making to optimally match interventions to the characteristics and needs of the particular child and family (Golding, 2000). On-going research may allow a decision-making path that allows choice of evidence-based intervention based on the risk factors present in any family.

OVERALL CONCLUSIONS

Currie (2000) warns against the expectation that a short intervention at a particular age will reduce a lifetime of deprivation. However with regard to the title, the current state of evidence allows for the tentative support of the assertion "Early intervention works".

Sufficient methodologically-sound evidence is available to answer the basic question of whether early intervention works for conduct disorders (ODD and CD). Less, however is
known about ADHD. Existing evidence further provides a sufficient basis for continuing to develop the availability, accessibility and nature of early intervention services, so that where possible behaviour problems can be prevented from occurring or difficulties can be identified and targeted as early as possible (Day & Davis, 1999). Wider societal changes in terms of policies, funding and systems are required in order to co-ordinate and integrate necessary services. The influential role of socio-economic factors, such as poverty and housing, in the causation and maintenance of behaviour problems must not be overlooked.

Wolpert et al., (2002) consider evidence-based practice to be “the integration of individual clinical expertise with the best available external clinical evidence from systematic research” (Page 5). More systematic research is needed to allow decisions about “which combination of treatments works best for which families” (Golding, 2000; Page 368)
REFERENCES


OLDER PEOPLE ESSAY

‘Race and ethnicity are relatively unimportant variables in both the incidence and treatment of mental health difficulties in older people.’

Critically discuss this statement.

August 2003

Year 2
INTRODUCTION

After clarifying definitions, literature debating and investigating the influence of race/ethnicity firstly, for the incidence of mental health difficulties in older adults and secondly, for mental health treatment will be considered. Depression and dementia are mainly considered. Issues relating to migration and refugee status and the formation of mental health difficulties are not explored.

Epidemiological studies and population surveys describe a continuing change within the age profile of the UK population; increasing numbers of people of all races/ethnicity are reaching pensionable age (Daker-White, Beattie, Gilliard & Means, 2002; Haley, Han & Henderson, 1998). This population shift has wide-ranging implications for UK services and mental health professionals. Professionals will be assessing, treating and caring for greater numbers of older people who will be increasingly from diverse racial/ethnic backgrounds. Consideration of the importance of race/ethnicity for mental health among older people is therefore necessary since this might indicate different rates of incidence than those found in the older white population, or indeed, unique issues regarding diagnosis and treatment.

Definitions Of Older Age, Race And Ethnicity

'Older age' is typically determined by chronological age within western cultures. However the category of older age is socially-constructed (Fennell, Phillipson & Evers, 1994) since each society determines how age differences are structured (Dein & Huline-Dickens, 1997) and social status accorded (Abramson, Trejo & Lai, 2002). Hence experiences of aging and psychological distress vary across cultures (Palmore, 1983). Indeed older people services often vary in their age for inclusion. Haley et al., (1998) use the following classifications: "young-old" (65-74 years), "old-old" (75-84) and "oldest-old" (85 and above).

"Race refers to the genetically determined characteristics that an individual is born with" (Risby & Van Sant, 1999; Page 239); it is considered permanent. Culture refers to behaviour and attitudes such as language and religion that are learned as part of upbringing and perceived changeable through assimilation and acculturation. Ethnicity is characterised by a sense of belonging and group identity that are determined by social pressures and psychological need; it is perceived as partially changeable (Fernando, 1991; Risby & Van Sant, 1999). However these terms are often used interchangeably in the literature, cannot always be neatly defined (Bhurga & Bahl, 1999) and are difficult to disentangle in practical
Older People Essay

While acknowledging definition and measurement difficulties, the current analysis will use the term 'ethnic elder' to refer to older people who have a different cultural heritage to that of the UK white majority (Manthorpe & Hettiaratchy, 1993). This may include people of white Irish, Afro-Caribbean, Chinese and Indian sub-continent origins (Census 2001) and East European, Jewish, Middle Eastern origins (Manthorpe & Hettiaratchy, 1993).

**INCIDENCE**

Incidence indicates new cases and might refer to first ever episode, all episodes or onsets up to a certain time-point (Silman, 1995). However little incidence data seems available for mental health difficulties among older ethnic elders. Database literature searches instead identify prevalence data for ethnic elders or incidence data for ethnic 'youngers' (PsycINFO, EBSCO, OVID). The current analysis therefore chooses to focus on the racial/ethnic variables that influence incidence through their impact on accurate detection and diagnosis. Although perhaps itself reflecting ethnocentricity, dementia and depression will mainly be considered due to their particular emphasis within the National Service Framework for Older People (NSF-OP; Department of Health, 2001) and the availability of literature.

Five percent of people over 65 are thought to have dementia; 20% of people over 80 years of age (Department of Health, 2001; NSF-OP; 7.34). Between 10-15% of people over 65 are thought to be depressed at any one time (Baldwin, 1996; Cited-in NSF-OP; 7.20). However there are ideas about why ethnic elders might experience different levels of psychological distress than their white counterparts. There are notions that family structures among certain ethnic groups, such as among Japanese and Taiwanese elderly, protect against psychological distress (Krause & Liang, 1992). Ethnic elders have also been thought of as 'hardy survivors' who have been prepared for the challenges of old age by previous adversity (Haley et al., 1998). Existing alongside these ideas are psychological, sociological and biological hypotheses about why ethnic elders might however experience higher levels. For example, cumulative losses and life stresses, low income and education, and cerebrovascular risk factors among Black-American elders might place them at higher risk for depression and dementia (Manthorpe & Hettiaratchy, 1993; McCracken, Boneham, Copeland, Williams, Wilson, Scott, McKibbin & Cleave, 1997; Steffens, Artigues, Ornstein, & Krishnan (1997). There are also theories of 'triple jeopardy' where ethnic elders already disadvantaged by ageism and racism are further disadvantaged by socio-economic circumstances that cause or
exacerbate disadvantages in mental health (Norman, 1985; cited-in Manthorpe & Hettiaratchy, 1993; Fennell et al., 1994). Gender may add further disadvantage or confer advantage (Ebrahim, 1992; cited-in Manthorpe & Hettiaratchy, 1993).

A preliminary look at the literature shows comparable prevalence rates of dementia across different racial/ethnic groups (Review by Daker-White et al., 2002) but inconsistent findings about rates of depression. While some studies describe lower rates of depression among ethnic elders (Unützer, Katon, Callahan, Williams, Hunkeler et al., 2003), others describe higher rates.

**Racial/Ethnic Factors Influencing Incidence**

However since incidence relies upon the presentation of individuals at services and their accurate diagnosis (Silman, 1995), racial/ethnic factors are likely to be important for incidence (Flaskerud, 2000). They may influence research participation, service accessibility and appropriateness (actual and perceived). Racial/ethnic factors may influence the individual’s perception of the problem and what might be considered acceptable help. They may also influence how difficulties are expressed and communicated. Racial/ethnic variables are further introduced by the manner in which clinicians assess presented symptoms and the ability of assessment tools to meaningfully measure these (Flaskerud, 2000). Such aspects are likely to vary according to an individual’s level of ethnic identity and acculturation.

**Ethnic Identity And Acculturation**

Acculturation determines the degree to which an individual “relinquishes traditional values, customs, beliefs and behaviours of the minority culture and adopts those of the majority culture” (Morales, 1999; Page 142). Instruments have been developed to measure acculturation. Individuals vary in the degree to which they assimilate majority culture while retaining their ethnic identity (Lee, 1996; cited-in Harris, 1998); both are important for incidence. Lower acculturation is associated with lower socio-economic status, smaller social network, lower service use and higher rates of depressive symptoms, adjustment disorder and substance misuse (described in Haley et al., 1997). Acculturation has also been found to play a role in length of time before symptoms of dementia are diagnosed among Hispanic elders (Fitten, Oritz & Pontón, 2001).

**Research Participation**

Studies commonly report difficulty recruiting ethnic elders which in turn skews available incidence data (Olfsen & Klerman, 1992; cited-in Steffens et al., 1997). Aranda (2001)
describes barriers to ethnic elders' participation in dementia-related research that may be accentuated by vivid memories of historical discrimination and methods of recruitment.

**Service Use**

There is substantial evidence that mental health services are under-used by older people of all races/ethnicity (review by Lagana & Shanks, 2002; Social Services Inspectorate, 1997; cited-in NSF-OP, Department of Health, 2001). However USA and UK evidence suggests this is particularly noticeable among ethnic elders (Manthorpe & Hettiaratchy, 1993; Steffens et al., 1997; McCracken et al., 1997). Indeed dementia is less likely to be detected among ethnic elders and they are less likely to be treated at specialist clinics (Tang, Stern & Marder, 1998; cited-in Haley et al., 1998). However it remains unclear whether lower service-use reflects levels of psychological distress, help-seeking behaviour, or, detection by services.

**Accessibility, Acceptability And Appropriateness**

The NSF-OP acknowledges that services might not be readily accessible nor fully appropriate for ethnic elders (Department of Health, 2001; 7.3). Indeed Nazroo (1997) has highlighted the negative relationship between race/ethnicity and care quality, and, ethnic minorities report feeling that services are not for them because they are not white (Bahl, 1999). Opinions are based on experiences (and perceptions) of direct discrimination such as staff behaviour, and indirect discrimination, such as services not provided in the right language (Hutchinson & Gilvarry, 1998; cited-in Marwaha & Livingston, 2002; Bahl, 1999).

Some suggested racial/ethnic differences, such as perceived stigma, poor knowledge and understanding of services (Shah, Lindesay & Jagger, 1998; Lindesay, Jagger, Hibbet, Peet & Moledina, 1997; both cited-in Marwaha & Livingston, 2002), have also been found to be true of white elders (Marwaha & Livingston, 2002). Indeed all older people face ageism and potentially sexism (Laganà & Shanks, 2002), but ethnic elders may face an additional level of discrimination – ethnocentrism (Skodra, 1991). Furthermore unique cohort and historical experiences such as discrimination and segregation by black-Americans may have led to a sense of ‘cultural mistrust’ that extends to avoidance of social and health organisations. Although it may be that such experiences have also been protective in developing unique coping resources (Haley et al., 1998).

**Beliefs About Symptoms And Treatment**

Help-seeking and presentation at services are also influenced by the explanatory models that individuals hold about illness (Canino, Lewis & Bravo, 1997). Such models suggest the
likely meaning, cause, course and treatment of an illness and are at least partly determined by cultural/ethnic factors. Many ethnic elders turn to their natural support systems of family, community, church, folk/traditional healers before more formal services (Morales, 1999). Less acculturated ethnic elders may hold stronger cultural beliefs (Kleinman, 1996; cited-in Haley et al., 1998).

Marwaha and Livingston (2002) compared black African-Caribbean and white elders living in the UK and found racial/ethnic differences in terms of ideas about aetiology and appropriate places to seek help for depression. Participants previously treated for depression held more positive views of mental health services. More black elders viewed depression to be of a spiritual cause, through failure of religious duties or faith; White elders considered depression to be the individual’s fault. Black elders also cited lack of social contact with people of their own kind as an important causal factor. They also held a pessimistic view that nothing could be done to help. Furthermore many, irrespective of ethnicity or previous depression, did not view depression a mental illness for which medical attention should be sought (in contrast to believing medical attention should be sought for psychosis). Other studies indicate that categories of mental health difficulties do not always have equivalence or meaning across all societies, such as dementia among Australian Aborigines and Vietnamese and Chinese migrants to USA (Pollitt, 1997; Braun, Takamura, Forman, Sasaki & Meninger, 1995; both cited-in Daker-White et al., 2002). They are faced with more urgent housing, education and primary health needs.

Family attributions of symptoms also influence help-seeking. Asian and Pacific Islander Americans consider the symptoms of dementia a “natural and untreatable consequence of aging” rather than a diagnosis (Larson & Imai, 1996; cited-in Daker-White et al., 2002; Page 105). Many black-American families normalise dementia-related cognitive impairments and prefer to provide care at home (Dilworth-Anderson & Anderson, 1994; Cited-in Haley et al., 1998). There is also evidence that African-Americans have different appraisals and coping responses to care-giving that result in less subjective stress and depression than equivalent white families (Haley et al., 1998). However authors warn against generalising to all individuals within an ethnic group. For example, psychological distress may be accentuated among families where traditional expectations of family care are not upheld by differently acculturated younger generations (Haley et al., 1998).
Measurement and Diagnostic Issues

Detection and diagnosis are based on history-taking, mental status examination and the use of assessment scales; all of which may be influenced by racial/ethnic factors. Flaskerud (2000) writes that there is a “high tendency for mis-diagnosis when clinicians and clients do not share cultural meanings or language” (Page 9). This might influence what difficulties are elicited and/or noticed, how these are given diagnostic significance.

History-taking

History-taking is likely to be hampered by language ability and the use of western concepts of mental health. Where English is not the first language, standard questions may be posed more simply and thereby elicit inaccurate responses or responses that are mis-interpreted (Espino & Lewis, 1998). Errors may be compounded through translation, especially when family members are used as untrained interpreters, or trained interpreters provide biased or inaccurate paraphrasing (Putsch, 1985; cited-in Espino & Lewis, 1998). Assessments are likely to take longer when working with an interpreter (Shah, 1997). Language may therefore contribute to different treatment processes and outcomes. For example, Australian research found that non-English speaking elderly patients were less likely than English speaking patients to be admitted voluntarily to an acute psychogeriatric unit and less likely to be diagnosed with affective disorder (Hassett, George & Harrigan, 1999).

Depending on level of acculturation, western concepts may fail to elicit or identify non-western symptoms or symptoms not seen in western cultures, such as culture-bound syndromes (Haley et al., 1998). Language was also a marker for poorer performance on cognitive tests that tested knowledge within the dominant culture (e.g. Geriatric Mental State Examination; McCracken et al., 1997).

Although individual variations exist, clinicians are advised that effective interviewing and interpretation requires some knowledge of the belief systems and symptom presentation characteristic of the ethnic group. Clinicians should use terminology that is familiar to the ethnic elder (Tsai & Carstensen, 1996; cited-in Abramson et al., 2002). They are further urged to consider the individual’s unique historical experiences such as racism, discrimination and migration in order that symptoms might be contextualised.

Symptom Presentation

There are debates whether there is a universal common core of depressive symptoms or whether depression manifests uniquely in different cultural settings (Krause & Liang, 1992).
Conclusions are hard to draw since much of the research takes an ‘etic’ approach and makes ethnic comparisons using western constructs and instruments (Canino et al., 1997). For example, while Krause and Liang (1992) found Japanese, Taiwanese and Chinese elderly less likely to endorse positive statements about themselves, they used a western developed scale (Epidemiological Studies Depression Scale, CES-D). Furthermore, some research does not report age-differences or compare ethnic with white elders. There is also the question of whether differences may be attributed solely to race/ethnicity. For example, Blazer, Landerman, Hays, Simonsick & Saunders, (1998) found minimal differences on individual symptoms of depression after controlling for socio-economic factors. The one remaining significant difference for interpersonal symptoms of depression was speculated to reflect the effects of real-life prejudice for African-Americans. There is some evidence that symptom presentation may vary by acculturation. While white elders are also more likely to report somatic than psychological symptoms of depression (Livingston, Manela & Katona, 1997; cited-in Marawah & Livingston, 2002), less acculturated ethnic elders show more somatisation than white elders (Gonzalez & Griffith, 1997; cited-in Haley et al., 1998).

Assessment Tools
Although DSM-IV outlines a cultural formulation that requires the consideration of cultural variables in explaining symptoms (American Psychiatric Association, 1994), some question whether diagnostic criteria and instruments based on western egocentric world-view can be valid and reliable for people holding a more “sociocentric” relational world-view (Risby & Van Sant, 1999; Page 240). Kleinman (1987; cited-in Nazroo, 1997) also talks about ‘category fallacy’, where a category of illness developed in one culture is applied to another. This may result in ‘false positives’ or failure to identify individuals because a category lacks coherence in another culture. Since cultural norms determine what constitutes unusual, bizarre or dangerous behaviour, the threshold between case and non-case may also vary across races/ethnicity (Haley et al., 1998; Canino et al., 1997). Instruments developed for white elders often do not have reliability, validity and norms for ethnic elders and should therefore be used with caution (Haley et al., 1998).

Socio-demographic Factors
Performance on cognitive tests is strongly influenced by education (Ramirez, Teresi, Silver, Holmes, Gurland & Lantigua, 2001) which is in turn closely associated with ethnicity among older adults living in America (Haley et al., 1998). This has particular relevance for detecting dementia among ethnic elders. For example, while NICE guidelines recommend use of the MMSE in dementia assessment (Department of Health, 2001; 7.40), this has been found to
yield higher false positive results for Blacks and/or Latinos than for Whites and for those
with lower education levels (Ramirez et al., 2001). However there is still uncertainty as to
whether rates of dementia do indeed differ according to educational level or vary as an
artefact of educational or cultural bias (Ramirez et al., 2001).

Researchers disagree whether data should be adjusted for socio-economic factors (Krause &
Liang, 1992), yet this has an enormous impact on conclusions about racial/ethnic differences,
either in exaggerating or masking differences (Canino et al., 1997). Adjusting for factors
such as education, income, chronic health problems and cognitive impairment has shown
similar or lower levels of depressive symptoms among African-Americans than among white-
Americans (Blazer et al., 1998). An East London study comparing first generation Bengalis
and Somalis and white elders, more cautiously concluded that ethnic group differences in
anxiety and depression were partly due to social inequalities (Silveira & Ebrahim, 1998).
However other authors argue that removing socio-economic factors “strips away the very
essence of the black experience that is responsible for the observed differences in
psychological distress” (Kessler & Neighbors, 1986; cited-in Krause & Liang, 1992; Page
187).

CONCLUSIONS REGARDING INCIDENCE

Research Limitations
Since western concepts of mental health difficulty may not have coherence in non-western
cultures, existing data may be biased due to the ‘etic’ approach often taken. There are also
questions of whether findings from small samples or ethnic sub-groups can be meaningfully
generalised to the wider population or entire ethnic group (Carlson & Rosser-Hogan, 1993;
cited-in Risby & Van Sant, 1999; Krause & Liang, 1992). Ethnic minority elders may be
thought as having the greatest cumulative experience of culture (Dein & Huline-Dickens,
1997), yet they are not a homogenous group. They encompass great diversity in terms of
ethnic group, ethnic identity, acculturation, religious preferences, patterns of migration,
settlement, continuities and discontinuities across the life-cycle, family constellations, gender,
socio-economic status and physical disability or illness (Aranda, 2001; Fennell et al., 1994;
Manthorpe & Hettiaratchy, 1993). Problems with generalisation are often accentuated when
studies do not adequately describe their research participants (Bhurga & Bahl, 1999) or
explore the effect of variables that confound the interaction between race/ethnicity and mental
health (Canino et al., 1997). It is often not clear whether race, ethnicity or culture is being
measured. Furthermore, much data originates from USA and might not be generalisable to
the UK due to the unique historical, political and social experiences of USA ethnic elders.
UK and USA ethnic elders also comprise of different ethnic groups who live within differing social, health and welfare systems.

Summary
While current research limitations make it difficult to firmly quantify the unique impact of racial/ethnic variables, there is sufficient evidence to suggest their importance for incidence. Ethnic and white elders share similarities in some help-seeking attitudes and in some of the ways that symptoms are interpreted and presented, yet ethnic elders may face greater barriers to service-use. Even when ethnic elders do present at services, mental health difficulties are not always accurately detected due to racial/ethnic differences in symptom presentation, linguistic or communication problems and the ability of clinicians and assessment tools to meaningfully assess and diagnose these. Conceptualisations of the self, other, aging and mental health, diagnostic categories, and instruments that are based on a western worldview and used without cautious consideration are likely to result in biased estimates. The importance of race/ethnicity is however, likely to be mediated by individual characteristics such as generation, acculturation and socio-demographic profile.

TREATMENT
While issues of diversity arise between clients and therapists of a shared racial/ethnic background, there is a growing literature describing the particular considerations for clients and therapists from different racial/ethnic backgrounds working together. Ethnicity may be important for treatment since it influences the development of the personality, ideas about the self and other, fulfilment of roles, family structures, community involvement, attitudes towards aging, conceptualisations of illness and what is perceived as stigma (Dein & Huline-Dickens, 1997). However while individual members of an ethnic group may share characteristics, there is very clear evidence that each individual/family should be considered on a case-by-case basis, according to their unique biography, ethnic identity and degree of acculturation (Manthorpe & Hettiarachy, 1993; Cardemil & Battle, 2003; Khan & Pillay, 2003).

Therapeutic Approaches
While there is empirical support that ethnic elders prefer more directive approaches, it is not clear whether this preference is unique to ethnic elders (Atkinson & Lowe, 1995). Abramson et al. (2002) and Morales (1999) recommend particular approaches for particular ethnic groups, especially where elders are more traditional and less acculturated. They suggest behavioural approaches for elder Asians, behavioural and cognitive-behavioural approaches
for elder Hispanics, and focused, brief problem-solving and social skills training for African-Americans. On the whole, they advise against insight-oriented and psychodynamic approaches since these might increase shame for elder Asians by focusing on internal conflicts or might not fully consider racism and discrimination faced by some ethnic elders. Experiences of racism and discrimination may be particularly important to address (Cardemil & Battle, 2003), especially when facilitating life review (Natale, 1986; cited-in Laganà & Shanks, 2002). There are also suggestions that family therapy approaches might allow flexibility to work in a culturally-sensitive way with ethnic elders and their families (Dein & Huline-Dickens, 1997). Attention needs paying that culturally-sensitive materials are used, like for example, in dementia reminiscence groups or reality orientation sessions (Brownlie, 1991; cited-in Manthorpe & Hetfield, 1993).

Medication
There is evidence that race/ethnicity is an important variable for psycho-tropic medication. Particular ethnic groups, such as Asian- and African-American show different metabolism of tricyclic anti-depressants and lithium (Lin, Anderson & Poland, 1995; Strickland, Lin & Fu, 1995; both cited-in Risby & Van Sant, 1999) that have implications for dose and toxicity. Differences may be attributable to cross-cultural differences in lifestyle, such as diet (Lin, 1996a; cited-in Flaskerud, 2000) or gene alterations (Risby & Van Sant, 1999). Adherence may be poor where the client does not share the clinician’s ‘medical’ understanding of the difficulty, has different expectations regarding speed of effect or side-effects, or where instructions have not been provided clearly in the correct language (Flaskerud, 2000). There may also be difficulties with interactions with traditional folk or herbal remedies (Esplin & Lewis, 1998).

Therapist-Client Relationship
The extent that racial/ethnic differences effect the therapeutic process is likely to vary according to the clinician’s degree of cultural competence, client’s degree of acculturation and the ethnic identity of each (Atkinson, 1983; Sue, 1988; both cited-in Cardemil & Battle, 2003). Such factors may well influence how comfortable a client feels working with a therapist from a different, typically majority, racial/ethnic background, and similarly the way a therapist approaches racial/ethnic issues with clients (Cardemil & Battle, 2003).

Therapist Variables
There is evidence of a preference for, and more positive outcomes when ethically similar clients and therapists work together (Sue & Zane, 1987; cited-in Atkinson & Lowe, 1995).
However matching for ethnicity alone may not guarantee benefits since variables such as social class and acculturation may be equally important. The age and gender of the therapist in relation to the ethnic elder may also be important for the therapeutic alliance. For example elder Hispanics believe age brings wisdom and will prefer a therapist who is older or married with children (Morales, 1999). Therapists are advised to increase their cultural competence through enhancing their knowledge of ethnic groups in such a way that avoids racism and stereotypical labelling but encourages dialogue (Wilson, 2001). Active initiation and willingness to have open conversations about racial identity, acculturation, power, privilege and racism are thought to strengthen the therapeutic alliance (Cardemil & Battle, 2003). Therapists are also encouraged to examine their personal assumptions and recognise the value of non-western cultural beliefs and traditions (Cardemil & Battle, 2003). However the impact of therapist variables have not been fully explored (Atkinson & Lowe, 1995).

Communication And Interaction Styles
Language is likely to be a unique variable when working with ethnic elders. It may be a fundamental barrier to establishing rapport (Cheng & Lo, 1991; cited-in Abramson et al., 2002). For example, most Hispanic elders only speak Spanish or feel that feelings can only be conveyed using their own language (Morales, 1999). The difficulties of working with an interpreter have not been fully quantified (Shah, 1997), however it is likely to alter the therapeutic relationship. Even where therapist and client both speak the dominant language, they may not share the same terminology to describe emotional states and care must be taken to use the client’s expressions (Haley et al., 1998). Etiquette about using titles and surnames and waiting for explicit permission to be more informal may be universal to all older people (Abramson et al., 2002), however there are racial/ethnic differences in non-verbal communication that may lead to mis-communication and gradually disturb the therapeutic relationship (Sue, 1990; cited-in Cardemil & Battle, 2003). These include recognising appropriate eye-contact, distance, body movements, topics of conversation (Abramson et al., 2002).

Expectations
Ethnic elders and their families may hold different expectations of mental health services (Skinner, 1995; cited-in Haley et al., 1998; Page 405; Sue, 1988; cited-in Cardemil & Battle, 2003). Morales (1999) describes how Asian elders often wait for crises to seek counselling but will then expect immediate and specific solutions to sometimes long-standing and severe difficulties. Hispanic and Asian elders may view the therapist as an expert which may pose difficulties working collaboratively. Hispanics elders may also feel it disrespectful to correct
the therapist if they have been misunderstood so it is important to actively check for clarification. Therapists are advised to define their services, prior experiences and training and use a professional title.

**Family/Community Involvement**

The individualistic perspective of Western psychotherapy may not be meaningful for cultures holding more collectivistic perspectives (Helms & Cook, 1999; cited-in Cardemil & Battle, 2003). There may therefore be different ideas about what constitutes an appropriate therapist-client relationship or appropriate treatment goals or solutions. For example, the client might infer that the therapist is not committed to the therapeutic process unless they involve the family (Tsai & Carstensen, 1996; cited-in Abramson et al., 2002). Regard and respect for the family must be shown (Haley et al., 1998). Further, the support of respected individuals within the community or service location within a valued community venue may be necessary for participation by Hispanic and African-Americans in care-giving support groups (Henderson, Gutierrez-Mayka, Garcia & Boyd, 1993; cited-in Haley et al., 1998). Equally however, clinicians must caution against holding stereotypical views about supportive and close-knit family and community integration (Manthorpe & Hettiaratathy, 1993). It is not appropriate to assume that family are willing to provide care (Walker & Ahmed, 1994; cited-in Dein & Huline-Dickens, 1997).

**Shared Understanding**

There are likely to be difficulties where the client and therapist do not share a common understanding of the situation (Haley et al., 1998). The degree of understanding between their explanatory models about illness and treatment will at the least, influence engagement, early termination and adherence to medication (Flaskerud, 2000). It is important to formulate problems within the client’s belief system (Atkinson & Lowe, 1995) which will mean integrating beliefs about healing, spiritualism, fatalism into western conceptualisations (Abramson et al., 2002). This may be particularly pertinent when working with less acculturated ethnic elders such as elder Hispanics who may hold stronger folk beliefs or spiritual interpretations of mental health difficulties (Morales, 1999). Older black women may especially value spirituality and self-help techniques (Wilson, 2001). Cultural norms determine factors such as how the ethnic elder may view themselves, their roles and patterns of deference. These may differ from western ideas and may be important in identifying what are considered acceptable solutions for difficulties (Morales, 1999).
Death And Dying

Attitudes towards death and dying are firmly “rooted in ethnic heritage” (Haley et al., 1998; Page 406). There is strong evidence that ethnicity influences preferences for decision-making and informed consent about life-saving treatment, truth-telling and advance planning. For example, the current practice of truth-telling and ideas of autonomy are at odds with Chinese-Canadians, Ethiopian-, Mexican- and Japanese-Americans ideas of fatalism, maintaining hope and family decision-making (Turner, 2002; Perkins, Geppert, Gonzales, Cortez & Hazuda, 2002). Race/ethnicity will also influence attitudes about autopsy, preferences for funeral practices, expression of condolences and grief (Barrett, 1998; cited-in Haley et al., 1998; Goodman, Rubinstein, Alexander & Luborsky, 1991). However attitudes vary by education, social class and acculturation (Blackhall, Frank, Murphy, Michel, Palmer & Azen, 1999; cited-in Turner, 2002).

CONCLUSIONS REGARDING TREATMENT

The reviewed literature mainly relates to USA ethnic elders and mainly explores ethnicity. It is also unclear whether literature is based on clinical opinion or empirical data. However while particular findings may not be directly generalisable to UK ethnic elders, they raise awareness of the ways in which race/ethnicity enters treatment and the therapeutic relationship. Racial/ethnic variables may influence whether rapport will be established and therapy engaged with, also how and what type of therapy might be conducted. However their salience in the therapeutic encounter is mediated by client factors such as social class, ethnic identity and degree of acculturation, and may well be mediated by therapist factors such as cultural competence.

OVERVIEW

More anthropological and qualitative research is required to improve understanding of the ways that different races/ethnicity express psychological distress ( Nazroo, 1997). This will help inform the development of culturally-sensitive ways to assess and identify difficulties that require intervention. Further research is also needed to substantiate ideas about the impact of racial/ethnic variables for the process and outcome of therapy and determine whether differences are unique to race/ethnicity ( Atkinson & Lowe, 1995) and older age. Services may also benefit from developing culturally-sensitive outreach strategies to address actual and perceived barriers to service-use.

The experience of race/ethnicity is likely to be specific to a particular culture and dynamic across time. Research is therefore most likely to be useful where it clearly defines its sample
and is representative of the population to which it is to be applied. There is a particular need for UK-based research. An important conclusion for clinical practice is the recognition that individual differences in acculturation, migration, generation, unique life experiences will determine the degree to which characteristics of the ethnic group are salient. While it is important to remain open to racial/ethnic factors in assessment and treatment, each client/family should be treated in their uniqueness.
REFERENCES


CLINICAL DOSSIER
INTRODUCTION TO THE CLINICAL DOSSIER

The clinical dossier contains summaries of the clinical experience gained over the three-year training program and summaries of the five case reports submitted. Full versions of the five case reports as well as placement documentation (placement contracts, logbooks of clinical experience and placement evaluation forms) can be found in Volume Two of the portfolio. Due to the confidential nature of the material contained, Volume Two is held in the Department of Psychology at the University of Surrey.
SUMMARIES OF CLINICAL EXPERIENCE GAINED DURING TRAINING

Adult Mental Health
People with Learning Disabilities
Children and Families
Specialist Placement – Adult Psycho-Oncology
Older People
Specialist Placement – Addictions

PsychD Clinical Psychology

October 2001 to September 2004
CORE PLACEMENT: ADULT MENTAL HEALTH

Dates: October 10\textsuperscript{th} 2001 to March 22\textsuperscript{nd} 2001
Supervisor: Dr Alex Reid
NHS Trust: Surrey Oaklands NHS Trust,
Base: North and South Tandridge Community Mental Health Teams
Caterham and Oxted, Surrey

Setting and clients: This placement involved working as part of an out-patient CMHT. Clients seen were males and females (age range 22-69 years) from a predominantly White British background.

Presenting problems: Panic disorder, generalised anxiety, specific phobia, post-traumatic stress disorder, anger management, depression, bereavement, low self-esteem, assertiveness training, stress management, interpersonal difficulties, bulimia nervosa, OCD, memory difficulties following recurrent depression and assessment of cognitive functioning.

Assessments: Assessment for treatment interviews with clients, Thought Diaries, Panic Diary, BAI, BDI-II, SCL-90, WAIS-III, WMS-III, Schonell Reading Test, Dissociation Events Scale, Impact of Life Events Schedule, Novaco Anger Scale, Eating Disorder Inventory II, Meta-Cognitions Questionnaire

Interventions: Interventions predominantly used a cognitive-behavioural model with elements of existential and humanistic approaches, supportive counselling and bereavement therapy.

Other experience: The Service Related Project, investigating the process of allocating referrals for initial assessment during MDT meetings, was carried out on this placement (see Research Dossier). As well as presenting the research findings, the Trainee also facilitated a teaching session to the MDT about 'Obsessive-compulsive disorder: Characteristics and Treatment'.
CORE PLACEMENT: PEOPLE WITH LEARNING DISABILITIES

Dates: April 3rd 2002 to September 20th 2002
Supervisor: Dr Gill Koheeallee
NHS Trust: South West London Community NHS Trust
Base: Merton and Sutton Community Team for People with Learning Disabilities, Mitcham, London

Setting and clients: This placement involved working as part of an out-patient community team. Assessment and interventions were carried out with clients, staff and relatives who were seen in their homes (family or group homes), an Autistic Provision school and day centres. Clients seen were males and females (age range 7-60 years) from a variety of cultural backgrounds with different degrees of learning disability.

Presenting problems: Autism with schizophrenia and challenging behaviours, autism with bipolar disorder and poor engagement with day centre, challenging behaviours, development of personal hygiene skills, recurrent affective disorder, assessment of dementia (baseline and follow-up), psychometric assessment to determine eligibility for learning disabilities services and assessment of capacity to consent.

Assessments: Assessment for treatment interviews with clients, staff and relatives, WAIS-III, Leiter International Performance Scale, Short-form HALO, Assessment of Cognitive Deterioration in People with Learning Disabilities, Motivational Assessment Scale, Reinforcement Inventory, Functional assessments, behaviour monitoring diaries and observational monitoring.

Interventions: A behavioural model was predominantly used while also drawing on cognitive-behavioural and systemic thinking. Work with parents used psycho-educational and supportive counselling approaches.

Other experience: The trainee co-facilitated one session of an Education Group and one session of a Communication Group at the day centre.
CORE PLACEMENT: CHILDREN AND FAMILIES

Dates: October 16th 2002 to March 28th 2003
Supervisors: Ruth Hind and Diana Cooke
NHS Trust: South London and Maudsley NHS Trust
Base: Southwark Child and Family Services, Southwark and Bermondsey, London

Setting and clients: This placement involved working at GP surgeries, schools and family homes. Assessments and interventions were carried out with children, parents and school-teachers; children were males and females (age range 5-15 years) from a variety of cultural backgrounds. Involved liaison with SENCo, Educational Psychologist and GPs.

Presenting problems: Panic attacks, health anxiety, bereavement, sleeping difficulties, behavioural difficulties, conduct disorder, anger management, attachment problems, family relationship difficulties, lack of motivation at school, disruptive classroom behaviour and assessment of cognitive functioning.

Assessments: Assessment for treatment interviews with children, families and school-teachers, WISC-III, WORD, All About Me, Strengths and Difficulties Questionnaire, Parenting Stress Questionnaire, Spence Anxiety Scale, Panic Diaries, Sleep Diaries, observational monitoring.

Interventions: Behavioural and cognitive-behavioural techniques were mainly used, while also drawing on person-centred, family therapy and narrative approaches and considering attachment and systemic issues. Joint working was carried out with the Supervising Clinical Psychologist in the co-facilitation of a 9-week parenting course for parents of children aged 4-11 with behavioural difficulties (Parents Plus Programme: Behavioural and solution-focused models of therapy).

Other experience: Case presentation discussed in a reflecting team style.
SPECIALIST PLACEMENT: ADULT PSYCHO-ONCOLOGY

Dates: April 9th 2002 to September 28th 2003
Supervisor: Dr Maggie Watson
NHS Trust: The Royal Marsden NHS Foundation Trust
Base: Department of Psychological Medicine, The Royal Marsden Hospital, Sutton

Setting and clients: This placement involved working on an out-patient and in-patient basis, with patients diagnosed with cancer and their family members (both individuals and couples). Clients seen were males and females (age range 26-77 years) from a predominantly White British background who were diagnosed with different types of cancer and who were at different stages in their treatment.

Presenting problems: Anticipatory grief, adjustment disorder, pre-operative distress, depression, anxiety, anger, stress, chronic pain, fear of disease recurrence, low self-esteem, memory problems, interpersonal/marital difficulties and talking with children about cancer.

Assessments used: Assessment for treatment interviews with patients and their families, self-monitoring diaries (for thoughts, coping strategies and relaxation), Activity Scheduling, Visual Analogue Pain Scales, Everyday Memory Questionnaire and Present State Examination.

Interventions: While a cognitive-behavioural model was mainly used, interventions also used psycho-educational, supportive counselling and person-centred approaches, and drew on systemic ideas.

Other experience: Involvement with a seven week psycho-social support group for women with breast cancer, weekly attendance at MDT ward rounds and weekly meetings with the research group to screen research questionnaires to identify ‘at risk’ families and discuss appropriate sources of support. Parents, children and teachers completed questionnaires as part of a study investigating the impact of parents’ cancer on children (e.g. Child Behavioural Checklist, BDI-II, Family Cohesiveness Scale, Cancer Worry Scale). Also presented findings from research investigating the acceptability and effectiveness of Alcoholics Anonymous in addiction treatment.
CORE PLACEMENT: OLDER PEOPLE

Dates: From 15th October 2003 to 26th March 2004
Supervisor: Lynn Beech
NHS Trust: South West London and St. Georges NHS Trust
Base: Sutton Community Mental Health Team for Older People, Surrey

Setting and clients: This placement involved working with clients across home, out-patient, Day Hospital and in-patient settings. Clients seen were males and females (age range 60-89 years) from a predominantly White British background.

Presenting problems: Panic attacks, loss of self-confidence, adjustment to physical health problems, OCD, relationship difficulties, assessment of suicidal risk and mental health status, dementia and assessment of memory problems.

Assessments: Assessment for treatment interviews, HADS, BDI-II, MEAMS, WTAR, WAIS-III, AMIPB, Everyday Memory Questionnaire, Well-being and Ill-being scale, self-monitoring diaries (panic attacks and obsessional checking) and Activity Scheduling.

Interventions: Cognitive-behavioural and supportive psycho-analytic models were mainly used.

Other experience: Joint working was carried out with the Assistant Psychologist in setting up, co-facilitating and evaluating a seven week pilot Validation Therapy Group for people with dementia attending the Day Centre.
SPECIALIST PLACEMENT: ADDICTIONS

Dates: From 7th April 2004 to 26th September 2004
Supervisor: Dr Akiko Murakami
NHS Trust: South West London and St. Georges NHS Trust,
Base: Rowan, Sycamore and Heather in-patient wards, Springfield Hospital,
Tooting, London, and, Addiction Treatment Centre, Queen Mary’s University Hospital, Roehampton, London

Setting and clients: This placement involved working on in-patient drug and alcohol wards (acute detoxification and recovery) and as part of a community drug team. Clients using a range of substances (e.g. alcohol, crack cocaine, methadone, ketamine) and at different stages of recovery were seen. They were males and females (age range 24-53 years) from a predominantly White British background.

Presenting problems: Anxiety management (social anxiety), unresolved grief, anger management, relapse prevention work, motivational interviewing, and memory difficulties in the context of chronic alcohol use.

Assessments: Assessment for treatment interviews, substance use diaries, craving diaries, Stages of Change Questionnaire, Situational Confidence Questionnaire, STAXI, Novaco Anger Scale, BAI, BDI-II, NART, WAIS-III, WMS-III, Cognitive Estimation Test, test of verbal fluency (FAS), Cognitive Estimation Test, WCST, TMT, BADS.

Interventions: Motivational interviewing and cognitive-behavioural therapy were the main models used within this placement, however interventions also drew upon systemic and psycho-analytic thinking. Interventions were carried out on an individual and group basis.

Other experience: Included attending MDT meetings on the in-patient drug detoxification and recovery wards and the community drug team, a case presentation to the ‘Psychologists in Addiction Peer Group’, a three-day ‘Motivational Interviewing’ course and ‘Basic Group Skills’ training. Joint working was carried out with the Assistant Psychologist in facilitating a Relapse Prevention Group on the in-patient drug recovery ward.
SUMMARIES OF SUBMITTED CASE REPORTS

Adult Mental Health
People with Learning Disabilities
Children and Families
Specialist Placement – Adult Psycho-Oncology
Older People

PsychD Clinical Psychology

October 2001 to April 2004

PLEASE NOTE:
Please note that all client names and identifying details have been changed in case report summaries in order to preserve anonymity.
ADULT MENTAL HEALTH CASE REPORT SUMMARY

Cognitive-Behavioural Therapy with a 51-year-old woman presenting with Generalised Anxiety Disorder and Specific Phobia, Situational Type

Reason For Referral
MARY was referred to the Community Mental Health Team by her GP for help coping with panic and claustrophobia.

Assessment Procedure
The assessment was conducted over two sessions by clinical interviews, SCL-90 and BAI. The MCQ, daily relaxation record and weekly Thought Record Forms were later completed. Difficulties were thought to fulfil DSM-IV criteria for Generalised Anxiety Disorder and for Specific Phobia, Situational Type.

Presenting Problems
During the initial assessment Mary described experiencing daily uncontrollable and catastrophic worrying that was often related to the safety of her family and accompanied by somatic symptoms of anxiety. She also described panic attacks in corridors, staircases, tunnels and underground places. She experienced thoughts and images of suffocation. Anticipation of panic attacks had resulted in avoidance of feared situations. Mary described herself as having been a ‘worrier’ and feeling uncomfortable in enclosed spaces as a child. However these difficulties had become more problematic following major life events, bereavements and stressors experienced over the last fifteen years. She had decided to seek treatment following the disruption of a family vacation three-months ago and increasing levels of tension, irritability, fatigue, low mood and low self-worth. Such difficulties were interfering with her family relationships and restricting family life. Also identified were unresolved feelings relating to events around her father’s death and estrangement from her sister, self-criticism and a preoccupation for others’ well-being to the detriment of her own.

Background
Mary lived with her husband and two teenage sons. She was in close contact with her mother and eldest sister but was estranged from her middle sister. Her father died four years ago from Alzheimer’s disease having been nursed for the previous three years. As a child she had viewed her father as a ‘stern Victorian’ and a ‘worrier’ and her mother as ‘more fun-loving’.
She recalled frequent arguments between her parents, urges to protect her mother and anxiety when separated from her mother. Mary was the youngest of three sisters and in comparison was felt ‘not quite good enough’.

**Initial Formulation**

Mary’s difficulties were formulated using a cognitive model of worry and a cognitive-behavioural model of phobia. It was formulated that worry may have developed as a coping strategy during Mary’s childhood through rehearsal triggered by frequent arguments between her parents and modeling of her father’s worrying. It also seems likely that Mary developed early beliefs about how to show or gain love through responsibility for others and positive meta-worry beliefs, with multiple life stressors serving to activate and reinforce these beliefs. Mary showed evidence of cognitive biases that together with positive and negative meta-worry beliefs may have further perpetuated difficulties.

Generally an anxious child, Mary vividly recalled a terrifying childhood incident in which she felt suffocated. Discomfort in enclosed spaces has continued since then but the more recent combination of a panic attack during a time of high stress may have served to confirm fears. Cognitive biases, avoidance and escape behaviours may have helped maintain anticipatory anxiety, beliefs about coping and feared consequences.

**Intervention**

Following assessment, the formulation and following goals were agreed with Mary. The cognitive-behavioural intervention aimed to: (1) provide some relief from distress, (2) reduce symptoms of anxiety, worry, irritability, fatigue and (3) increase coping with phobic fears and (4) enhance overall quality of life. Mary attended fifteen sessions held at the CMHT base; weekly sessions were later increased to a fortnightly basis to prepare for ending therapy.

Earlier techniques included empathic listening, psycho-education, developing relaxation skills and pleasurable activity scheduling. Thought Record Forms were used to draw attention to the influence of thoughts, assumptions and core beliefs on behaviour and mood. Verbal attribution techniques were used help modify negative thoughts, thinking errors and assumptions and to create dissonance between positive and negative meta-worry beliefs, with evidence for these evaluated cognitively and behaviourally. When presented with a worry, Mary found it helpful to work through a decision tree, naming the worry and problem-solving this.
Socratic questioning about upsetting interpersonal interactions helped to identify desired changes and assumptions about herself and others. Assumptions were then evaluated using cognitive-behavioural techniques and desired changes were problem-solved. New skills were role-played in session and tested out in behavioural experiments, helpful strategies written onto coping cards and placed in useful places in the home.

Behavioural experiments in the form of graded exposure (imaginal and in vivo) were used to encourage Mary to 'test out' the validity of her beliefs about feared consequences and coping, and to encourage her to drop safety behaviours and develop more helpful beliefs. The final stages of treatment focused on relapse prevention and maintaining changes.

Outcome
The BAI and SCL-90 showed lower levels of anxiety, depression and irritability. Mary reported experiencing a reduction in frequency and intensity of worry (to 15% of the pre-treatment levels) which she considered 'normal'. She also reported decreased anticipatory anxiety and avoidance of, and increased coping with, feared situations.

A number of changes at a cognitive level were apparent including modified assumptions, meta-beliefs about worry and insight into thinking errors. Within-sessions, she showed less self-criticism and greater self-tolerance; outside sessions she reported participating in more enjoyable activities, a more positive outlook and more relaxed family relationships. Previously unaware of the number of stressful life-events experienced over the last fifteen years, Mary had begun to process these emotionally.

Prognosis
Mary showed evidence of generalising techniques outside of areas worked on in therapy, which together with above changes, written records of treatment, preparation for the end of therapy and her motivation to avoid revisiting pre-treatment levels of distress, suggested treatment gains were likely to be maintained.
PEOPLE WITH LEARNING DISABILITIES CASE REPORT SUMMARY

Implementing bedtime routines with a 7 year old boy with autism and a moderate learning disability

Reason For Referral
TOM, a 7-year old white boy diagnosed with autism and a moderate learning disability was referred to the community team for people with learning disabilities (CTPLD) by the duty social worker. The referral requested help for Tom’s mother (Sarah) in managing his “very challenging behaviours”.

Assessment Procedure
An extended assessment was conducted over six sessions:
1. Initial Health Assessment, a semi-structured questionnaire developed by the CTPLD, was completed with Sarah to gather background information and identify current needs. Bedtime behaviours were selected as an initial goal for change.
2. Assessment for treatment interviews drawing on social learning principles to gather information specifically relating to bedtime behaviours and routines and, more generally to Tom’s skills, preferences and routines at both home and school.
3. ‘Bedtime role-play’ with Sarah to overcome difficulties obtaining a clear verbal description of sequence of events.
4. Motivation Assessment Scale to ascertain the function of screaming.
5. Reinforcement Inventory to identify potential reinforcers for new behaviours.
6. Observation of Tom with family.
7. Observation of Tom at school (structured & unstructured time) and a face-to-face interview with class-teacher drawing on principles of Functional Analysis to gain an idea of behaviour in another context.
8. Risk Assessment: Child Protection issues were continually considered through monitoring, reinforcing and supporting Sarah’s coping resources; close contact was maintained with Social Services through telephone calls and letters.
9. The referring social worker’s departure from the UK and lack of hand over to another team member presented difficulties with inter-agency liaison.
Presenting Problems
While a number of behavioural difficulties were identified, Tom’s refusal to go to bed had been particularly problematic since the family’s house-move (five-months ago), especially on nights when his father worked. Tom consistently responded to verbal instructions and physical attempts to guide him to bed with screaming at a piercingly high volume, physical resistance, kicking, biting, pushing and throwing furniture. Once in the bedroom, Tom would continue screaming, running around, pushing over furniture and banging on the walls for up to several hours. The aversive and prolonged nature of bedtimes caused distress to all family members and created complaints from neighbours. ‘Bed-refusal’ added to an already strained family situation due to Tom’s need for a high level of supervision, his ‘intolerance of family outings’ and lack of formal or informal respite. Previously used strategies were no longer effective due to his refusal to use PECS and his increasing physical strength; sedative medication had previously been unsuccessful. Current difficulties challenged hopes for improvements as Tom grew older.

Initial Formulation
Literature relating to autism and principles of learning theory helped identify factors that seemed to be triggering and maintaining problem behaviours. Characteristics associated with autism such as the need for predictability and resistance to change were likely to have made the recent move in family home an upsetting event for Tom. Lack of a set bedtime and routine for both Tom and his siblings had also not allowed him to settle into a predictable routine. He may have found the manner in which bedtime instructions were given unpredictable, threatening and inconsistent; these may have helped trigger, aggravate and maintain target behaviours. Systemic factors such as each parents using different strategies, the twins shouting and crying, Sarah’s sense of stress and depleted coping resources were all likely to contribute to the difficulties. Observations of the family home-coming and Tom at school showed that he responded well to a calm, quiet, structured environment.

Intervention
Behavioural principles and emotional support were used to support Tom’s parents in introducing a predictable, consistent and calm bedtime routine using clearly-given instructions, reinforcement of positive behaviours and extinction (‘planned ignoring’) of target behaviours of kicking, throwing furniture, screaming and resistance.

The trainee met with Sarah in the family home on a total of twelve occasions, eight of which were intervention sessions. Tom’s father attended part of three sessions. It was necessary to
develop a routine that balanced the needs of the three siblings and was manageable in the face of changing family situations. In addition to reviewing progress with bedtime guidelines and reinforcing the need for consistency, a large component of sessions were used to reinforce Sarah's coping, monitoring her mood, providing emotional support and containing worries for the future. Discussion with the team further agreed the importance of liaising with Social Services to highlight the urgent need for respite and tangible support and with Child and Adolescent Services for longer-term psychological input beyond the trainee's placement.

Outcome

Outcome was based on reports by Sarah and use of individually tailored charts to rate each of the target behaviours on a nightly basis. While there may be issues regarding the reliability and 'specificity' of verbal reports, these importantly reflected Sarah's perception of the problem and her degree of coping. Ratings showed an overall decrease in the intensity and frequency of target behaviours with increases following changes in routine or in environment. A follow-up telephone call one month after the final session suggested sustained positive outcomes. Reports indicated that Tom often walked independently up the stairs and no longer screamed, kicked, threw furniture or resisted. Reports further indicated that while changes in routine continued to trigger screaming and resistance, Sarah felt able to cope with these.

Prognosis

Monitoring over the intervention period suggested that Tom may continue to use screaming to communicate distress in response to changes in routine or environment. De-escalation of such behaviours may partly rely on Sarah's ability not to fall back on apparently easier responses (i.e. not follow through with instruction) or reflexes (i.e. shout), however there had been some evidence of Sarah's generalising behavioural principles during later sessions. Systemic changes such as the younger siblings starting school giving some personal time for Sarah, Sarah seeking psychological support, respite support and a referral to Child and Adolescent Services in place, suggested that positive changes may be maintained.
CHILDREN AND FAMILIES CASE REPORT SUMMARY

Implementation and Evaluation of ‘Parents Plus Programme’: A parenting course for parents of children aged 4-11 years

Referral Process
The Child and Family Service offer three Parents Plus Programmes for parents of children aged 4-11-years each year, held at local community centres with creche facilities. Referral is through a variety of sources including self-referrals from parents concerned about their children’s behaviour, professionals within the Child and Family service, teachers, school nurses, GPs. The group consisted of ten mothers and one father; three of whom were currently married. All parents had at least one child between the ages of 4 and 11-years. While from an ethnically diverse area, all were of white UK origin.

Assessment Procedure
Parents were asked to identify a goal for behaviour change for their child and a goal for themselves and indicate their current position on these goals (Goal Form) and to complete the Strengths and Difficulties questionnaire (child behaviour problems) and Parenting Stress Index.

Presenting Problems
Parents completed a pre-course Registration Form on which parents reported similar difficulties; many requested help with child behaviour that ranged from being described as “stroppy” to non-compliant, aggressive and destructive. Parents shared common goals for (1) themselves such as keeping calm, feeling in control and setting consistent limits and (2) their children, such as listening to instructions and sharing with their siblings better. Responses on standardised questionnaires showed that parents were experiencing clinically significant levels of child behavioural problems, high levels of difficulty in their parent-child relationship and high levels of stress in their social environment.

Initial Formulation
Individual formulations were not possible due to limited information. However it seemed likely that referred parents might benefit from participation in a parenting course that aimed to increase positive parent-child interactions and manage difficult behaviour in a more positive and consistent manner (Webster-Stratton & Taylor, 2001; Sharry & Fitzpatrick, 1998).
Evidence of the strong association between child behaviour problems and (among other factors) harsh, inconsistent parenting and high family stress (Webster-Stratton & Taylor, 2001) has led to the development of parent-focused interventions. It was also possible that the group of mainly single-parents with high levels of stress might especially benefit from some of the processes considered therapeutic within group settings such as: Imparting information, instillation of hope, universality, altruism, development of socialising technique, imitative behaviour, interpersonal learning and group cohesiveness.

**Intervention**

The Parents Plus Programme was a manualised, video-based educational package developed in Ireland (Sharry & Fitzpatrick, 1998) that incorporated video input, role-play, group discussion and homework tasks. While ideas were largely based on social learning theory, they were also drawn from humanistic and solution-focused approaches, Rogerian ideas and Alderian Psychology. The key idea centred on how children's behaviours are reinforced by the attention they receive, such that if parental attention becomes valuable to the child through active listening, play, special time, encouragement and praise, rewards, then it may be used to positively influence behaviour. Rule-setting, active ignoring, time out, sanctions and solution building were also addressed. Importantly, the programme aimed to build up parents' strengths, avoided a blaming stance and attempted to work collaboratively with parents. The programme was conducted over nine weekly sessions. Sessions were co-facilitated by the trainee and supervising clinical psychologist.

**Outcome**

Significant progress was made on goals identified by parents for themselves and for their childrens' behaviour. They described feeling more confident and calmer as parents and considered their child-related difficulties to have become at least 'A little better'. All felt positively about recommending the course to other parents. While parents reported reductions in child behaviour problems, no child was rated as having moved from the clinical to non-clinical range. It became apparent that factors wider than parenting style contributed to some of the group members' difficulties (e.g. housing, financial and relationship difficulties), such that a time-limited parenting course alone would not be sufficient and additional involvement necessary.
Adjustment Disorder in a 41-year old white woman
(wife of patient undergoing treatment for leukaemia)

Presenting Problems
FLORA, a 41-year old white woman was referred for psychological support by her husband, Harvey, a 39-year old white male undergoing in-patient treatment for Acute Binophenotypic Leukaemia.

Assessment Procedure
1. The Hospital Information System regarding husband’s medical condition, prognosis and treatment
2. Multi-disciplinary (MDT) ward rounds
3. Relatives Support Officer with whom Flora had met on two occasions.
4. Assessment for treatment interview
5. Present State Examination (PSE)

The presenting difficulties were considered to fulfil DSM-IV criteria for Adjustment Disorder With Mixed Emotion of moderate to severe intensity.

Presenting Problems
Nursing staff reported difficulties containing Flora’s anxiety and were concerned about the impact of disruptive behaviour such as crying and shouting on Harvey’s well-being. The Relatives Support Officer described Flora as experiencing great distress, feeling isolated and needing to talk.

Flora described current problems to have begun one month ago, soon after her husband’s diagnosis and admission to hospital. She was experiencing uncontrollable and distressing levels of worry about her husband’s illness and treatment and most distressingly, her ability to cope. This resulted in distress, physical tension, tension headaches, low mood, tearfulness, disturbed sleep, loss of energy, lack of enjoyment and guilt. She also reported interpersonal difficulties with her husband and family, uncertainty over how to support her husband and feeling let down by both him and their families.
Background History
Flora and Harvey had been married for eighteen years and had no children. Harvey took responsibility for household matters and was Flora’s main source of practical, emotional and social support. They had only ever been separated overnight on one occasion and have experienced no previous adverse life events. Flora had worked full-time within the same company for the last twenty years. They had regular contact with their parents, whom were described as holding traditional views of male-female marital roles.

Medical Context
At time of assessment Harvey was close to completing the first month’s in-patient admission for induction chemotherapy. He was expected to return home in the following week and subsequently undergo a repeat bone aspirate in order to decide further treatment. If remission were achieved, the usual course of treatment would consist of bone marrow transplant or consolidation chemotherapy to prevent re-growth of residual leukaemic cells.

Initial Formulation
Cognitive-behavioural theory and literature describing psychological responses to diagnosis and treatment for leukaemia, family responses, coping and adjustment disorder were used to formulate Flora’s difficulties.

A number of factors seemed likely to have increased Flora’s vulnerability to experiencing greater than expected distress from the sudden diagnosis and separation. These included Flora’s appraisal of her husband’s diagnosis as a major threat combined with her negative appraisal of her ability to cope, a longstanding tendency to worry, absence of traumatic or difficult life experiences from which to draw confidence or resources, and reliance on her husband for emotional, practical and social support.

Additional factors seemed to perpetuate the cycle of worry and other presenting symptoms. Flora did not appear to have insight into or be able to make links between specific events, her interpretations and emotional responses. She presented with a global sense of not coping that made her feel overwhelmed and out-of-control. Thinking errors led to an inaccurate and unhelpful appraisal of stressors and interpretation of interpersonal communication; meta-worry precipitated further worry and distress. Later information highlighted Flora’s difficulty asking for support from others. Positively, there were a number of factors that may have protected against further distress such as her husband responding well to induction treatment, supportive, flexible employers, supportive neighbours and work colleagues.
Intervention
Despite the prevalence of adjustment disorder, no randomised-control treatment trials are reported and "choice of intervention remains a clinical decision" (Strain, 1998; Page 514). Strain (1998) and clinical supervision were therefore used to develop a treatment plan that entailed reducing the stressor's impact and strengthening coping resources. The intervention balanced emotional ventilation, containment and reflective listening with facilitating changes through more structured, cognitive-behavioural strategies.

Emotional ventilation and containment were essential components of all sessions in allowing a safe place for Flora to talk about her experiences. Other therapeutic techniques included:
1) Psycho-education
2) Introduction of coping strategies such as a) progressive muscular relaxation, b) controlling and diverting attention, c) creative visualisation, d) planning ahead, e) pleasant activity scheduling and f) problem-solving
3) Cognitive restructuring of appraisals of a) stressors, b) coping as a concept and her own coping responses and c) social support
4) Mobilising social support resources through identifying her needs and role-playing clearly expressing needs.

Effective strategies were written on coping cards; diaries were used to test and develop evidence of coping confidence and efficacy. Summarising and reflective listening helped to increase self-awareness and highlight Flora's coping resources.

Flora attended a total of 13 sessions over 3.5-months, goals and progress were regularly monitored and reviewed. The nursing team were asked to offer regular and timely informational support to help manage Flora's worry.

Outcome
While responses on the PSE showed marked and stable improvements from initial levels of presenting difficulties, symptoms continued to fluctuate in response to changing external stressors. Self-report showed a reduction in the number of 'bad days' (i.e. low mood, poor coping) and increased self-confidence in coping. Flora also described more flexible images of coping, reported less distress from worry and greater ability to provide practical and emotional support to her husband. She had not become tearful at recent medical consultations and had successfully coped with an unforeseen distressing incident.
Prognosis

Flora’s mental health and coping might be expected to fluctuate in response to changes in her husband’s medical and psychological status. However these are likely to be buffered by further psychological support by a Clinical Nurse Specialist in Psychological Care, Flora’s greater familiarity with the illness, hospital system and treatment, her stronger coping resources and abilities to limit worry.
OLDER PEOPLE CASE REPORT

A Psychometric Assessment Of Memory Difficulties In A 60-Year Old Man

Reason For Referral

MR KING was referred to the CMHT for Older People by his G.P. for investigation of increasing forgetfulness and suspected dementia.

Assessment Procedure

1. Mr King was initially assessed by the team Specialist Registrar (SpR) who made a preliminary diagnosis of depression. While a CT scan excluded vascular pathology, atrophy of the cortical sulci over the temporal and parietal lobes was ambiguously suggestive of normal ageing and early Dementia of Alzheimer’s Type (DAT). However a score of 30/30 on MMSE showed relatively intact cognitive functioning. An administration error resulted in lack of blood screen results at the time of commencing neuro-psychological assessment.

2. The trainee conducted an initial face-to-face clinical interview and administered the Everyday Memory Questionnaire to gain background information and HADS as a measure of anxiety and depression.

3. The following range of neuro-psychological assessments were then used:
   a) Middlesex Elderly Assessment of Mental State (screen of global cognitive impairment)
   b) Beck Depression Inventory-II (measure of depression)
   c) Wechsler Test of Adult Reading-UK Version (estimate of pre-morbid cognitive functioning)
   d) Wechsler Adult Intelligence Scale-III UK (measure of current cognitive functioning)
   e) Adult Memory and Information Processing Battery (measure of current memory functioning)

Presenting Problems

Mr King described a history of gradually increasing forgetfulness over the last five years that had become more distressing over the last nine months. He reported poor concentration, low mood, tearfulness, irritability, worry, low self-confidence, decreased enjoyment and strained marital relations. These represented changes from an ‘almost photographic memory’ and ‘jovial, calm, humorous’ approach to life. The HADS identified a ‘borderline’ level of
depression. While Mr King could not recall any significant events occurring around onset of memory difficulties, he became very tearful describing the deaths of his mother, son and 'brother' who died within six-months of each other six years ago. There were no difficulties in day-to-day living and self-care.

Background
Mr Kind lives with his wife. He retired from working as a chauffeur nine years ago due to physical health problems and currently suffers from arthritis and a painful hand condition. He has suffered life-long physical health difficulties, including a left-leg amputation at the age of five; he did not start school until he was ten years old. Mr King reported a "nervous breakdown" 15-20 years ago resulting from "business stress". There is no known family history of dementia.

Discussion of Assessment Findings
There was no evidence of gross or specific cognitive impairment characteristic of DAT. In comparison to age-matched norms, Mr King showed 'Average' to 'High Average' cognitive abilities on all tasks except a timed task involving processing and motor speed that may be accounted for by sensorimotor difficulties, an unhelpful visual memory strategy and depression. Although cognitive deterioration from a higher level of functioning could not be confidently ruled out, there was no significant neuro-psychological evidence to support this. While Mr King did show some areas of impaired memory functioning ('Below Average' immediate recall), these were not consistently found across all areas of his memory performance. Memory difficulties appeared to relate to the initial acquisition of information, often indicative of problems with distractibility, poor attention and concentration and commonly impaired by depression. There was no evidence of 'rapid forgetting' that is characteristic of DAT and he demonstrated a clear strength in working memory and number skills.

On balance, the assessment findings suggested that Mr King was experiencing clinical depression which may be impacting on his memory functioning. Indeed scores on the HADS ('borderline' range) and BDI-II ('Moderate-Severe' range) indicated clinical depression (although these may be inflated by aging and physical health difficulties) and Mr King described tearfulness, feelings of melancholy, stress, worry and frustration. Difficulties in the acquisition stage of memory, his negative view of and distress at memory difficulties were also in keeping with depression. Furthermore Mr King described and was observed becoming
distressed and intensely frustrated by poor recall, slowness and mistakes; such responses were likely to reduce concentration and performance.

Feedback
The trainee met independently with Mr King to discuss the assessment results; a written summary was also provided. The results were explained as indicating no overall cognitive difficulties but rather some areas of memory difficulties that were likely to be related to clinical depression. Verbal feedback was provided at the multi-disciplinary team meeting; a report written to the referring SpR.

Recommendations
A number of recommendations were made:
1) Regular review of depression
2) Re-evaluation of memory and cognitive performance following treatment of depression
3) Two sessions to provide a) written and verbal psycho-education regarding memory strategies, coping with depression and improving sleep and b) cognitive-behavioural approaches to enhance frustration management.

Intervention
Cognitive-behavioural approaches were used to evaluate and counter unhelpful beliefs, increase awareness of early signs of anger/frustration and identify self-calming strategies. Strategies were summarised in a written letter.

Outcome
The assessment ascertained Mr King’s level of memory and cognitive functioning, determined a baseline to monitor future cognitive changes and identified some helpful management strategies. The balance between neuro-psychological and person-centred approaches provided Mr King with valuable reassurance and allowed time to develop an understanding of how difficulties had developed and their emotional significance. At the final session, Mr King reported greater acceptance of his present memory/concentration difficulties, openness to using memory strategies and self-tolerance. Although he had not seen any memory improvements, he described feeling more positive and relaxed with no sudden tearfulness and fewer losses of temper.
Prognosis

While Mr King's wife had attended the initial assessment with the SpR, he did not consider it helpful for her to attend subsequent sessions. However his seeking formal help had helpfully prompted greater family support and a positive comparison of his memory with school peers. The reduced frustration and use of memory strategies, together with commencement of anti-depressant medication would be expected to improve his perceived and actual memory performance.
RESEARCH DOSSIER
INTRODUCTION TO THE RESEARCH DOSSIER

The research dossier contains the Research Logbook documenting research-related activity conducted throughout the three years of training, the Service-Related Research conducted during Year 1, the group Qualitative Research Project conducted during Year 2 and the Major Research Project completed in Year 3.
LOGBOOK OF RESEARCH EXPERIENCE

The following research logbook outlines the research skills and experience acquired over the course of clinical training.

<table>
<thead>
<tr>
<th>Research Skill/Experience</th>
<th>Description of how research skill/experience acquired</th>
<th>Date research skill/experience acquired</th>
</tr>
</thead>
</table>
| Conduct a literature search | Literature searches have been conducted throughout the clinical training for essays, case reports, clinical work, and research.  
Range of tools used for literature searches included: PsycInfo, Medline, CINAHL, BINS, the Cochrane database, and online full text services.  
Literature search conducted for:  
- Service related (SRRP) project on referrals to CMHTs  
- Qualitative (QR) on qualitative research methods (in particular Interpretative Phenomenological Analysis, IPA) and personal therapy during clinical psychology training  
- Major Research Projects (MRP) on experiences and coping by stroke-survivors  
- Evidence-base for therapeutic approaches throughout clinical placements, e.g. anxiety/stress/anger management, PTSD, OCD, depression, dementia, coping with diagnosis and treatment of cancer, relapse prevention in substance use etc. | 2001-2004  
Jan 2002  
March-May 2003  
March 2003-Sept 2004  
2001-2004 |
| **Critically review the literature** | Critical appraisal of the literature was a salient aspect of all essays written through clinical training. Literature appraised included CBT and psychoanalytic treatments for OCD, assessment and treatment of dementia in people with learning disabilities, early intervention treatments for childhood behavioural problems, influence of race and ethnicity for incidence and treatment of mental health problems in older people.

Literature was appraised for presentations given during training, i.e. Treatments for OCD and anxiety, Twelve-step approaches for treatment of substance misuse.

- SRRP: Critical review of the literature on referrals to CMHTs
- QRP: Critical review of the literature on trainee’s perceptions of personal therapy during clinical and counselling training courses
- MRP: Critical review of the literature investigating experiences and recovery from stroke, particularly theoretical and methodological limitations | 2001-2004

| **Formulate a specific research question** | Specific research questions were formulated for SRRP in consultation with research supervisor at University, placement supervisor and CMHT where study was conducted.

Research questions were developed for QRP. These were formulated jointly with a research group with guidance from qualitative research lecturer experienced in using qualitative research methods.

Research questions were formulated for MRP for initial research proposal on the basis of the reviewed literature and in consultation with research and field supervisor. Later refined and reformulated for ethics submission | 2001-2004

| **Write a brief research proposal** | Brief structured research proposals were written for the course team at the planning stages for:

- SRRP
- MRP | 2001-2004

|  |  | Jan-June 2002

March-May 2003

Oct 2002; March 2003-Sept 2004

Nov 2001

March/April 2003

Oct 2002; March 2003; July 2003

Dec 2001

Oct 2002 |
<table>
<thead>
<tr>
<th>Write a detailed proposal/protocol</th>
<th>Detailed protocols and proposals were written to gain ethical approval to conduct MRP—these were submitted to the Ethical Committees at a local NHS Trust and University of Surrey</th>
<th>July 2003 &amp; Sept 2003</th>
</tr>
</thead>
</table>
| Obtain appropriate supervision/collaboration for research | Supervision was obtained for the SRRP from a University research supervisor and placement supervisor. Also involved discussion with CMHT where study conducted. Supervision for QRP: This research was conducted as part of a research group which allowed peer supervision and collaborative working on the shared tasks. Guidance and supervision was also provided by the qualitative lecturer (an experienced qualitative researcher). Supervision for MRP:  
- Supervision was obtained from a University research supervisor who was an expert in the field of health psychology and experienced in qualitative research  
- Supervision was also obtained from the field supervisor, an experienced clinician working in the field of stroke  
- Peer-group supervision was gained by meeting with peers using IPA to discuss process of analysis  
| Write a participant information sheet and consent form | Participant Information Sheets were written for clinical staff completing audit forms for the SRRP  
- Participant Information Sheets and Consent Forms were written for Third Year Trainee Clinical Psychologists taking part in QRP and participants taking part in the MRP  
- Consent forms were written for clients to give permission for sessions to be tape-recorded or information to be shared with third parties | Jan 2002 March 2003; July 2003 Sept 2001-Aug 2004 |
<table>
<thead>
<tr>
<th>Date of activity</th>
<th>Event description</th>
<th>Date(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Oct 2003-Aug 2004</td>
<td><strong>Judge ethical issues in research and amend plans accordingly</strong> Ethical issues, such as sharing concerns with relevant services and responding sensitively to distress arising during interviews, were considered and addressed when designing the study protocol for the MRP. Levels of distress during interviews necessitated a sensitive balance between roles of clinician and researcher and allowing longer time for debriefing following the interview. The presence of significant others during interviews necessitated sensitivity when following up on questions and asking about relationship changes. Cancellation of clinics required amendment of protocol to include home visits and to consider the researcher’s safety.</td>
<td></td>
</tr>
</tbody>
</table>
| July 2003; March 2004; Aug 2004 Sept 2003 | **Obtain approval from a research ethics committee** Ethical approval was obtained to conduct the MRP from the:  
- Local NHS Trust Ethical Committee, with protocol amendments made on two further occasions.  
- University of Surrey Ethical Committee |                  |
| Jan-March 2002 | **Collect data from research participants** SRRP: Quantitative and qualitative data were collected by trainee by recording the process of CMHT Referral Meetings, i.e. CMHT members’ discussion and allocation of referrals. Data were also collected via an audit form completed by CMHT members.  
QRP: Interview data was collected from Third Year trainee clinical psychologists via a semi-structured interview, which was transcribed and analysed.  
MRP: Interview data were collected from 11 stroke-survivors attending a NHS Review Clinic via semi-structured interviews. Demographic data were collected by reviewing patient notes. |                  |
| April 2003 |                                                                 |                  |
| Oct 2003-Aug 2004 | **Set up a data file** Set up an SPSS data file for data collected as part of the SRRP |                  |
| April 2002 |                                                                 |                  |
| Preparing raw data for analysis | Audit forms completed as part of the SRRP were given code numbers to maintain anonymity.  
Demographic forms and transcripts for QRP and MRP were given participant codes and separated from corresponding consent forms to maintain confidentiality. All identifying material was removed from transcripts and participants given pseudonyms to protect anonymity; transcripts were prepared by numbering each line so that instances could be identified. Transcripts were repeatedly re-read. | Jan-March 2002  
May 2002  
July-Sept 2004 |
| Analyse quantitative data | Analysed quantitative data collected from SRRP audit forms. Used SPSS to provide descriptive statistics. Insufficient sample size for further statistical analysis. | April-June 2002 |
| Analyse qualitative data | Analysed qualitative data from audit forms using content analysis. Analysed qualitative semi-structured interview data using Interpretative Phenomenological Analysis for:  
- QRP  
- MRP | April-June 2002  
May 2002  
July-Sept 2004 |
| Summarise results in figures/graphs | Produced bar-charts and pie-charts to summarise descriptive results in SRRP project write up and presentation provided to feedback to CMHT service. | June 2002 |
| Interpret results from data analysis | Results of data analysis interpreted for:  
SRRP: Results interpreted in relation to the existing literature on mental health referrals and issues of priority and appropriateness; national guidelines considered.  
QRP: Results were interpreted through IPA and involved identifying core themes that characterised trainees’ perceptions of the desirability of personal therapy during clinical training. Suggestions for training courses were made.  
MRP: Results were interpreted through IPA to identify themes characterising stroke-survivors experiences, making sense of and managing post-stroke experiences. Themes were considered in relation to previous related research and psychological theories, as well as implications for service development. | April-June 2002  
April-May 2003  
June-Sept 2004 |
<table>
<thead>
<tr>
<th>Present research findings/ plans to an audience</th>
<th>Research Logbook</th>
</tr>
</thead>
<tbody>
<tr>
<td>SRP, findings were presented using PowerPoint to the CMHT's involved in the auditory clinical psychologists.</td>
<td>Product presented to Second Year trainee clinical psychologists using PowerPoint.</td>
</tr>
<tr>
<td>MRP, plans were presented to Second Year trainee clinical psychologists using PowerPoint.</td>
<td>Research reports were completed for the SRP, QRP, and MRP and submitted as part of the PsychD Clinical Psychology assignment requirements.</td>
</tr>
</tbody>
</table>
SERVICE RELATED RESEARCH PROJECT

An Audit Of Referrals For Initial Assessment
Two Community Mental Health Teams

June 2002

Year 1
ACKNOWLEDGEMENTS

I would like to thank the CMHT members for their help, tolerance and time in facilitating data collection. I would also like to give sincere thanks to both the supervising Clinical Psychologist and Research Tutor for their generous support and guidance throughout this audit.
ABSTRACT

Title: An audit of referrals for initial assessment to two community mental health teams

Objectives: The audit aimed to describe local rates of, and criteria for, ‘inappropriate’ and ‘urgent’ referrals received by the CMHTs; further considering how frequently these criteria were provided in referral correspondence.

Methods: Referrals received over seven-weeks were considered before and after assessment. Pre-assessment data consisted of allocation discussions recorded during Allocation Meetings and analysis of referral correspondence; post-assessment data of assessors’ judgements of inappropriateness and urgency.

Results: 115 referrals were received. One-in-eight were judged inappropriate from the referral correspondence; one-in-six of assessed referrals were judged inappropriate. Criteria for inappropriateness included ineligibility due to age, catchment area, presence of learning disability, and absence of mental health needs. While multiple criteria were used to judge urgency, risk of self-harm/harm-to-others was most frequently used. One-in-five referrals were judged urgent, with good agreement observed between pre- and post-assessment judgements. Referral correspondence more frequently provided information to determine ‘inappropriateness’ than ‘urgency’.

Discussion: The rate of inappropriate referrals was similar to the lowest estimates of comparable research. However conclusions must be drawn cautiously from post-assessment data since data was unavailable for two-thirds of allocated referrals. While correspondence did not consistently provide information to determine urgency, reliable judgements were observed for the sub-sample followed-up.

Conclusions: Inappropriate referrals may be further reduced through information-based interventions to facilitate direct referral to appropriate services and reduced waiting time for more appropriate and urgent referrals.
INTRODUCTION

Background Information
Two Community Mental Health Teams (CMHTs) in Surrey perceived an increasing proportion of referrals to be 'inappropriate' or for referral correspondence to omit significant information on which to base allocation decisions. Both issues have been investigated in previous research. Rates of inappropriate referrals range from 15% of referrals received by 42 CMHTs across Scotland (Mauthner, Naji and Mollinson, 1998) to 39% of referrals received by a South London CMHT (Train, 1999). Inappropriate referrals have important implications for waiting times and providing access to appropriate help at time of need.

CMHTs face a common dilemma regarding what constitutes an appropriate client group (Mauthner et al., 1998). Tension exists between focusing on 'health' as better coping with severe mental illness, or, as coping with a wide range of emotional and cognitive disorders (Cahallan, 1994; cited-in Job, 1999). Mauthner et al., (1998) found CMHTs played a 'gatekeeping' role, balancing a formal remit to provide care for severely mentally ill clients with a broader remit of providing for those referred to as the 'worried well' (Page 738). It appears that decisions are often based on historical patterns of service provision or clinician attitudes (Wells, 1996). Indeed varying local needs (Kerwick & Goldberg, 1997) may result in varying criteria to determine inappropriateness.

In addition to considering the appropriateness of a referral, allocation decisions may also require consideration of urgency or priority. This fits with the national agenda of explicit priority-setting (Wells, 1996) and may be of particular salience where services are in high demand (Job, 1999). While some national priorities have been set, for example, Health of the Nation targets (Department of Health, 1992), Job (1999) highlights the absence of national guidelines for establishing the priority of referrals. As with appropriateness, decisions regarding urgency are made locally (Meylan, 1997; cited-in Job, 1999). Some authors have discussed the merits of a single criterion for determining priority, such as suicide (Job, 1999; Cubbin, Llewellyn-Jones & Donnelly, 2000) and others have warned against using diagnosis over personal distress (Meylan, 1997). Job (1999) recommends use of multiple criteria.
Independent of systems used to judge appropriateness and urgency for assessment, decisions rely on the quality of referral correspondence. Correspondence needs to be clear and concise with sufficient information to aid professions involved (Jenkins, Arroll, Hawken & Nicholson, 1997). More specifically, General Adult Psychiatrists identified the following information as necessary for referral correspondence from General Practitioners (GPs) (Pullen & Yellowless, 1985 cited-in Raheja & Singh, 2001): Reasons for referral, main symptoms or problems, past psychiatric history, medication prescribed so far, and family history.

Rationale
Although inappropriate referrals have been investigated by previous research, the CMHTs under audit would like to establish the extent of this problem locally. They would further like to summarise the criteria used to determine ‘inappropriateness’ and ‘urgency’ for initial assessment, and identify the frequency with which referral correspondence include these criteria. Additional interest lies in describing the profile of treatment-seekers. As well as informing the teams, it is hoped that relevant information may be passed onto referrers to contribute towards a more efficient allocation process through reducing waiting time for more appropriate and urgent referrals (Job, 1999).

Main research questions:
1. What is the profile of referrals received by the CMHTs in terms of referrer, presenting problem, demographic characteristics, ‘inappropriateness’ and ‘urgency’ for assessment?
2. What are the criteria by which the CMHTs judge ‘inappropriateness’ and ‘urgency’ for initial assessment from referral correspondence?
3. How frequently does referral correspondence provide sufficient information to judge ‘inappropriateness’ and ‘urgency’ for initial assessment?

The audit further aims to consider post-assessment judgements of ‘inappropriateness’ and ‘urgency’, examining agreement between pre- and post-assessment judgements of ‘urgency’.

METHOD
Design
The audit used a non-experimental descriptive design with analysis before and after assessment.
Sample
The sample consisted of referrals received by the CMHTs over the seven-week period between February 6th and March 21st 2002.

Setting
The audit was based across two CMHTs in Surrey. The teams consist of Psychiatrists, Community Psychiatric Nurses (CPNs), Social Workers, Occupational Therapists, Clinical Psychologist and Assistant, Substance Misuse Worker and a Physiotherapist/Counsellor. Clinicians work across both teams.

There is an open referral system allowing referral by agencies or individual clients. Referrals are allocated for initial assessment on a weekly basis at Allocation Meetings. While attendance varies, core team members present for allocation include the CMHT Co-ordinator, a CPN, Clinical Psychologist, and Psychiatrist. Assessments are offered on a same-day basis to crisis situations (Duty Work system), or within three weeks of receipt for less critical referrals (Personal Communication by CMHT Co-ordinator, 2002).

Measures and Procedures
Questionnaires were developed through a process of expert consultation (See Figure 1).

Figure 1: Development of Audit Measures

<table>
<thead>
<tr>
<th>Identification of audit objectives through discussion with team</th>
</tr>
</thead>
<tbody>
<tr>
<td>Questionnaires developed to meet objectives:</td>
</tr>
<tr>
<td>Form A: Pre-assessment Data</td>
</tr>
<tr>
<td>Form B: Post-assessment Data (Appendix One)</td>
</tr>
<tr>
<td>Questionnaires discussed with team</td>
</tr>
<tr>
<td>No ethics approval required for collection of audit data</td>
</tr>
<tr>
<td>(See Appendix Six for Audit Declaration Form)</td>
</tr>
<tr>
<td>Questionnaires piloted at two Allocation Meetings</td>
</tr>
<tr>
<td>Questionnaires modified</td>
</tr>
<tr>
<td>Data collection</td>
</tr>
</tbody>
</table>

125
Pre-assessment data was gathered by the Trainee Clinical Psychologist through completion of Form A at weekly Allocation Meetings. This recorded referral information and the allocation process and outcome, yielding both quantitative and qualitative data.

Post-assessment data regarding appropriateness and urgency for initial assessment were collected through completion of Form B by allocated assessors. This was attached to referral correspondence and distributed to assessors for their completion following assessment. Assessors were given two reminders to complete forms: (a) A verbal reminder at Allocation Meetings, and (b) Written individualised reminders listing clients assessed, date of allocation and extra Form Bs (See Appendix Two).

Data Analysis
Referrals to each team were considered together since examination of team differences lay outside the audit’s remit. Descriptive statistics were used to summarise the demographic profile of referrals and their categorisation in terms of 'appropriateness' and 'urgency'. Statistical comparisons were limited by small sample sizes (See Discussion).

Unstructured data, such as discussions of inappropriateness, urgency and allocation decisions, were recorded during the meeting, collated into text-files (See Appendix Three) and examined through Content Analysis. The Trainee considered the first ten referrals and on the basis of the current data and previous literature (Pullen & Yellowless, 1985; Job, 1999) proposed criteria for the following areas of investigation:

(a) To describe the main presenting problem
(b) To determine 'inappropriateness' for assessment
(c) To determine 'urgency' for assessment
(d) To determine quality of referral correspondence [include (b) and (c)]

The Trainee then allocated the first thirty referrals to ascertain how well the proposed criteria represented and summarised referral information. Discrepancies were refined and all referrals coded. Inter-rater reliability for a random 20% of referrals showed 99% agreement between the Trainee and an independent rater for presenting problems and 97.5% for inclusion of criteria in referral correspondence. Criteria obtained from the unstructured data were subsequently used for quantitative analysis.
RESULTS

1) Profile of referrals received by the CMHTs

1.1) Referrers

115 referrals for assessment were received over the seven-weeks of data collection. Figure 2 shows the referring agencies. GPs contributed the greatest number of referrals (88, 77.2%); Inter-team referrals the second highest (14, 12.3%) (1 missing-data).

Figure 2: Referrers To The CMHTs

NOTE: ‘External Agencies’ include Psychotherapy, Social Services, CMHT from another catchment area

1.2) Demographic Characteristics

Referrals requested assessment of one set of parents (0.9%), 69 (60.0%) females and 45 (39.1%) males. They were a mean age of 37.7 years (s.d.=12.5; median=35.5; mode=32.0; minimum=18, maximum=76 years; 5 missing-cases).
1.3) **Presenting Problems**

Table 1 below shows primary reasons for referral. Depression- and anxiety-related disorders were the most frequent reasons for referral. (See Appendix Four for fuller description of categorisation).

<table>
<thead>
<tr>
<th><strong>Main Presenting Problem</strong></th>
<th><strong>Frequency (%)</strong> (N=113)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Depression</td>
<td>29 (25.7%)</td>
</tr>
<tr>
<td>(2) Anxiety</td>
<td>22 (19.5%)</td>
</tr>
<tr>
<td>(3) Anxiety &amp; Depression</td>
<td>12 (10.6%)</td>
</tr>
<tr>
<td>(4) Substance-Misuse</td>
<td>10 (8.8%)</td>
</tr>
<tr>
<td>(5) Risk of harm-to-self or others</td>
<td>9 (8.0%)</td>
</tr>
<tr>
<td>(6) Behavioural problems</td>
<td>9 (8.0%)</td>
</tr>
<tr>
<td>(7) Bereavement</td>
<td>5 (4.4%)</td>
</tr>
<tr>
<td>(8) Trauma</td>
<td>4 (3.5%)</td>
</tr>
<tr>
<td>(9) Psychosis</td>
<td>4 (3.5%)</td>
</tr>
<tr>
<td>(10) Carers Assessment</td>
<td>3 (2.7%)</td>
</tr>
<tr>
<td>(11) Eating Disorder</td>
<td>2 (1.8%)</td>
</tr>
<tr>
<td>(12) Other</td>
<td>4 (3.5%)</td>
</tr>
</tbody>
</table>

NOTE: 2 missing-data (Correspondence unavailable at meeting)

2) **Allocation Decision From Referral Correspondence**

Of the 115 referrals received, 101 (87.8%) were judged ‘appropriate’ for assessment, fourteen (12.2%) were judged ‘inappropriate’ for assessment (two of which contained insufficient information to allow allocation).
2.1) *Relationship Between Referrer And Referral Appropriateness*

While insufficient numbers in each group prevent statistical comparison, there does not appear to be a relationship between referrer and pre-assessment judgement of appropriateness (See Table 2).

**Table 2:** Referrer by Referral Appropriateness

<table>
<thead>
<tr>
<th>Referrer</th>
<th>Appropriate Frequency (% within referrer)</th>
<th>Not appropriate Frequency (% within referrer)</th>
<th>Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Self-referral</td>
<td>2 (100.0%)</td>
<td>0 (0%)</td>
<td>2</td>
</tr>
<tr>
<td>(2) General Practitioner</td>
<td>79 (89.8%)</td>
<td>9 (10.2%)</td>
<td>88</td>
</tr>
<tr>
<td>(3) ‘Specialist’</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(3.1) Inter-team</td>
<td>20 (83.3%)</td>
<td>4 (16.7%)</td>
<td>24</td>
</tr>
<tr>
<td>(3.2) Duty Work</td>
<td>6</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>(3.3) External Agency</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Totals</td>
<td>101</td>
<td>13*</td>
<td>114</td>
</tr>
</tbody>
</table>

**NOTE:** 1 missing data

Table 3 describes the criteria for inappropriate referrals and resulting action decided by the allocating team.

**Table 3:** Criteria For ‘Inappropriateness’ And Resulting Action

<table>
<thead>
<tr>
<th>Category</th>
<th>Qualitative Criteria</th>
<th>Action from meeting</th>
<th>Frequency (Percent) N=14</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>“No obvious mental health difficulty”</td>
<td>Refer to counselling service</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>“G.P. is requesting counselling”</td>
<td>Refer to counselling service</td>
<td>N=2 (14.3%) in all categories</td>
</tr>
<tr>
<td>3</td>
<td>“G.P. is requesting Psychotherapy”</td>
<td>Refer to psychotherapy service</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>“Inappropriate age for adult mental health services” (Aged 67 and 76)</td>
<td>Refer to Older Adults team</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>“Wrong catchment area”</td>
<td>Refer to CMHT in appropriate catchment area</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>“Client with learning disabilities”</td>
<td>Refer to Learning Disability team</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>“Insufficient information to judge appropriateness”</td>
<td>Unclear – contact referrer for further information</td>
<td></td>
</tr>
</tbody>
</table>

**NOTE:** Category 7: Insufficient information regarding (1) Request by referrer (2) Referral route, (3) Client characteristics and, (4) Mental health needs.
3) Urgency Of Appropriate Referrals

Figure 3 shows the proportion of referrals allocated to each level of urgency. The majority of referrals (66, 65.3%) were not discussed regarding their urgency but allocated for assessment within the service 'Standard'. Referrals judged to require more urgent assessment than the service standard of three weeks, were allocated for assessment either by the current day's 'Duty Worker' or for assessment 'As soon as possible' (ASAP) by the allocated assessor.

Figure 3: Level of Urgency Determined From Referral Correspondence
Table 4 shows the criteria used to allocate to each level of urgency. Allocations to ‘Duty Work’ were characterised by multiple criteria (shown as “+
additional criteria”) indicating risk, allocations for assessment ‘As soon as possible’ by one risk criteria and ‘Standard’ assessment by one or multiple criteria indicating no risk.

**Table 4: Criteria Used to Judge ‘Urgency’**

<table>
<thead>
<tr>
<th>Criteria for urgency:</th>
<th>‘Duty Work’</th>
<th>‘As Soon As Possible’</th>
<th>‘Standard’</th>
</tr>
</thead>
<tbody>
<tr>
<td>(1) Suicidal ideation/intention</td>
<td>✓ + additional criteria (n=10)</td>
<td>✓ Occasional ideation with no plans (n=7)</td>
<td>✓ No risk (n=7)</td>
</tr>
<tr>
<td>(2) Self-injurious behaviour</td>
<td>✓ + additional criteria (n=1)</td>
<td>✓ Of no immediate harm (n=1)</td>
<td>✓ + additional information (no suicidal risk) (n=2)</td>
</tr>
<tr>
<td>(3) Risk of harm-to-others</td>
<td>✓ + additional criteria (n=1)</td>
<td>✓ (n=1)</td>
<td>✓ (n=1)</td>
</tr>
<tr>
<td>(4) Referrer expressing concern</td>
<td>✓ + additional criteria (n=4)</td>
<td>✓ (n=1)</td>
<td>✓ (n=1)</td>
</tr>
<tr>
<td>(5) Past mental health history/Current diagnosis</td>
<td>✓ + additional criteria (n=1)</td>
<td>✓ + additional criteria (n=1)</td>
<td>✓</td>
</tr>
<tr>
<td>(6) Distress/hopelessness</td>
<td>✓ + additional criteria (n=1)</td>
<td>✓ + additional information (no suicidal risk) (n=1)</td>
<td>✓</td>
</tr>
<tr>
<td>(7) Able-to-function</td>
<td>X</td>
<td>X</td>
<td>✓ + additional criteria (n=3)</td>
</tr>
<tr>
<td>(8) Taking medication</td>
<td>X</td>
<td>X</td>
<td>✓ + additional criteria (n=1)</td>
</tr>
<tr>
<td>(9) Worrying indicators**</td>
<td>X</td>
<td>X</td>
<td>✓ (n=2)</td>
</tr>
</tbody>
</table>

NOTES: Referrals were rated across multiple criteria.

**Worrying indicators refer to “Referrer hints at severe underlying problem but described client as ‘mentally better’” [Case 37]; “Referrer described ‘worsening depression’ but gives little other information” [Case 79].
4) Quality of Referral Correspondence

Referral correspondence was rated to indicate inclusion of information to judge ‘inappropriateness’ and ‘urgency’ (inclusion is indicated by an ‘X’ in Table 5).

Table 5: Proportions Of Referral Correspondence Providing Information To Judge Inappropriateness And Urgency

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Frequency N=113 (%) (2 missing data)</th>
<th>Criteria for 'Inappropriateness'</th>
<th>Criteria for 'Urgency'</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Client characteristics*</td>
<td>107 (94.7%) (X) (included)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 Expectations from referral/specific request</td>
<td>62 (54.9%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 Referrer’s concern</td>
<td>16 (13.9%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 Description of presenting complaints</td>
<td>107 (94.7%) (X) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 Indication of duration</td>
<td>57 (50.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 Indication of severity</td>
<td>22 (19.5%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 Current risk of harm-to-self/others</td>
<td>46 (40.7%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 Current medication</td>
<td>54 (47.8%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>9 Medication response</td>
<td>20 (17.7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 Day-to-day functioning</td>
<td>39 (34.5%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 Relevant background history</td>
<td>79 (69.9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 Stressors</td>
<td>64 (56.6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 Support (formal/informal)</td>
<td>23 (20.4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 Previous risk of harm-to-self/others</td>
<td>12 (10.6%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 Previous mental health history</td>
<td>54 (47.8%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>16 Previous mental health treatment</td>
<td>34 (30.1%) (X)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Possible range of total scores</td>
<td>0-16</td>
<td>0-3</td>
<td>0-9</td>
</tr>
<tr>
<td>Mean (s.d.) criteria per letter</td>
<td>6.9 (2.3)</td>
<td>2.4 (0.57)</td>
<td>3.3 (1.6)</td>
</tr>
<tr>
<td>Mode</td>
<td>6</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Minimum, maximum observed</td>
<td>0, 13</td>
<td>0, 3</td>
<td>0, 8</td>
</tr>
</tbody>
</table>

NOTE: *Category 1 includes information best reflecting criteria used to judge ‘inappropriateness’: Sex, age, address, GP.
5) **Post-assessment Judgements of Appropriateness for Assessment**

Figure 4 summarises post-assessment judgements of appropriateness for the 30 (29.7%) allocated referrals with available data (64, 63.4%, were not returned by assessors; a further 7, 6.9% did not attend assessment). Small sample sizes were not sufficient to analyse how representative available data were (e.g. in terms of referrer, presenting problem).

![Figure 4: Post-Assessment Judgements of Appropriateness for Assessment (N=30)](image)
6) Concordance Between Pre-And Post-Assessment Judgements Of ‘Urgency’

As shown in Table 6, there was complete concordance between pre- and post-assessment judgements of the 21 referrals allocated for ‘Standard’ assessment. Greater discrepancy was observed within the group initially allocated for more urgent assessment.

Table 6: Concordance between Pre-assessment and Post-assessment Judgements of ‘Urgency’ for Initial Assessment (N=28)

<table>
<thead>
<tr>
<th>Pre-assessment Judgement</th>
<th>Post-assessment Judgement of Urgency for Assessment:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>‘Urgent’*</td>
</tr>
<tr>
<td>(1) ‘Urgent’*</td>
<td>4 (57.1%)</td>
</tr>
<tr>
<td>(2) Not discussed but allocated for ‘Standard’ assessment</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Totals</td>
<td>4</td>
</tr>
</tbody>
</table>

NOTE: *‘Urgent’ represents referrals allocated to ‘Duty Work’ and ‘ASAP’

DISCUSSION

The aims of the current audit were to determine local rates of, and criteria for, ‘inappropriate’ and ‘urgent’ referrals received by the CMHTs. Further aims were to consider the frequency identified criteria were provided in referral correspondence. It was hoped that findings could be used to streamline referral and allocation processes.

Almost one-in-eight (12.2%) referrals were judged inappropriate for assessment from the correspondence; increasing to one-in-six (16.7%) of assessed referrals. The overall estimated rate of one-in-six (16.7%) falls in the lower range of comparable research findings (15%; Mauthner et al., 1998). However post-assessment rates are likely to be under-estimated due to low return of post-assessment forms and high non-attendance for assessment (19%). There is evidence that non-attenders are inappropriately referred and poorly motivated for treatment (Farid & Alapont, 1993).

While GPs, filters between primary and secondary care (Goldberg & Huxley, 1980; cited-in Job, 1999), were the largest group of referrers, equivalent proportions of inappropriate referrals were
made by each of the referring agencies. Pre-assessment criteria for inappropriate referrals related to the absence of mental health problems, catchment area and the request of services not provided by the CMHTs, such as older adults, people with learning disabilities, counselling and psychotherapy. Criteria used to judge inappropriateness from referral correspondence related to (1) Client characteristics, for example, age and catchment area, (2) A description of presenting problems and, (3) Expectations from the referrer, for example, medication review or counselling. While nearly all referral letters provided information for criteria (1) and (2), just over half included criterion (3).

In the absence of national guidelines for priority (Job, 1999), it is relevant to make local decision-making explicit. Indeed “rational, coherent and systematic” decision-making (Callahan, 1994; Page 455) and “transparent and equitable” systems have been advocated (Job, 1999). However only one-in-three referrals were discussed regarding their urgency, suggesting the teams’ more ‘intuitive’ approach. Although the current data only allows speculative explanation, particular referral information may have triggered explicit discussion.

While a broad range of information was considered when determining urgency, risk of harm-to-self or others was most frequently used. Other criteria included distress and functioning (recommended by Job, 1999), referrer’s concern, presenting problems, current medication, and history of harm-to-self or others, mental health problems and treatment. Unlike Job (1999), motivation and contact with other services were not considered.

Correspondence did not consistently include information to allocate urgency. For example, while presence or absence of harm-to-self or others was most frequently used to determine urgency, it was indicated in under half of referrals. However pre- and post-assessments (for referrals with data available on both occasions) were largely in agreement. The few observed discrepancies reflected over-caution and were allocated for assessment more urgently than post-assessment information judged. Available findings suggest the value of the current system for determining urgency.

Strengths of the audit are in its response to local questions concerning inappropriateness and urgency, and its provision of baseline data against which to measure future rates. Further strengths are in its naturalistic and semi-qualitative approach to examining clinical opinions and
decision-making. However while reflective of the clinical situation, data may have been compromised by varying verbalisation of allocation decisions according to time pressures and different team members.

A longer period of data collection may have overcome difficulties with statistical analysis. For example, small or unequal group sizes prevented statistical comparison of inappropriate and appropriate referrals by referrer, presenting problem and quality of referral correspondence. A less ambitious post-assessment questionnaire and more vigilant follow-up procedures may have maximised return rates. Low return rates raised questions about the representativeness of follow-up data, and limited the description of post-assessment criteria for inappropriateness and statistical investigation of concordance between pre- and post-assessment judgements of urgency.

Further research might develop more sensitive techniques to examine referral correspondence than those used in the current audit. These might weight the importance of different types of referral information and describe level of detail necessary for appropriate allocation decisions. It may have been useful to measure ease with which decision-making occurred, investigating the relationship between referral quality, discussion-time and appropriate allocation decisions.

CONCLUSIONS

Fewer inappropriate referrals were received than the team anticipated. Nevertheless approximately one-in-six referrals were inappropriate for assessment by the CMHT and were better referred directly to other services. Findings require more detailed discussion with the team. However information-based interventions targeting potential referrers may help to further reduce inappropriate referrals, thereby resulting in faster access to CMHT services for appropriate clients and direct referral to more appropriate non-CMHT services. Interventions therefore might usefully make known the types of services available within and outside of the CMHT and, referral information pertinent to allocating most appropriately with respect to service and urgency. Referrers may benefit from guidelines for differentiating between referrals to counselling, psychotherapy and adult mental health services. It may be useful to implement a routine monitoring system to record the profile of referrals or to re-audit following implementation of interventions.
REFERENCES


APPENDIX ONE

(1) Form A (Pre-assessment Data Form)
(2) Form B (Post-assessment Data Form)
## FORM A (PRE-ASSESSMENT DATA FORM)

### AUDIT OF REFERRALS: ALLOCATION FROM REFERRAL CORRESPONDENCE

<table>
<thead>
<tr>
<th>CODE</th>
<th>Referrer (Name &amp; Organisation)</th>
<th>Referral addressed to:</th>
<th>Referral information: Main presenting problems, duration, severity, expectation, medication, support, PMH/Tx etc...</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEX</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGE</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**GP name:**

---

**Q1: PRIORITY FOR ASSESSMENT:** On the basis of the referral letter, how soon does this referral require assessment?

<table>
<thead>
<tr>
<th>INAPPROPRIATE REFERRAL</th>
<th>DUTY WORK:</th>
<th>ASAP:</th>
<th>STANDARD:</th>
<th>UNCLEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

What information did you use to judge the priority of this referral? (E.g. Risk factors/ Etc.)

What other information is needed to help judge the priority of this referral?

- **GO TO 2A**
- **GO TO Q2**
- Not discussed
- **GO TO Q2**

---

**Q2: APPROPRIATENESS FOR ASSESSMENT:** On the basis of the referral letter, is this referral appropriate for assessment within the CMHT?

<table>
<thead>
<tr>
<th>2A</th>
<th>NOT APPROPRIATE</th>
<th>2B</th>
<th>APPROPRIATE</th>
<th>2C</th>
<th>UNCLEAR</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Why is this referral not appropriate for assessment? (E.g: Catchment area/ Etc)

Who has been allocated to assess this client?

Why was this team member selected to assess this client? (E.g: Match between needs & profession or interest/ Time available on caseload)

What is a more appropriate pathway for this client? (E.g: Refer on to specialist service/ counselling/ Etc)

Why is allocation unclear? What other information is needed to make an appropriate allocation?

Action (E.g: Contact referrer/ Assess/ Etc.)
FORM B (POST-ASSESSMENT DATA FORM)

<table>
<thead>
<tr>
<th>REQUIRED AUDIT INFORMATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Please read each question, ticking the relevant box (YES/NO/UNSURE), adding extra comments where necessary</td>
</tr>
</tbody>
</table>

### Q1
Do you consider yourself to have been an appropriate team member to assess this client? (For example, match with profession, skills, time, caseload mix, etc.)

- **YES** □
- **NO** □ ➔ **IF NO, why not?**

### Q2
Was this an appropriate assessment for the CMHT?

- **YES** □
- **NO** □ ➔ **Why was this not an appropriate referral? (E.g: Outside of catchment area, no mental health needs, etc.)**

- What would be a more appropriate pathway for this referral? (E.g: Refer to specialist service)
- **UNSURE** □ ➔ **Why are you unsure of the appropriateness of this referral?**

### Q3
This referral was judged to require assessment URGENTLY ON DUTY/AS SOON AS POSSIBLE/WITHIN STANDARD TIME. How urgently did this referral require initial assessment?

- **URGENTLY** □ ➔ **What factors determined this level of priority? (E.g: Suicide risk, harm to others)**
- **ASAP** □ ➔ **What factors determined this level of priority?**
- **STANDARD** □ ➔ **What factors determined this level of priority?**
- **UNSURE** □

### Q4
Is this client appropriate for treatment within the CMHT?

- **YES** □ ➔ **Will you become Care Co-ordinator?** YES/ NO
- **NO** □ ➔ **Why is this client not appropriate for treatment? (NO mental health needs, not motivated for therapy, requires specialist service, etc.)**

- What is a more appropriate treatment pathway for this client? (E.g: Refer on)
- **UNSURE** □ ➔ **What action will now be taken (E.g: Discuss at Team meeting)**

What other information is needed to make an appropriate allocation for treatment?

Please complete the following questions and return to: Dr , Clinical Psychologist

THANK YOU VERY MUCH FOR YOUR HELP
APPENDIX TWO

Reminder letter written to team members to complete and return Form B
MEMO: March 20th 2002

Dear <Team member>,

Re: Audit of Referrals

'Form B' was attached to referral letters distributed following Allocation Meetings from February 6th to March 7th 2002. These were intended to provide post-assessment information regarding the appropriateness of referrals for assessment and treatment within the CMHTs. However I understand that these forms are not very clear to complete and would like to both apologise for this and also take this opportunity to distribute an amended and hopefully easier-to-complete form.

While pre-assessment data has been collected during Allocation Meetings, some of the analysis will not be possible without your judgements of appropriateness following assessment (please see overleaf for audit objectives). I appreciate that each assessment already generates plenty of paperwork but would be very grateful if you could complete the attached forms retrospectively for the following assessments:

Referrals allocated for your assessment:

<table>
<thead>
<tr>
<th>Date of allocation</th>
<th>Client to be assessed</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Please could you return these forms to............................

Thank you very much for your help in this.

Yours sincerely,

........................................, Trainee Clinical Psychologist
Working under the supervision of Dr ............................., Clinical Psychologist
Outline of overall objectives:

- To describe the profile of referrals received by the CMHT. As well as describing referrals in terms of age, gender and presenting problems, the audit particularly aims to determine the proportion of appropriate, inappropriate and 'unclear' referrals made to the team.

- To describe the profile of appropriate and inappropriate referrals to the team as judged (a) from referral correspondence and (b) following assessment.

- To identify the type of referral information necessary to make informed decisions about allocation and, to identify how frequently this information is provided in referral correspondence.

- To identify the criteria used to allocate referrals to team members for assessment (for example, is allocation based on professional skills, time on caseload, etc.?)

- To describe the pathway of referrals through the CMHT (for example, who assesses? Who treats?)

The findings from this audit will be presented at a Team Meeting in June or July 2002.

Thank you for your help.
APPENDIX THREE

Qualitative coding form
EXAMPLE OF QUALITATIVE CODING FOR TWO CASES

<table>
<thead>
<tr>
<th>Referral information</th>
<th>Case 3</th>
<th>Case 53</th>
</tr>
</thead>
<tbody>
<tr>
<td>[Date of birth, age, sex, address, GP address]. Increasing depression since Christmas, not sleeping, poor appetite, poor concentration, unable to work. Stressors are work-related and recent split from [partner]. Previous depression at university. Thinking about suicide but no active plans. Speaking to Samaritans. Started medication at Christmas which didn’t help; new medication (not been on long enough) but not yet effective. Concerned about this gentleman.</td>
<td></td>
<td>[Date of birth, age, sex, address, GP address]. Split from [partner] 9 months ago. They both attended Relate and there is no future for reconciliation. Describes feeling low when at weekends without the children. Not coping. No relevant mental health history.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Allocation decision: Appropriateness</th>
<th>Appropriate for assessment</th>
<th>Not appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criteria used by allocating team to determine appropriateness</td>
<td>-</td>
<td>&quot;No mental health needs described&quot;</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Allocation decision: Urgency</th>
<th>Duty Worker allocated to check out suicidal ideation</th>
<th>-</th>
</tr>
</thead>
<tbody>
<tr>
<td>Criteria used by allocating team to determine urgency for assessment</td>
<td>1) Suicidal ideation but no plans</td>
<td>-</td>
</tr>
<tr>
<td>2) Referrer expressing concern (verbally &amp; through faxing referral)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Main presenting problem | Suicidal ideation & depression. | Low mood & not coping. |

<table>
<thead>
<tr>
<th>Categorisation for presenting problem</th>
<th>RISK OF SELF-HARM/ HARM-TO-OTHERS</th>
<th>DEPRESSION</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Client characteristics</td>
<td>✓ Provided</td>
<td>✓ Provided</td>
</tr>
<tr>
<td>2. Expectations from referral/specific request</td>
<td>X None specified</td>
<td>X None specified</td>
</tr>
<tr>
<td>3. Referrer’s concern</td>
<td>✓ “concerned about this gentleman” &amp; expressed through faxing referral</td>
<td>X Not specified over and above the referral being sent</td>
</tr>
<tr>
<td>4. Description of presenting complaints</td>
<td>✓ “Increasing depression since Christmas, not sleeping, poor appetite, poor concentration, unable to work”</td>
<td>✓ “...feeling low.... Not coping”</td>
</tr>
<tr>
<td>5. Indication of duration</td>
<td>✓ “Increasing depression since Christmas”</td>
<td>✓ “9 months”</td>
</tr>
<tr>
<td>6. Indication of severity</td>
<td>✓ “Thinking about suicide but no active plans”; “unable to work”</td>
<td>X Not indicated</td>
</tr>
<tr>
<td>7. Current risk of harm-to-self/others</td>
<td>✓ “Thinking about suicide but no active plans”</td>
<td>X Not indicated</td>
</tr>
<tr>
<td></td>
<td>Current medication</td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-------------------</td>
<td>---</td>
</tr>
<tr>
<td>8.</td>
<td>✔ “Started medication at Christmas which didn’t help; new medication (not been on long enough) but not yet effective.”</td>
<td>✗ Not indicated</td>
</tr>
<tr>
<td>9.</td>
<td>✔ “Started medication at Christmas which didn’t help; new medication ... but not yet effective”</td>
<td>✗ Not indicated</td>
</tr>
<tr>
<td>10.</td>
<td>✔ “unable to work”</td>
<td>✔ “Not coping”</td>
</tr>
<tr>
<td>11.</td>
<td>✗ None provided</td>
<td>✔ “Relate… no future for reconciliation…. When does not have children at weekends”</td>
</tr>
<tr>
<td>12.</td>
<td>✔ “Stressors are work-related and recent split from [partner]”</td>
<td>✔ “Split from [partner] 9 months ago”</td>
</tr>
<tr>
<td>13.</td>
<td>✔ “Speaking with Samaritans”</td>
<td>✗ Not indicated</td>
</tr>
<tr>
<td>14.</td>
<td>✗ None indicated</td>
<td>✗ Not indicated</td>
</tr>
<tr>
<td>15.</td>
<td>✔ “Previous depression at university”</td>
<td>✔ “No relevant mental health history”</td>
</tr>
<tr>
<td>16.</td>
<td>✗ None indicated</td>
<td>✔ Not indicated (specifically but implied)</td>
</tr>
</tbody>
</table>

**Total number of criteria included in correspondence**

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>8.</td>
<td>12</td>
</tr>
<tr>
<td>9.</td>
<td>8</td>
</tr>
</tbody>
</table>
APPENDIX FOUR

Table of presenting problems
TABLE OF MAIN PRESENTING PROBLEMS

<table>
<thead>
<tr>
<th>Main Problem</th>
<th>Presenting</th>
<th>Includes.../ With....</th>
<th>Frequency (%) (N=113)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Depression</td>
<td></td>
<td>Includes: Low mood &amp; emotional issues</td>
<td>29 (25.7%)</td>
</tr>
<tr>
<td>2. Anxiety</td>
<td></td>
<td>Includes: Panic, phobia, Obsessive-compulsive-disorder, stress, worries &amp; hypochondriasis.</td>
<td>22 (19.5%)</td>
</tr>
<tr>
<td>3. Anxiety &amp; Depression</td>
<td>Also includes: Chronic Fatigue Syndrome</td>
<td></td>
<td>12 (10.6%)</td>
</tr>
<tr>
<td>4. Substance-Misuse</td>
<td></td>
<td>With: depression/ anxiety/ bipolar disorder</td>
<td>10 (8.8%)</td>
</tr>
<tr>
<td>5. Risk of self-harm/</td>
<td></td>
<td>Includes: Suicide ideation, overdose, self-injurious behaviour &amp; safety of children.</td>
<td>9 (8.0%)</td>
</tr>
<tr>
<td>6. Harm-to-others</td>
<td></td>
<td>With: Depression</td>
<td></td>
</tr>
<tr>
<td>7. Behavioural problems</td>
<td></td>
<td>Includes: Impulsive/destructive/aggressive behaviour &amp; anger</td>
<td>9 (8.0%)</td>
</tr>
<tr>
<td>8. Bereavement</td>
<td></td>
<td>Includes: Relationship loss through death/ divorce</td>
<td>5 (4.4%)</td>
</tr>
<tr>
<td>9. Trauma</td>
<td></td>
<td>Includes: Post-traumatic-stress, domestic violence &amp; sexual abuse</td>
<td>4 (3.5%)</td>
</tr>
<tr>
<td>10. Psychosis</td>
<td></td>
<td>Includes: Schizoid psychosis, depression with psychosis, hearing voices &amp; paranoia</td>
<td>4 (3.5%)</td>
</tr>
<tr>
<td>11. Carers Assessment</td>
<td></td>
<td></td>
<td>3 (2.7%)</td>
</tr>
<tr>
<td>12. Eating Disorder</td>
<td></td>
<td>With: depression</td>
<td>2 (1.8%)</td>
</tr>
<tr>
<td>13. Other</td>
<td></td>
<td>Includes: Housing issue, reminder for appointment, medication review &amp; low self- esteem</td>
<td>4 (3.5%)</td>
</tr>
</tbody>
</table>

NOTE: 2 missing-data (Correspondence unavailable at meeting)
APPENDIX FIVE

Feedback to the CMHTs
Miss Jennifer Harris  
Trainee Clinical Psychologist  
c/o Department of Psychology  
School of Human Sciences  
University of Surrey  
Guildford  
GU2 7XH  

Our ref: AR/km  
29th October 2002  

Dear Jenny  

I am writing to thank you for the presentation of your SSRP findings to our teams.  

As you no doubt gathered, the presentation was well received. The information your study offered us was indeed valuable and has been of use in developing our referral and allocation procedures.  

I have since had good feedback from our team members concerning your presentation. They found it both interesting and informative.  

Good luck with the remainder of your course.  

Yours sincerely  

Clinical Psychologist
APPENDIX SIX
Audit Declaration Form
The nature of the proposed project is such that I am satisfied that it will not require scrutiny by the trust’s ethical committee.

Name of Supervisor: ....

Signature of Supervisor

Name of Trainee: JENNIFER HARRIS

Title of SRRP: AN AUDIT OF REFERRALS TO TWO COMMUNITY MENTAL HEALTH TEAMS

Date: DECEMBER 7TH 2001
QUALITATIVE RESEARCH PROJECT

The Desirability Of Having Personal Therapy During Clinical Psychology Training: A Qualitative Analysis Of The Views Of Third Year Trainee Clinical Psychologists

May 2003

Year 2

PLEASE NOTE:
Details have been changed to preserve the confidentiality and anonymity of participants.
Pseudonyms have been used.
ACKNOWLEDGEMENTS

The research group would like to thank their third year trainee 'buddies' for generously giving their time to participate in this research.
INTRODUCTION

Personal therapy is a mandatory requirement of all British counselling psychology and many psychotherapy training courses (Grimmer & Tribe, 2001; Williams, Coyle & Lyons, 1999). It is thought to aid personal and professional development (Grimmer & Tribe, 2001) and indeed such benefits have been perceived, although not empirically established (Williams et al., 1999), by recently qualified and trainee counselling psychologists (Williams et al., 1999; Grimmer & Tribe, 2001). Negative outcomes have also been described or suggested such as damage to marriages, destructive acting-out (Macaskill, 1988) and preoccupation with emotional turmoil (Greenberg & Staller, 1981; cited-in Grimmer & Tribe, 2001).

However while the Division of Clinical Psychology [DCP] recognises that “personal and professional development often go hand in hand” (DCP, 1995; Page 30), personal therapy is viewed as one of several routes to attending to personal development. UK trainee clinical psychologists are therefore not required to undergo personal therapy as part of their training and little is known about their perceptions of its desirability. Some related research has been conducted in the USA and Canada. This suggests that a substantial proportion of graduate clinical psychologists do undergo personal therapy (McEwan & Duncan, 1996; Holzman, Searight & Hughes, 1996) and that they view this as important in practising as a therapist, beneficial in dealing with transference (Holzman, 1995) and helpful for personal development (Holzman, Searight & Hughes, 1996). Those who did not undergo therapy cited lack of need and finances as reasons (Holzman, Searight & Hughes, 1996).

It was therefore within this context that the authors, themselves trainee clinical psychologists mid-way through their training on a UK course, conducted the present research. They aimed to gain a description of some of the views that trainees held about the desirability of having personal therapy during their three years of training. They were interested in the perceived advantages and disadvantages of having personal therapy, how these views developed over training and what sort of policy trainees would advocate as director of a training course.

METHOD

Setting and Participants

The research was conducted at the University of Surrey where the clinical training course regard personal therapy as a “matter of individual choice” and are supportive of, but unable to provide funding for, all routes to personal growth (Course Handbook & Programme Regulations, 2001-2002; Page 28, 11.4).
Trainee clinical psychologists who were currently in their third year of training were approached for an individual face-to-face interview. It was thought that being about to begin their sixth and final clinical placement would place this year group in a good position to reflect on the research topic and allow the development of views to be captured. The research group invited their ‘buddies’ (See footnote) to participate by means of an email request that outlined the topic under investigation, expected length of interview and measures to protect confidentiality. All those approached consented to participate.

**Interview Guide And Procedure**

From reviewing the related literature and group discussion, it was hypothesised that desirability might be explored through asking participants about their perceived advantages and disadvantages of having personal therapy, how views had developed over training and what policy they might advocate as director of a clinical training course. Open-ended questions and prompts designed to elicit such views were therefore incorporated into a semi-structured interview guide (*Interview Guide: Appendix One*).

The face-to-face interview began by participants giving their informed consent to participate in the research (*Information Sheet: Appendix Two; Consent Form: Appendix Three*) and completing the demographic information questionnaire (*Appendix Four*). Interviews lasted between 20-30 minutes. All were audio-taped and transcribed verbatim (*Sample transcript: Appendix Five*).

**Analytic Strategy**

The data were analysed using interpretative phenomenological analysis (IPA) (Smith, 1996a; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999). IPA was selected as it provided a systematic way to explore participants’ experiences, cognitions and meaning-making (Coyle & Rafalin, 2000), allowing the inclusion of both group and individual experiences. This was important given the likely variety and personal meaning of views about the topic under consideration. It further seemed likely that the research group’s position as trainee clinical psychologists would influence the content and process of the interview, as well as any subsequent analysis. It therefore seemed appropriate to select an analytic method that allowed for and recognised this dynamic interaction between the participant’s account and the researchers’ interpretative framework.

1 'Buddy' is a second year trainee assigned by the course to the first year trainee. They are available for informal peer support during first two years of training. Buddy relationships vary in frequency of contact.
Following the method recommended by Coyle (Personal Communication, 2003), each interviewer repeatedly read their individual transcript while noting key phrases, associations, connections, feelings and preliminary interpretations. These were noted in the left-hand margin of the transcript. The group then met together to discuss their preliminary interpretations and in order that themes were at a similar level of interpretation across all transcripts, the group used the richest transcript to together propose themes that both interpreted and summarised preliminary notes. Again themes were checked to ensure these could be illustrated by the data. Each interviewer then developed a list of themes that both interpreted and summarised their individual transcripts, noting themes in the right-hand margin. Themes from individual transcripts were discussed and a table of major themes and sub-themes that were recurrent across and summarised all transcripts was developed. Again the links between themes and the data-set were discussed and checked. Themes were then ordered to “produce a logical and coherent research narrative” (Coyle & Rafalin, 2000; Page 26).

Analysis of this nature is shaped by the researchers’ interpretative frameworks and inevitably involves a certain amount of subjectivity. Therefore criteria traditionally used to evaluate quantitative research are inappropriate and the reader may refer to Elliot, Fischer and Rennie (1999) or Yardley (2000) for a full description of criteria appropriate for qualitative research.

**ANALYSIS**

**Demographic Information**

Participants were currently in their third year of a clinical doctorate. The sample were a mean age of 28.4 years (range 26-30) and consisted of 5 (71.4%) females and 2 (28.6%) males. The majority were legally of single marital status (6, 85.7%) (See Table 1 for demographic characteristics). While no explicit question about personal experience of personal therapy was asked, all participants inferred this during their interviews.
TABLE 1: Participants' Demographic Information

<table>
<thead>
<tr>
<th>Name</th>
<th>Sex</th>
<th>Age</th>
<th>Ethnicity</th>
<th>Legal Status</th>
<th>Marital Status</th>
<th>Children</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alice</td>
<td>Female</td>
<td>26</td>
<td>White</td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>Clive</td>
<td>Male</td>
<td>28</td>
<td>British</td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>Sally</td>
<td>Female</td>
<td>28</td>
<td></td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>Naomi</td>
<td>Female</td>
<td>29</td>
<td></td>
<td>Married</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>Betty</td>
<td>Female</td>
<td>29</td>
<td></td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>29</td>
<td></td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
<tr>
<td>Anne</td>
<td>Female</td>
<td>30</td>
<td></td>
<td>Single</td>
<td>Single</td>
<td>No children</td>
</tr>
</tbody>
</table>

Description of Main Themes

The four main themes agreed by the research group as being reflected in and as summarising the data are shown in Table 2 together with illustrations from the data. Independent of whether participants had personal experience of therapy, all were able to perceive benefits to having personal therapy during training ("Perceived Benefits"). Benefits were described in terms of support with personal life events and aiding personal and professional development, echoing benefits reported by counselling psychologists in Grimmer and Tribe's study (2001). Trainees were also able to describe disadvantages to having personal therapy during clinical training ("Perceived Drawbacks"). These included practical and emotional constraints such as lack of money (also found by Holzman, Searight & Hughes, 1996), time and energy, facing stigma and coping with anticipated emotional turmoil (also suggested by previous authors such as Greenberg & Staller, 1981; cited-in Grimmer & Tribe, 2001). Interestingly, it seemed that participants who had undergone personal therapy during training did recognise disadvantages but that these somehow seemed less salient for them.

Trainees talked of benefits and drawbacks being mediated by or dependent on whether there were individual choices over whether to seek therapy, the type of therapeutic model that might be used, the duration of therapy and whether alternative support was thought helpful or accessible ("Individual Choices"). A further theme that arose during the analysis was the development of views over clinical training; views appeared dynamic and open to influence by on-going life events, personal experience of therapy, training experiences and specialist teaching ("Influences").
### TABLE 2: Themes, Sub-Themes And Illustrations From The Data

#### 1: PERCEIVED BENEFITS

<table>
<thead>
<tr>
<th>Sub-themes</th>
<th>Illustrations from the data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Super-ordinate themes</strong></td>
<td></td>
</tr>
</tbody>
</table>
| 1.1: Personal development/ self-awareness | ‘in terms of what it's revealed for me about myself, the way I think, you know, the influence of my upbringing, the way I am in relationships has been really valuable and important’ [Sally]  
'I think its really important as a group to perhaps look at our motivation for this kind of work' [Sally] |
| 1.2: Specific personal situation/ problem-solving | ‘I had a life event that meant that I found it useful to actually have somebody to talk to’ [Betty] |
| 1.3: Professional development: | |
| 1.3.1: Reflective practice | ‘it enables you to actually think about how your own beliefs and ideas can influence your clinical work...then you are much freer to be able to do your work’ [Betty] |
| 1.3.2: Learning from experienced therapist | ‘learning from an experienced therapist’ [Sally] |
| 1.3.3: Developing clinical practice | ‘I've come to be much more aware of the therapeutic relationship’ [Sally] |

#### 2: PERCEIVED DRAWBACKS

| 2.1: Practicalities: | |
| 2.1.1: Time and money constraints | ‘I personally don't feel I have the time or money for it’ [Anne]  
'on the course, my head always feels full of all sorts. You know, trying to juggle placements, assignments, research, all of that so, and personal life and social life, so I don't, its almost as though you couldn't have the time to be able to fully engage in it' [Naomi] |
| 2.1.2: Competing demands | |

| 2.2: Stigma | |
| | ‘I haven't found it stigmatising from my peer group at all’ 'I think probably more stigmatising in terms of the wider kind of general population’ ‘are you then competent to do your job if you need help from somebody else?’ [Betty]  
'I think I'd find it really hard going from a ward to see my therapist! I don't know why it's still there; I know it's one
Qualitative Research Project

| 2.3: ‘Opening Pandora’s box’/ Emotional energy | ‘But there’s a slight feeling of a sort of Pandora’s Box that I don’t know if I could afford for that to be opened whilst I’m in training and while things are pretty stressed’ [Anne] |
| 3: INDIVIDUAL CHOICES | |
| 3.1: Mandatory or voluntary? | ‘its personal choice.... I don’t think you can actually force people to do something like that.... because its going to be counterproductive....It could be advocated a little bit more strongly on the course’ [Naomi] |
| 3.2: Which model? | ‘Partly because I’m very CBT-oriented I think, I’m not a big one for therapy as building your personality. I think its more of a skills development and problem-solving exercise’ [John] |
| 3.3: Alternative support (supervisors/ course tutors/ friends/ family)? | ‘but usually people I know, supervisors have been superb’; ‘I suppose as a trainee there are also other support avenues out there like clinical tutors’; ‘There’s an awful lot people get, not through therapy, but through friends and family and that sort of support’ [Anne] |
| 4: INFLUENCES | |
| 4.1: Personal experience of therapy | ‘I’ve had these sorts of discussions with my personal therapist as well and that’s shaped my thinking a little bit about personal therapy’ [Sally] |
| 4.2: Specialist teaching on course | ‘I think also a big influence has been the psychoanalytic teaching we have had here on the course’ [Sally] |
| 4.3: Development of views through clinical training | ‘I always did have the view that it seemed odd not to go through that process [personal therapy] yourself’; ‘it [personal experience of therapy] confirmed all my views prior [to the course]’ [Clive] |
|  | ‘Before I started training.... I probably wouldn’t have had a great um notion of going to therapy for myself. I think I’d be more open to it now’ [John] |
The Importance Of Individual Choice

Although both counselling and clinical psychology trainees face similar personal and professional challenges during training, the two courses differ in their requirements for personal therapy. It therefore seemed interesting to examine how participants balanced perceived benefits and drawbacks with the importance of individual choice. This also highlighted the complexities of advocating an acceptable course policy.

While all participants recognised the substantial benefits of undergoing personal therapy during training, they all firmly agreed that the decision to undergo therapy was a matter of individual choice. Even those who strongly and fully recommended personal therapy agreed that enforcement could be counterproductive. All alluded to the possible disadvantages of imposed therapy and some talked more specifically about feelings of resentment, frustration, defensiveness and how enforcing therapy might alter its potential benefits.

'I think that is likely to make you feel quite resentful of the experience, particularly if um, the course sort of enforces that you have to do it, I think it makes a difference to how you feel about it and what you take from it' [Clive]
'Because it would be quite easy to sit there and be very defensive if you were forced into
the situation' [Anne]

There appeared to be complex interaction between enforcement, undergoing therapy 'just for
the experience' and having no specific therapeutic reason. The following extracts show how
this situation might lead to drawbacks detracting from the potential professional benefits:

'Talking to supervisors I've had who have counselled counselling trainees .... it could be
you are just going round the houses and not really getting anywhere and it can be quite
frustrating for the person involved and the supervisor or counsellor' [Naomi]

'I just felt I was too much under pressure for other work to really be able to fully focus on
the sessions. I mean I suppose that's different when you've got a specific focus for the
sessions, so there's reason for you being there.' [Clive]

Some views about the potential aimlessness of personal therapy for experience's sake were
based on experiences of the reflective practitioner group (a peer-support/experiential learning
group for a training year instigated by the course; initially attended on a voluntary then later
on a mandatory basis).

'But (pause) if you're just there to get the experience of being a client, um, I mean, with
the reflective practitioner groups, I've felt that sometimes they've just felt a bit aimless.
Um, and I'm assuming that with the group going through that kind of experience and
week upon week we just couldn't find a particular reason for these sessions and I'm sure
you've gone through a similar thing?' [Clive]

Participants also raised the question of whether training with all its demands was the best time
to address underlying personal issues, particularly if this was not a voluntary decision.

'we already juggle of lot of roles and work very, very hard... I think also that any therapy
does in many ways open a can of worms for you... that perhaps if you are not ready for
it, or its something you feel you can't deal with at the moment, then maybe its not
appropriate for you, because then it could involve a lot of, it could be just really hard for
you as a person' [Sally]

Participants did not perceive an optimal time to undergo therapy during training, perhaps
reflecting their different training experiences and life events. Some felt that personal therapy
might help juggling the many training and life demands, whereas others felt that therapy itself would be an added demand. Hence it would be important to be able to choose whether, when and for how long to undergo personal therapy.

'It would depend on how the relationship was going, whether you were getting something from the therapy. If it was working for you it would be good. If you were doing it for the sake of doing it as part of say like a course recommendation then I can see it being a real pain' [John]

'it might be useful to sit down and talk it through with someone in therapy for an hour, it might be again you’ve got the time issue thinking ‘Oh, I could’ve written a couple of hundred words in that time’ [John]

There appeared to be an overall fit between participant views and those held by the course – both agreed upon the importance of individual choice. However nearly all felt that the course could do more to fully recommend personal therapy and to support trainees in making an informed decision:

‘I think it would have been quite interesting for us, to have perhaps, a talk maybe on a kind of individual basis at the beginning, I don’t know, maybe every six months, just so it might ring bells for people.’ ‘It would be nice to get a clearer picture about what it might involve’ [Alice]

‘I think what I’d perhaps do is have a very brief sort of session...maybe work through with people what they think the advantages and disadvantages could be, um, and set up options with people’ [John].

Some talked about ‘accountability’ and providing individual time for trainees to explore their reasons for deciding not to undergo therapy:

‘I’d almost quite like there to be just one single session to examine why you don’t want to do it and maybe talk about what the ramifications are for that’; ‘you just leave them with the questions in their mind about are they really making the right kind of decision. So, almost give them a platform to re-examine their reasons’ [Clive]

Explicit discussion with peers on the course and the course team was proposed as a way to address concerns about competency and perceived stigma:
I guess promoting more open discussion that things do go wrong, we don’t get better in two weeks. The clients don’t either; ‘Maybe not being felt, made to feel its [having personal therapy] something that’s bad, or something that you have to keep hidden. Um, and actually you can be a competent psychologist and have life events and difficulties.’ [Betty]

Several participants raised their concerns about using scarce and limited NHS resources or student counselling services. They highlighted the importance of increasing the accessibility of personal therapy and suggested strategies for overcoming practical drawbacks such as time, money and course demands.

‘I think as course organiser, what I would want to do it make it more accessible for people who wanted it’ [Anne]

‘I guess I’d like to make time available for that so, put that into the timetable perhaps every Wednesday morning, people can have the morning off to go and have personal therapy and presumably it would need some resources to help people finance that’ [Sally]

OVERVIEW

It was hoped that by working together as a group would overcome idiosyncratic interpretations and that detailing the research process and including extracts from the data-set to illustrate interpretations would allow the reader to assess the transparency, persuasiveness and coherence of the analysis. However there were a number of points to bear in mind when considering the research process and analysis. It was likely that the shared understanding brought by the author’s and participant’s positive experiences of personal therapy during training resulted in some lack of clarification by the author during the interview, particularly regarding perceived benefits and drawbacks. Lack of piloting and therefore familiarity with the interview guide was also likely to have hindered the interview process. Furthermore, while individual researchers became familiar with all transcripts, practical limitations prevented the group from sufficiently meeting together. The resulting analysis was therefore unlikely to have reached its full potential or richness.

Participants in the current study were not required to undergo personal therapy as a mandatory part of training. However they perceived similar benefits to those described by counselling psychologists undergoing mandatory therapy (Grimmer & Tribe, 2001; Williams, Coyle & Lyons, 1999), in terms of support with personal life events, personal and professional development and experiential learning. They also perceived a number of drawbacks with
undergoing therapy during training, namely that therapy might impose an added demand on already strained emotional, time and financial resources.

However the perception of potential benefits and drawbacks appeared to be greatly influenced by the theme of ‘Individual Choices’ that recurred throughout all interviews despite it not being an explicit line of investigation. Participant views about the importance of making an individual choice about undergoing personal therapy were consistent with those held by their training course. However nearly all advocated a fuller recommendation by the course, with more explicit discussion of personal therapy to facilitate more informed decision-making and to address perceived stigma. Course changes were also suggested to address financial and time constraints. It might be beneficial to feed back such suggestions to the course team.
REFERENCES


APPENDIX ONE

Interview Guide
INTERVIEW GUIDE

"We are interested in trainees’ perceptions of the desirability of having personal therapy during clinical training. By personal therapy, we mean individual therapy of any theoretical orientation. Some people may feel that having personal therapy during clinical training is desirable whereas others may feel that it is not desirable. Some people may not have any strong opinions about this at all ...."

Q1) What are your views around having personal therapy during training?
"I’d like us to discuss some of the things you have mentioned in a little more detail now ...."

Q2) What do you see as the potential advantages of personal therapy during clinical training?
   a) For you personally and professionally
   b) For trainees in general

Prompts
• What have you based your decision on?
• What makes you say that?
• Do you think having personal therapy will have any advantages in terms of your clinical work?
• How have, if at all, your views on the advantages of personal therapy for yourself changed (developed) over the course of training?
• How have, if at all, your views on the advantages of personal therapy for trainees in general changed (developed) over the course of training?
• For you personally, would there be certain times when it is more desirable to have personal therapy? (use above prompts in conjunction with this)
• For trainees as a group, would there be certain times when it is more desirable to have personal therapy? (use above prompts in conjunction with this)
• For you personally, are there any particular issues for which you might consider personal therapy advantageous?
• For trainees as a group, are there any particular issues for which you might consider personal therapy advantageous?
• How do your views on personal therapy for trainees in general relate to/differ from your views on personal therapy for yourself?
Q3) What do you see as the potential disadvantages of personal therapy during clinical training?

a) For you personally and professionally
b) For trainees in general

Prompts
- What have you based your decision on?
- What makes you say that?
- How have, if at all, your views on the advantages of personal therapy for yourself changed (developed) over the course of training?
- How have, if at all, your views on the disadvantages of personal therapy for trainees in general changed (developed) over the course of training?
- For you personally, would there be certain times or periods when it is less desirable to have personal therapy? *(use above prompts in conjunction with this)*
- For trainees as a group, would there be certain times or periods when it is less desirable to have personal therapy? *(use above prompts in conjunction with this)*
- For you personally, are there any particular issues for which you might consider personal therapy a disadvantage?
- For trainees as a group, are there any particular issues for which you might consider personal therapy a disadvantage?

“I’d like to approach the topic from a slightly different perspective now........”

Q4) If you were the course director, what policies around personal therapy for trainees would you advocate/implement?

Prompts
- What makes you say that?
- Where have your ideas come from?
- Do you think this policy would be helpful to trainees? If so, how? / What would be your aims for advocating this kind of policy? / What would you hope to achieve through advocating this policy?
- How does this, if at all, differ from what you would like for yourself?
- Can you envisage any difficulties with that sort of policy?
- What might be the advantages/disadvantages of your policy?
• How would you describe the current culture around personal therapy on the course? How would you like the culture to be?
• How does your policy differ from or relate to the current course policy?
• How does this, if at all, differ from what you would like for yourself?

Q5) a) Is there anything else that you’d like to add that we haven’t already covered?
    b) How do you feel being interviewed about this topic?
    c) How do you feel being interviewed by another trainee?

Thank you so much for taking the time to participate in the research. The information you have given will be kept confidential and will be used for our qualitative research projects. If you would like to see a copy of the final report, I can make it available to you once it has been submitted and marked.
APPENDIX TWO

Information Sheet
INFORMATION SHEET

QUALITATIVE RESEARCH PROJECT

The Desirability Of Personal Therapy During Clinical Training

As part of our clinical training here at the University of Surrey we have been asked to conduct a piece of qualitative research and analysis. We saw this as an opportunity to explore trainees’ perceptions of the desirability of having personal therapy during clinical training. By personal therapy, we mean individual therapy of any theoretical orientation. Some people may feel that having personal therapy during clinical training is desirable whereas others may feel that it is not desirable. Some people may not have any strong opinions about this at all. However we are interested in your hearing about your opinions.

We are working in a research team of seven and each of us will interview one trainee in Year 3. The interview is semi-structured and will take approximately 20 minutes of your time. With your consent the interview will be tape-recorded and transcribed. The recording will be securely stored and destroyed after transcription. We will then, as a research team, analyse the interview using Interpretative Phenomenological Analysis (IPA) and individually write up a report for submission to the course research team and possibly submit for publication at a later date. Your interview transcript will be anonymised and all of our conversation will remain confidential within the qualitative research team. If you would like to see a copy of the final report, we will make it available to you once it has been submitted and marked.

If you have any questions that have not been addressed in the information above, we are happy to discuss these with you at any time before, during or after the interview. If you wish to verify information then please feel free to contact Dr (name of university supervisor), our university supervisor (telephone number).

Thank you very much for your time and help in conducting this research.
APPENDIX THREE

Consent Form
CONSENT FORM
QUALITATIVE RESEARCH PROJECT
The Desirability Of Personal Therapy During Clinical Training

I agree to participate in the research investigating the desirability of personal therapy during clinical training. I understand that participation will mean giving consent for the interview to be tape-recorded, transcribed and analysed by the research team conducting this research. I also understand that this information will remain confidential but will be included in an anonymised form in a written report and may be submitted for publication.

Signature of participant: .................................................................

Name of participant (CAPITALS) ....................................................

Signature of interviewer: ..............................................................

Name of interviewer (CAPITALS) ....................................................

Date: ..............................................................................................

Thank you very much for your time and help in conducting this research.
APPENDIX FOUR

Background Information
BACKGROUND INFORMATION

To begin, I’d like to get some basic information about you. This is so that I can show those who read my research report that I managed to obtain the views of a cross-section of people. The information that you give will never be used to identify you in any way because this research is entirely confidential. However it you don’t want to answer some of these questions, please don’t feel you have to.

1. Are you (please tick the appropriate answer) Male [ ] or Female [ ]?

2. How old are you? [ ] years

3. How would you describe your ethnic origins? Choose one from (a) to (e) and then tick the appropriate category to indicate your ethnic background.

   (a) White
       British [ ]
       Irish [ ]
       Any other White background, please write below:

   (b) Mixed
       White & Black Caribbean [ ]
       White & Black African [ ]
       White & Asian [ ]
       Any other mixed background, please write below:

   (c) Asian or Asian British
       Indian [ ]
       Pakistani [ ]
       Bangladeshi [ ]
       Any other Asian background, please write below:
(d) Black or Black British
Caribbean [ ]
African [ ]
Any other Black background, please write below:

(e) Chinese or Other ethnic group
Chinese [ ]
Any other, please write below:

4. What is your current legal marital status?
Single [ ]
Married [ ]
Divorced/Separated [ ]
Widowed [ ]

5. Do you have any children? Yes [ ] or No [ ];
If YES, how many children do you have? [ ]

<End of questionnaire: Thank you>
APPENDIX FIVE

Sample Interview Transcript with ‘Clive’
INTERVIEW TRANSCRIPT WITH ‘CLIVE’

I=INTERVIEWER
P=PARTICIPANT

I Well, thank you for agreeing to take part

P That’s alright

I Um, just... I know you’ve read the information sheet, but just to summarise we’re interested in people’s views, trainees’ views about having personal therapy during clinical training, and by personal therapy, we mean individual therapy of any theoretical orientation. Okay, we know that some people might have quite strong views and others perhaps less so, and we’re interested in your views.

P Okay

I So, what are your views about having personal therapy during clinical training?

P Um (pause), I think, I think its, its a good thing, because, umm, having done some, err used the counselling services at the university myself, it was an interesting experience just even in the (pause) of being a client, just even in the small aspects, such as say for instance in the first session, not knowing who the therapist is going to be, what they’re going to look like, what they’re going to say, what they’re going to think of you. (Pause). Um, then giving you much more of an appreciation of what its like to be a client because I think sometimes we can kind of take some of those, those aspects for-granted, just the little, just the little things (pause). We just sort of bang on with our therapy and don’t really take those kind of things into account that could be effecting things quite considerably, particularly in the initial assessment sessions and things like that. Um, so I think it’s really, it’s a really beneficial thing, I think.

I And what do you think about trainees in general having personal therapy, I mean for you it sounds like its been a very valuable experience?

P Yes

I How about for trainees in general?

P Whether, whether, what they would think or whether they should have it, do you mean?

I The benefits of having it

P The benefits of having it. Umm, er (long pause). I realise its quite difficult to generalise across trainees as a group going through training

P Um, yeah, um (pause). Do you mean (laughs) as far as how it would aid the process of the doctorate and their experience and stuff?

I Nods
P I think it would definitely be a good idea. I'm always, when I went through the process, I was umm (pause), finding it interesting, especially when we started the reflective practitioner groups and some of the trainees just flat out didn't seem to want to do that. I always found that interesting. Because we were going into a profession that expects other people to open up but when it comes to us opening up, some of us don't seem to want to do that. It kind of seems to, I don't know if selfishness is the right kind of word but I don't know. I think it should be a bit of two-way flow sometimes and the fact that we only want other people to open up, just seems a bit kind of odd to me. I think the benefits as I've said already, certainly about just knowing the experience of therapy, umm, but also just the sort of (pause), larger aspect of therapy as well for when people are going through the doctorate just learning about (pause) further down the therapy road what the client would expect and umm, how the client's feeling, whether the client's feeling a little bit lost in the therapy and (pause), making sure that they feel there's a certain sense of direction and you certainly go through that experience when you have therapy yourself so (pause), so I think if someone's going through the doctorate it just seems to make sense that they'd also have that kind of client experience as well.

I It sounds as though you think it would benefit trainees a great deal professionally?

P Um, yeah.

I What have you found the benefits to be for you more personally.... If that's not too personal a question

P Um (pause), er (pause), um (pause)

I I guess, um, because we were trying to find out whether there was a difference between benefits personally and professionally and benefits for trainees as a group going through the process of training

P Um (long pause) I'm just thinking about that one... I think there's definitely a difference because professionally, as I've already said, you get the client's angle of how to do therapy, how therapy feels, umm (pause), and (pause), just all the emotions associated with going through therapy. On a personal level, um (pause), yeah, (pause), I'm just trying to think, there's obviously for me because there was quite a personal situation occurred for me to have therapy in the first place. There were definite personal benefits in as far as going through the process that I was going through at the time. Um (pause), so it helped me enormously as far as helping me through the thing I was going through but umm, as far as how personally it might have influenced er, me on the course or something like that, umm

I Sorry I realise I've asked what seems like a very intrusive question

P No, no, no, not at all. I'm just trying to think of how to answer it (long pause)

I I guess... would you like to think about that and come back to it later?

P Yeah, yeah okay. It's a really good question and there's a good answer there and I'm trying to formulate the answer but I just can't quite get there at the moment.

I Nods and smiles... Another thing we're interested in was whether people's views changed over training... because as you're now close to finishing

P Yeah
And thinking, you know, back to when you started the course, about what were your views about having personal therapy then and, how those developed

Umm, I think right at the start of the course, my view always was that personal therapy would be a good idea. Umm, just because I always did have the view that it seemed odd not to go through that process yourself. Umm, because you’re relying so much on other people divulging things to you and it would be important to go through that experience yourself. And then when I went through this sort of personal situation and did wind up having therapy, it almost confirmed all of my views sort of prior to how beneficial it would actually be. (Pause) Um, I mean I actually sort of... almost going back to your question before I suppose, on a personal level as far as how professionally its benefited me is I suppose my approach to clients is, it feels a little bit more informed. I feel like, er, like I’m a little bit more aware of what they’re going through and what kind of things in the session could be affecting how they’re behaving and particularly I think I find, I’m a little bit more (pause), I suppose I’m a little bit more gentle in the initial session because I kind of remember the nervousness that I had before the session and that kind of thing. So I suppose (pause)

Sounds like you feel a bit more empathic, sensitive and being able to put yourself in the client’s shoes?

Yeah, yeah. I think it helps, in, that kind of sense, in being able to put yourself in their shoes throughout the whole, um, load of therapy. So in a way its almost a repetition of my answer before of, um, just having a bit more of an appreciation of how the client’s finding it, but particularly, if you’re not completely sure in what direction the sessions are going, its pretty definite that the client’s going to be sitting there feeling fairly unsure about it as well, so (pause)

Yes

I think there’s a definite professional benefit to having personal therapy.

Thank you.

That’s alright.

We’re also interested in looking at the other side of it, and wondered whether you can think of whether there might be any disadvantages of having personal therapy during training?

Yes. I think for me especially when the reflective practitioner group started, I found that the main disadvantage was time. I felt time was, very, was very short. I think if you’re going to have it, it would be better, I mean (pause) I suppose, it would be good if you could have it say for instance, for the first half of your training and then have it end half-way through. Which might sound a bit odd, but I just felt I was too much under pressure for other work to really be able to fully focus on the sessions. I mean I suppose that’s different when you’ve got a specific focus for the sessions, so there’s reason for you being there. But (pause) if you’re just there to get the experience of being a client, um, I mean, with the RP groups, I’ve felt that sometimes they’ve just felt a bit aimless. Um, and I’m assuming that with the group going through that kind of experience and week upon week we just couldn’t find a particular reason for these sessions and I’m sure you’ve gone through a similar thing?

Nods
I'm theorising that you might still go through that kind of experience on an individual level if you're just turning up for therapy just for the experience and not for a specific reason. So, and that's, I think that's likely to make you feel quite resentful of the experience, particularly if um, the course sort of enforces that you have to do it, I think that makes a difference to how you feel about it and what you take from it. Um (pause), so (pause)

I So you had a very specific reason for going that overcame the disadvantage of time?

P Yeah, yeah. And also it was quite early on in the course, so it didn't feel like it was too much of a sacrifice for my time, whereas say for instance now that I'm in the third year, I've got the MRP going on and all those sort of things (pause). If I felt the course was saying to me you have to got to therapy sessions, particularly when I haven't really got a terribly good reason for going, apart from just to get the experience, I think that would be an experience that I'd probably start getting quite frustrated with.

I Well, that leads us very nicely into the last area we're looking at, and that is, if you were the course director, what policies around personal therapy for trainees would you advocate?

P Um (pause). As far as (pause), I wouldn't like to (pause). I'm kind of against making trainees go through the process, um (pause)

I What makes you say that?

P Because I suppose it could turn into a negative experience if you really don't want to do it and you don't see a particularly good reason for doing it. Then fair enough. But having said that, if you didn't want to do it, I'd almost quite like there to be just one single session to examine why you don't want to do it and maybe talk about what the ramifications are for that, particularly, you know, if (pause) are there issues around not feeling comfortable about not divulging your own issues but then expecting others to do that throughout your 30, 40 year career. So, I mean I'm sure that wouldn't be a terribly ethical (laughs) sort of process to have to go through, but almost, fully recommended to the students, don't make it mandatory but for those students that don't want to do it, maybe have some kind of session with a personal tutor or something like that, about why not. If there's some perfectly legitimate reasons then fair enough (pause). But if there's perfectly legitimate reasons there, then I'm not saying you then make them go and do it, but you just leave them with the questions in their mind about are they really making the right kind of decision. So, almost give them a platform to re-examine their reasons.

I Yes, Um. How would you describe the current, the course's current stance on personal therapy?

P Do they have one? I'm not even sure if they have one or not (laughs)

I (Laughs), that's an interesting telling response then isn't it? Yeah.

P Yes, I don't know (pause), because I think the only time we've ever really discussed personal therapy is in the first week when (pause) the guy from the counselling service approached us and said if you want to use us, we're here and go ahead. I don't think the course has ever really (pause) made a statement about their views on trainees doing personal therapy. I know that on other courses, such as psychodynamic training and so on, its I think its mandatory actually isn't it? Um, I don't know, I don't really know what their views are, I'm assuming that they probably look on it, in quite a beneficial light because of the RP
groups. I'm assuming that the RP are almost trying to do that with the whole group in one fowl swoop, Um, but the RP group just feel so 'wishy-washy' and lacking in goal that I don't really see the benefit of them.

I Because we had the RP from day one of the course and we had to go, was it the same situation for your year?

P Well for us, we didn't have it in the first year, we had it I think we had it when you guys came in. But I think it was worked into your contract that you have to attend. Whereas for us, because we started when they weren't happening, um, (mobile rings!) ..... it wasn't in our contract, we were told quite forcibly that we should go but at the end of the day they couldn't make us but there was nothing they could do.

I Right

P To stop us if we didn't want to go. And in fairness, I think a lot of us did turn up for the first few ones but then we seemed to have session upon session, I think we must have spent at least five sessions talking about what we were going to talk about, what we weren't going to talk about, about confidentiality issues, and it was just painful. So its almost as if the course wants us to get into that kind of therapy mode but then we start these groups that don't really have any specific aim. While I think that's a good idea, I mean, when you look at it from the outside, having sessions where you can just decide for yourself what the purpose is, probably, seems like a good idea but in practice it just didn't seem to be at all. I mean I think a lot of our initial thoughts about the RP group was going to be about personal effects of therapy on ourselves and then when we got there, and then found it wasn't and we were just talking about what we were going to talk about. It just got very bizarre.

I How many are there in your year group?

P There's 24. I think it's the same as in your year. But now, and after a while, after 6 months they then sent out a slip saying right, that you're either going to tick this that you're permanently going to go or you're going to tick this that you're not going to go. Which I suppose is fair enough as some people, one week you'd have 10 people, another week you'd have 5 and it was quite disruptive to the people did permanently want to turn up. So eventually they have a group of something like 5 or 6 now. Which is apparently sounds like quite a nice group to have. But er, personally I prefer not to have RP groups and just have this recommended personal therapy, because that sounds much more beneficial.

I Do the think the course are helpful in making therapy accessible, do they help trainees in finding somewhere?

P They didn't, when I thought about going for some personal therapy, the course just said "Yeah, that's a good idea". And that was it, they didn't do anymore than that, though in fairness, they didn't really have to do more than that, I knew where the counselling service was and I just phoned them up and made an appointment.

I Right

P And I was in quite close contact with my clinical tutor at the time and every time I met her, she would ask, you know, "how are things going? Are you still going to the sessions?" and so on but I'm assuming that was quite particular to my own situation because there was a specific thing that happened to make me go whereas I'm assuming that they wouldn't keep checking in on trainees if they're just going for (pause)
Personal development?

(Nods) for personal development rather than a personal issue. Because when it’s a personal issue how you cope with that effects how you cope with the course. Whereas if its just for personal development, you’re likely to be coping okay with the course anyway. Um so, they didn’t really get that involved.

Thank you, I’m just going to check the interview guide to make sure I’ve covered everything.

Okay

When you were talking about the sort of policies you might advocate, um (pause) you were saying that you’d like it if the course recommended it but not made it mandatory, is that a fair summary?

To have it sort of recommended but not made mandatory

Yes, can you see any disadvantages of that?

Well, I suppose the obvious disadvantage of that would be that you’d have people opting out but that’s why I was suggesting that you have a session to really examine why that is. If it’s because people can’t be arsed or if there’s a really good reason why not, perhaps they’ve, maybe something’s happened, been quite difficult, earlier on in their lives and they’ve already had sessions or something like that. Um, but that’s probably the down-side. But then knowing that they’d have to be accountable for not doing it, might hopefully up the numbers that would do it.

To look at what’s really going on and why as you said earlier.

Yes.

Thank you, that’s been really interesting.

That’s alright.

How’s it feel being interviewed by another trainee?

Alright, I tend to be quite an open person anyway so, no, its been fine. Thanks a lot.

Thank you.

End of Interview
MAJOR RESEARCH PROJECT

LIFE AFTER STROKE:
Using Interpretative Phenomenological Analysis To Understand How
Stroke-survivors Make Sense Of And Manage Life After Stroke

October 2004

Year 3

PLEASE NOTE:
Details have been changed to preserve the confidentiality and anonymity of participants.
Pseudonyms have been used.
ACKNOWLEDGEMENTS

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ABSTRACT

Title: Using Interpretative Phenomenological Analysis (IPA) to understand how stroke-survivors make sense of and manage life after stroke

Objectives: The main objective was to consider the ways that participants managed, made sense of and attributed meaning to their stroke-related experiences, in order to identify areas for psychological input.

Design: A retrospective semi-structured interview study. Data collected through semi-structured interviews were analysed using the qualitative methodology of IPA.

Participants: Ten participants (five females and five males) aged 54-90 years, who had experienced their first stroke between 6-22 months previously, were recruited through two NHS out-patient Stroke Review Clinics.

Results: Two main themes emerged from the analysis. ‘Making sense of the stroke’ described how participants understood why the stroke had happened to them and its impact on their lives. This encompassed five sub-themes that made sense of the stroke in the context of their life narrative, through seeking causal explanations, drawing comparisons of the self against other selves, as an uncertain journey and as resulting in new life perspectives. Meaning-making also served as a means of coping. The second main theme ‘Managing life after the stroke’ described coping with stroke-related experiences. This encompassed six sub-themes that expressed how participants made the most of social support, experimented to find new ways around everyday activities, drew from inner resources, set goals, used thoughts to cope and strategies to manage emotions. Sub-themes incorporated both emotion- and problem-focused coping, and primary and secondary control processes. Meaning-making and coping evolved over the time since stroke-onset. Personal meaning was understood as a part of cognitive adaptation; it appeared to be linked with emotional responses and coping behaviours.

Conclusions: Participants actively sought to make sense of and manage the stroke’s occurrence and impact. Suggestions for adaptation and clinical intervention are made. Key clinical implications include firstly, the importance of improved professional communication (educational and emotional support) in facilitating adaptive meaning-making and longer-term coping. Secondly, the importance of cognitive processes in coping and therefore suggestions for cognitive intervention. Meaning-making and coping require further in-depth exploration.
INTRODUCTION

Overview
Each year 130,000 people in England and Wales will experience a first stroke (The Stroke Association, 2004). Stroke has a sudden onset and may result in long-term disability with far-reaching physical, psychological and social consequences for the lives of affected individuals and their families (Halligan & Cockburn, 1993; Barker & Mullooly, 1997). It also has enormous implications for health and social care services and is a key area for action in the National Service Framework (Department of Health, 2001). However historically much of the stroke literature has focused on short-term functional outcomes and relatively fewer studies have explored stroke experiences from the perspectives of stroke-survivors themselves. Areas particularly under-researched include how stroke-survivors cope with and make sense of stroke-related life-changes and experiences, although investigation of these areas is likely to contribute to our understanding of the psycho-social aspects of rehabilitation, recovery and adjustment. After an introduction to the area of stroke and historical research approaches, relevant findings from existing studies investigating the impact of stroke, post-stroke journey, coping and personal meaning are outlined. This is followed by identification of outstanding areas of related inquiry and the rationale for the current research.

Description Of Stroke
The medical term for stroke is ‘cerebrovascular accident’, commonly abbreviated to CVA. “'Cerebro' refers to the brain and 'vascular' refers to the blood supply. Thus, a stroke ... means that there has been damage to the blood supply of the brain.” (Page 1; King, 1990). It is defined as a sudden neurological disorder that lasts more than 24 hours (European Stroke Initiative, 2003). There are two main types of stroke. Ischaemic stroke is the most common and happens when a blood clot blocks an artery carrying blood to the brain and areas of brain cells subsequently die from lack of oxygen. The second most common type, haemorrhagic stroke, occurs when a blood vessel bursts and blood leaks in or around the brain (Schofield-Bronstein, Popovic & Stewart-Amidel, 1991). Stroke risk factors include hypertension, diabetes, substance abuse, alcohol consumption and smoking (Schofield-Bronstein, et al., 1991).

Of the 130,000 people in England and Wales who experience a first stroke each year, one in ten are under the age of 55 years (The Stroke Association, 2004). Incidence rises with age from 2.0 per 1000 for people aged 55-64 years, to, 20 per 1000 for people aged over 85 years
Major Research Project

(Office of Health, 2001). It is the third highest cause of death, with 35-40% of those affected dying within the first month. It is also the single largest cause of major disability in the UK (Royal College of Physicians, 2001; cited-in Cowdell & Garrett, 2003). Approximately 300,000 people live with the effects of stroke (Barton, Goudie & Scott, 2003), 30-50% of whom have a variable but permanent degree of chronic disability and handicap (Halligan & Cockburn 1993).

The acute onset of stroke brings about sudden cognitive, emotional and behavioural changes. Effects vary in severity but may include paralysis or weakness in legs and arms, confusion, memory problems, visual impairment, loss of sensation or awareness along one side of the body, and difficulty swallowing and communicating with others (Clarke, 2003). The worst effects are seen during the first 24 hours (King, 1990), followed by rapid initial improvement that gradually slows into a steady course of recovery. Current understanding suggests that the bulk of recovery in physical self-care occurs in the first six months and is most rapid over the first three months, although almost 50% of those who are very disabled continue to show improvements between six and twelve months (Ebrahim & Harwood, 1999). However it seems that variable patterns of recovery are documented, and may relate to differences in patient-group, criteria used to define independence, and the timing of observations.

Emotional Impact Of Stroke

Surveys demonstrate that a considerable proportion of stroke-survivors experience distressing emotional responses following a stroke. These may arise directly from the brain injury itself (Astrom, Adolfsson & Asplund, 1993), or more indirectly through psychological and social mechanisms such as distress associated with a severe life event, on-going disability and life changes (Morrison, Johnston & Mac Walter, 2000). Depression, anxiety and suicidal thoughts are most common (Nilsson, Jansson & Norberg, 1999). Prevalence figures for post-stroke depression may vary due to diagnostic difficulties and different sampling and measurement procedures. Nevertheless 10-25% of stroke-survivors have been found to experience major depression\(^1\) (Astrom et al., 1993), 10-40% minor depression\(^2\) (Morris, Robinson & Raphael, 1990) and 40% anxiety (Barton et al., 2003). Anxiety and depression often co-exist (Astrom, 1996) and some studies suggest that initial levels are not significantly lower at 3-5 years post-stroke (Astrom, 1996; Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell & Beech, 1996).

\(^1\) DSM-III criteria used
\(^2\) DSM-III criteria used
Some stroke-survivors may also experience hyper-emotionalism (Price, 1990), a condition with socially disabling effects (Calvert, Knapp & House, 1998).

Research Context

All in all, stroke is likely to be associated with great physical, psychological and social cost for affected individuals and their families, as well as financial costs for health and social services (Barker & Mullooly 1997). However historically the main body of stroke literature has focused on physical recovery to the relative neglect of psycho-social aspects (Ebrahim & Harwood, 1999). Such research had been dominated by surveys and short-term, quantitative outcome measures (Dowswell, Lawler, Dowswell, Young, Foster & Hearn, 2000) with an emphasis on diagnosis, prevention and treatment (Alaszewski, Alaszewski, Potter, Penhale & Billings, 2003). Recovery and outcomes were typically defined and measured in terms of physical and task-oriented improvement (Ellis-Hill & Horn, 2000), mobility and independence in self-care (Hafsteinsdottir & Grypdonck, 1997).

The past emphasis on physical recovery may have reflected the predominance of the medical model within rehabilitation. However there has been a recent shift towards paying greater attention to the psycho-social aspects of health and illness, and more specifically of stroke. Increasing numbers of both quantitative and qualitative studies have taken a wider perspective to exploring the aftermath of, and recovery from, stroke; some have explored the viewpoint of stroke-survivors themselves. These studies have used a wide-range of data collection methods including traditional face-to-face interviews, self-report questionnaires, retrospective analysis of published accounts (Easton, 1999), focus group interviews (Aleszweksi et al., 2003) and narrative accounts of photographs (Haggstrom, Axelsson & Norberg, 1994). Analytic approaches have included grounded theory (Folden, 1994), inductive analysis (Easton, 1999), phenomenological-hermeneutic analysis (Haggstrom et al., 1994; Nilsson, Janssen & Norberg, 1997, 1999; Kirkevold, 2002), content analysis (Cox, Dooley, Liston & Miller, 1998) and the repertory grid (Skelly, 2002). An extensive literature search was carried out however relevant studies were mostly identified through Nursing databases (e.g. CINAHL, BNI) and the bibliographies of subsequently identified papers. Few studies were cited in psychology-related research databases or published within psychology-related journals. Search terms included ‘Coping’, ‘Adaptation’, ‘Adjustment’, ‘Personal meaning’, ‘Life after stroke’ and ‘Experiences of stroke’. Additional background information was gained through internet resources and accounts by patient support groups.
Review Of Existing Research Findings

Findings from studies exploring the impact of stroke and post-stroke coping are described and critiqued in order to set the scene for the present study’s rationale.

‘The Early Days’

Interviews conducted during or looking back over the first six months after stroke identified dominant themes of shock, fear, loneliness, uncertainty, questioning and loss. Doolittle (1992) conducted serial interviews with thirteen lacunar stroke-survivors between 72 hours to six months post-stroke. The earlier interviews emphasised participants’ sudden confrontation with a immobile, passive, objectified body that required purposeful effort to control. ‘Struggle’ emerged as a dominant theme in Nilsson et al.’s (1999) phenomenological-hermeneutic analysis of interviews occurring three months post-stroke. This related to understanding what losses would be permanent, restoring self-image and coping with wide-ranging emotions. Many accounts describe a constant state of fear; fear of setbacks, falls, others’ reactions, further strokes and worsening disability (Doolittle, 1992; Folden, 1994; Cox et al., 1998; Alaszewski et al., 2003). Becker and Kaufman (1995; cited in Kirkevold, 2002) found that returning home from hospital was a significant milestone as survivors were faced with the realisation that they could no longer live life as before. Published accounts commonly share a discourse of ‘shattered lives’ and ‘biographical disruption’ that describes how stroke interrupts an expected life course and subsequently undermines sense of self-identity, assumptions and coherence, and creates an uncertain and unpredictable future (Pound, Gompertz & Ebrahim, 1998b; Ellis-Hill & Horn, 2000).

‘The Later Days’

Descriptive accounts and responses to open-ended questions and structured questionnaires typically show enduring changes at six-months or more post-stroke. At ten months post-stroke survivors have reported restrictions in housework, leisure activities, walking, talking, washing/bathing, relationships and confusion/memory problems (Pound et al., 1998a). Others have spoken of changes, such as profound fatigue, loss of confidence and fear, that are invisible to others yet present significant obstacles to regaining independence (Alaszewski et al., 2003). Still others talk of difficulty accepting continued and relatively permanent disability at 13-16 months post-stroke and uncertainty about how much more recovery might be made (Dowswell et al., 2000).
Major Research Project

Studies using the Head Injury Semantic Differential Scale and repertory grid technique identified significant and often negative changes in self-concept at 1-2 years post-stroke (Ellis-Hill & Horn, 2000; Skelly, 2002). However it seems unclear as to how much body changes and functioning contribute to negative self-concept since Ellis-Hill and Horn (2000) did not find a direct link between physical ability and self-concept, yet qualitative accounts described associations between these (Alaszewski et al., 2003). However Keppel and Crowe (2000) found that measures of body image were the most significantly reliable predictor of self-esteem. Pound et al. (1998a) summarised their accounts’ emphasis on the body as a “tangible, corporeal angst”. Indeed qualitative accounts have attributed lost confidence, frustration, altered body image and self-identity, quality of life, and changed social and family relationships to physical changes and functioning (Alaszewski et al., 2003; Clarke, 2003). Nilsson et al. (1999) conceptualised body changes as daily symbols or reminders of human frailty. However others have proposed how social changes may result from discomfort or shame with their new disabled state and changed self-identity, and the desire to avoid burdening others (Dowswell et al., 2000). Hafsteinsdottir and Grypdonck (1997) proposed that reliance on others for basic needs may change social interactions and lifestyle, and ultimately lead to lack of social control. Responses to open-ended questions revealed survivors’ utter frustration with communication difficulties and relying on others for basic needs and activities up to six years post-stroke (Mumma, 1986).

More positively, a small number of papers provided exceptions to the dominant discourse of ‘stroke as a crisis’. Pound et al. (1998b) for instance described how only two out of forty participants described “the idea of a happy ‘before’ and tragic ‘after’” (Page 495); the remainder minimised the stroke’s effects. The authors suggested that stroke may be accommodated or normalised within the context of already ‘hard-earned’ East End lives (Page 499) or normalised as expected within old age. In another report of the same sample, participants described how despite changes and compromises in their intimate relationships, these had not suffered significantly (Pound et al., 1998a). Cox et al. (1998) described positive relationship changes such as appreciating time together and realising the importance of family.

*Stroke As A ‘Bereavement’ And ‘Journey’*

Relatively few studies ground descriptive accounts of post-stroke life within theoretical frameworks (Dowswell et al., 2000). Among those that have, some have likened post-stroke emotional adjustment to that of grieving following bereavement (Wilkinson, 1995; Cited in 193
Barton et al. 2003) and have suggested phases of characteristic emotional responses and tasks to work through. Consistent with this, loss was a central theme for stroke-survivors up to six years post-stroke: Loss of activities, abilities and independence (Mumma, 1986).

However recovery has more commonly been conceptualised as a journey (‘illness trajectory’) with different stages characterised by specific emotional responses, tasks and challenges. This framework supposes that people pass through a series of chronological stages, i.e. a linear model. Kirkevold’s (2002) serial interviews with nine stroke-survivors identified four phases within the first year of stroke. These were ‘Acute onset’ characterised by surprise and suspense, ‘In-hospital rehabilitation’ (hard physical work, realising the impact of the stroke and making sense of it), ‘Post-discharge’ (psychosocial and practical adjustment; experimentation) and ‘Semi-stable’ (going on with life, continuing improvement and adjustment, integrating stroke into life and minimising its effects). Easton (1999) carried out a retrospective inductive analysis of published auto-biographical accounts of 15 stroke-survivors and identified six consecutive stages (‘Agonising’, ‘Fantasising’, ‘Realising’, ‘Blending’, ‘Framing’ and ‘Owning’). ‘Illness trajectory’ studies provide an eloquent and plausible perspective to recovery; they vividly describe the emotional responses and challenges faced at different times post-stroke. They highlight the long-term and bio-psycho-social nature of recovery (and corresponding implications for services). Some accounts, like Easton (1999), also provide encouraging descriptions of acceptance and adaptation. However they inform less about how stages are moved through, what promotes or hinders reaching an ‘adaptive’ end-point or what happens if survivors become ‘stuck’ at a particular stage.

Adaptation And Recovery

Sarafino (1994) defined ‘adaptation’ as the “process of making changes in order to adjust constructively to life’s circumstances” (Page 407). The stroke literature has indicated this by various measures of functional ability, psychological responses and social functioning. Stroke-survivors have defined recovery as a return to their pre-stroke life (Doolittle, 1992) or creating continuity between the ‘before’ and ‘after’ (Easton, 1999; Becker and Kaufman, 1995; cited in Kirkevold, 2002). Some have measured this against previous abilities, activities and roles (Dowswell et al., 2000) or success meeting self-defined goals (Hafsteinsdottir & Grypdonck, 1997; Alaszewski et al., 2003). Authors have concluded that adaptation includes adjusting to unspecified and unknown progress (Dowswell et al., 2000) or, confronting existential inevitabilities such as human frailty and death (Nilsson et al., 1999). Notwithstanding the ultimate outcome, personal accounts suggest that the bulk of
recovery work starts once stroke-survivors return home (Pound, Gompertz & Ebrahim, 1999; Burton, 2000).

**Indirect Relationship Between Physical Disability And Psycho-Social Adjustment**

There are complex, and as yet poorly understood, relationships between the physical, psychological and social facets of stroke recovery (Dowswell et al., 2000). It is known that psycho-social well-being is not solely determined by the degree of physical disability (Barton et al., 2003; Wilson & Cleary, 1995; cited-in Clarke, 2003). However psychological responses may jeopardise or enhance physical recovery (Chemerinski, Robinson and Kosier, 2001), quality of life (Carod-Artal, Egido, Gonzalez & Varela de Seijas, 2000) and social adjustment (Morris, Raphael & Robinson, 1992; cited-in Dowswell et al., 2000). Similarly availability, quality and perceived social support is correlated with depression (Astrom et al., 1993; Kneebone & Dunmore, 2000), recovery speed (Glass, Matacher, Belyea & Feussner, 1993) and adjustment to physical disability (Evans & Northwood, 1983; cited-in Glass et al., 1993). However many stroke-survivors experience changes in the quality of their social life (Schulz & Tompkins, 1990; cited-in Glass et al., 1993) and as previously outlined, considerable emotional responses.

**Coping With Stroke**

While there is an increasing body of literature describing the many challenges faced by stroke-survivors, MedLine and PsycLit database searches found only a comparatively limited number of articles considering coping with stroke from the perspective of survivors themselves. Much more is written from the perspectives of researchers, professional care-providers and family care-givers (Cox et al., 1998; Lyon, 2002). While it is beyond the scope of the present study to discuss this body of literature, speculative reasons for the comparative lack of work from the perspective of the stroke-survivors can be offered. It may reflect an assumption that little can be done to help survivors cope with difficult emotions (Lyon, 2002), practical barriers of interviewing stroke-survivors themselves due to communication or cognitive difficulties, or simply that looking at the participant's perspective represents a relatively new research phenomena in medical contexts.

**Models Of Coping**

Lazarus and Folkman (1984) put forward the most commonly used definition of coping. They viewed coping as a psychological mechanism for managing stress (Newman, 1990) and defined coping as "constantly changing cognitive and behavioural efforts to manage specific
external and/or internal demands that are appraised as taxing or exceeding the resources of the person" (Lazarus & Folkman, 1984; Page 141). Broadly speaking any behaviour or cognition, ranging from conscious and overt behaviours to unconscious intrapsychic processes, that take place in relation to a disease or illness can be considered an attempt to cope (Newman, 1990; Kahn, 1995). It may be considered both a personality style and/or a process that differs according to the specific stressor (Lazarus, 1993).

The transactional model of stress (Lazarus, 1966) and self-regulatory model (Levanthal, Nerenz & Steele, 1984) provide frameworks by which to understand coping. The former model proposes that stress is not inherent in the event itself but rather results from appraisals of the event ('primary appraisal') and personal resources to cope with perceived demands ('secondary appraisal'; Lazarus, 1966). It might however be argued that some events are objectively stressful. Appraisals subsequently determine choice and execution of coping (Carver, Scheier & Weintraub, 1989). The self-regulatory model proposes that individuals develop beliefs about the identity, cause, timeline, consequences, cure/control of their illness that guide emotional response and coping behaviours. These 'illness representations' are constantly re-evaluated and updated in the light of feedback from coping behaviours (Levanthal, Nerenz & Steele, 1984). Both models consider cognition (or meaning-making) as the key mediator of emotional response and adaptation following an illness (Lazarus & Folkman, 1984; Levanthal, Nerenz & Steele, 1984; Newman, 1990).

Coping is commonly categorised into problem-focused and emotion-focused strategies (Folkman & Lazarus, 1984). Problem-focused coping seeks to manage the external or internal problem. Strategies include problem-solving, direct action or reappraisal to change internal aspects. Emotion-focused strategies regulate emotional responses provoked by the situation. These include venting emotions, seeking social support or positive reappraisal of the situation. Seeking social support falls within both problem-focused and emotion-focused categories (Folkman & Lazarus, 1984). Another common categorisation classifies coping behaviours into avoidant and active (or approach/attention/non-avoidant) strategies (Suls & Fletcher, 1985, cited-in Newman, 1990). Avoidant coping includes strategies such as wishful thinking, detachment, denial, distraction, repression and suppression (Newman, 1990). Coping may be considered successful where it resolves affect associated with threat and loss, preserves physical integrity, helps maintain relationships and life-roles and positive self-concept (Lazarus, 1993; Sarafino, 1994). Unsuccessful coping may result in reduced levels of
psychological well-being, quality of life, social participation and health, together with high levels of emotions such as anxiety and depression.

**Investigations Of Coping**

Some studies have evaluated the effectiveness of different coping strategies through administering questionnaire measures of coping and adaptation. These have demonstrated how post-stroke depression and anxiety are associated with greater use of avoidance coping strategies and less frequent use of active cognitive coping (Wade, Legh-Smith & Hewer, 1987; Boynton De Sepulveda & Chang, 1994; cited-in King, Shade-Zeldow, Carlson, Feldman & Philip, 2002; Gillespie, 1997). While active coping was also identified as the most significant predictor of functional outcome three years post-stroke (Elmstahl, Sommer & Hagberg, 1996), Herrmann, Curio, Petz, Synowitz, Wagner, Bartels and Wallesch (2000; cited in King et al., 2002) found that stroke-survivors used this less than participants with other brain disorders. King et al., (2002) administered questionnaires on four occasions spanning from acute rehabilitation to two years post-stroke. They found that different coping strategies were useful at different time-points. Less frequent finding meaning and greater avoidance coping were significant predictors of early post-stroke depression, but not two years later. ‘Belonging support’ (being meaningfully connected to others) remained significantly predictive of depression in cross-sectional and prospective analyses. In contrast, Herrmann, Britz, Bartels and Wallesch (1995) found that coping styles remained stable over the first year after stroke.

Such questionnaire studies have been useful in showing the effectiveness of different coping strategies, however thus far, few have incorporated a longitudinal perspective to coping. Furthermore they at present seem limited in their ability to explain what makes particular strategies helpful or not helpful, or which strategy is useful for which problem area. However a small number of qualitative studies have begun to add a more descriptive, explanatory dimension to this area. These have allowed participants to describe coping from their own perspective and subsequently identified salient examples of problem-focused and emotion-focused coping. While this has begun to accumulate greater knowledge of how particular strategies are effective in managing post-stroke demands, further exploration would be valuable.

Existing qualitative studies have typically explored coping with overall life changes. These conducted semi-structured interviews and focus group interviews with 39 survivors (aged 63-
93) up to a year post-stroke (Cox et al., 1998), 40 participants (aged 40-87) ten months post-stroke (Pound et al., 1999) and 31 participants (aged 38-89) 6-18 months post-stroke (Alaszewski et al., 2003). While the method of content analysis was useful in describing and quantifying categories of coping, it provided less interpretation or explanation of elicited categories (Cox et al., 1998; Alaszewski et al., 2003). Additional accounts of coping were also generated in Clarke’s (2003) study of well-being among eight stroke-survivors aged 60-89. However the wide variation in time since stroke (eight months to nine years) presented difficulties in locating strategies within a particular phase of recovery.

Stroke-survivors do not passively accept changes (Pound et al., 1999) but rather develop numerous creative ways to manage the challenges resulting from stroke. Positive attitude, persistence, determination, patience and acceptance (Cox et al., 1998; Alaszewski et al., 2003) have featured as important factors in a number of studies. Unfortunately studies do not explore how acceptance is developed. Bays (2001) explored hope among stroke-survivors and found it to be of “life-sustaining value” (Page 26), strengthened or weakened by family connectedness, spiritual connectedness and goal achievement. Cognitive strategies included participants thinking of ways in which they were lucky (Cox et al., 1998) or comparing themselves with others who were more severely affected (Alaszewski et al., 2003), using self-talk to maintain day-to-day motivation and focusing attention on others rather than themselves. Other strategies included using humour (Cox et al., 1998) spiritual and religious resources (Clarke, 2003), faith and prayer (Cox et al., 1998), pacing activities and planning ahead (Alaszewski et al., 2003). Some found ways to ‘conceal’ their disabilities in order to protect their self-esteem (Pound et al., 1999).

Setting short-term and long-term goals was an important means of getting back to a ‘normal’ life. Alaszewski et al. (2003) usefully collated participants’ practical strategies to achieve goals inside and outside the home. Problem-focused strategies involved staying active, re-learning previous abilities, reorganising home environments or routines (Pound et al., 1999) and finding new ways to do tasks through using devices or taking things more slowly (Cox et al., 1998; Pound et al., 1999). Others described applying previous life skills to new problems, modifying salient pre-stroke roles (Clarke, 2003) and using exercise to ‘keep going’, provide a structure to the day and keep busy (Pound et al., 1999). Mobilising emotional and instrumental support was a key theme for many participants (Pound et al., 1999; Clarke, 2003); informal and formal supports played a complementary role (Pound et al., 1999). Support allowed participants to continue salient pre-stroke roles (Clarke, 2003), live alone in
their own homes and do daily self-care tasks (Pound et al., 1999). Cox et al. (1998) explored how participants learned to accept their new status as a ‘care-receiver’ through reciprocating care-giver’s assistance with economic and emotional support (‘reciprocity’).

Perry and McLaren (2003) were rare in providing a more in-depth analysis of coping and addressing a more specific area of difficulty. They used thematic analysis to explore eating disabilities among 113 stroke-survivors, six-months post-stroke. Two main themes of ‘Getting back to normal’ and ‘Getting by’ were identified. ‘Getting back to normal’ reflected striving for a previously experienced or newly defined ‘normal life’. This was expressed through sub-themes of ‘fighting’ the effects of stroke and denying or ‘accommodating’ impairments. ‘Getting by’ reflected adapting activities and lifestyle to accommodate the stroke’s effects and included ‘secondary gains’ or antagonistic ‘resignation’.

Coping may also be considered in terms of processes of perceived control. Individuals may attempt to gain control through changing the environment to meet their needs (Primary control) or where the environment cannot be changed, through bringing themselves into line with the environment (Secondary control). Causal attributions of predictive, illusory, vicarious and interpretive control may be involved in secondary control processes. Interpretive control allows control over, or acceptance of, an unchangeable situation through understanding and finding meaning in the situation (Rothbaum, Weisz & Snyder, 1982). Watson (1986) considers that “suffering inevitably involves meaning” (Page 179). Folkman (1997) considers ‘finding meaning’ as a coping strategy used to reduce the threat of a situation and enhance well-being.

Thompson (1991) provided one specific investigation of finding personal meaning after stroke. She interviewed forty stroke-survivors at an average of nine months post-stroke, 82% of whom were first-time strokes. Participants were asked to rate how much they had found meaning in their experience of a stroke on a five-point Likert scale. Ratings of ‘finding meaning’ correlated with better adjustment as measured by the Geriatric Depression Scale and a scale measuring meaningfulness in life. Thompson (1991) also found that different types of attributions were associated with different outcomes. Finding a cause for the stroke (‘causal attribution’) was associated with better adjustment which Thompson (1991) understood as an attempt to exert control and avoid a recurrence, and as indicating some re-evaluation and active learning. On the other hand, seeking to explain ‘Why me?’ (‘selective incidence’) was associated with poorer adjustment. Thompson (1991) suggested that this implied an upward
comparison with those unaffected by stroke and a view of being unfairly treated and of the self as a helpless victim. While the sample ranged widely in terms of time post-stroke (1-60 months), the findings provided some evidence of the impact of different ways of making sense of the stroke. Many authors have since referred to the importance of the stroke’s personal meaning in determining adaptation (Dowswell et al., 2000; Ellis-Hill & Horn, 2000; Skelly, 2002) but few have explored this further.

Overview Of Existing Research
The existing body of literature has greatly enhanced our understanding of the emotional responses and challenges that stroke-survivors experience following a stroke. Questionnaire responses and personal accounts richly demonstrate the wide-ranging and often devastating impact of a stroke. The experience of stroke extends significantly beyond physical disability and may impact upon individuals’ sense of well-being, self-esteem, self-identity, quality of life, social roles as well as repercussions for family and social relationships, work and leisure. Hence the stroke-survivor may be faced with major adjustments and challenges that may differ over time since stroke onset. The close inter-relationships between physical, psychological and social factors (Alaszewski et al., 2003) requires that rehabilitation programs move away from a predominantly functional approach and integrate psycho-social aspects (Anderson, 1993; Hafsteinsdottir & Grypdonck, 1997; Dowswell et al., 2000; Kirkevold, 2002) with a longer-term support strategy. The scant literature on coping offers some evidence of the benefit of active coping strategies for post-stroke adaptation and describes some ways in which categories of coping manifest and help survivors manage post-stroke demands. Specific recommendations include services developing interventions to promote on-going belonging support and active cognitive focused coping during at least, the early post-stroke period (King et al., 2002).

Outstanding Areas Of Inquiry
There continues to be a need to better understand the complexities of the post-stroke adjustment process (Kirkevold, 2002) particularly over the longer-term (Alaszewski, et al., 2003). Contemporary authors continue to call for additional person-centred studies in order to understand experiences from the perspectives of stroke-survivors themselves (Alaszewski et al., 2003), in particular the personal meaning of stroke (Dowswell et al., 2000; Ellis-Hill & Horn, 2000; Skelly, 2002) and coping (Cox et al., 1998; Alaszewski et al., 2003). Existing studies provide interesting descriptions of coping, however these are often cross-sectional and there are only a small number of studies from which to draw conclusions. While both
quantitative and qualitative approaches have been used, studies have more frequently used questionnaire measures to assess the effectiveness of different coping strategies. These usefully identify coping outcomes but say less about the process of coping and how this is promoted or hindered. Since coping appears to be a relatively under-researched area, some authors, like Pound et al. (1998a), are of the opinion that qualitative approaches may allow richer exploration, particularly of the process of coping, and uncover inter-relationships with other psycho-social variables. However thus far, qualitative studies have typically categorised and described coping, with few having taken a more interpretative approach to analysis. Reports may therefore have lacked more detailed, in-depth analysis of accounts, with less consideration of the personal thoughts, beliefs and meanings mediating the experience of stroke and coping processes. Furthermore, studies have rarely grounded findings in psychological theory (Dowswell et al., 2000) nor discussed their clinical implications to help inform service development. Social-cognition models postulate that appraisal, together with coping, might partly determine adjustment, and authors in the stroke field have highlighted the importance of personal meaning. However such psychological processes have rarely been systematically explored and are at best, alluded to within overall accounts of stroke. Studies that analyse coping and meaning-making using interpretative and theoretical perspectives, may help contribute to our understanding of psychological recovery and how this might be best supported.

The Present Research

The present study was designed to explore some of the less well-researched areas of psychological adjustment after stroke and particularly the ways that stroke-survivors manage, make sense of and attribute meaning to their experiences. It did not aim to test hypotheses but rather sought to add a psychological and theoretical perspective to the experience and management of stroke.

It was hoped that findings from the current investigation might add to the existing knowledge base and help bring a richer understanding of stroke-survivors' experiences, identifying psycho-social needs, coping strategies and the process of adjustment. The research also complements National Service Framework aim to develop early and continuing long-term person-centred support for stroke-survivors (Standards Two and Five, Department of Health, 2001). Gaining personal accounts also fits with the National Service Frameworks' call for greater service-user involvement. Further, it is hoped that findings might add to resources for self-help groups and to literature, for others who may experience a stroke or those who have
not yet found positive ways to cope with their stroke (Cox et al. 1998). It is also hoped the findings might promote understanding of survivors’ perspectives among families and professionals, and where possible, contribute towards developing appropriate support and psychological care. From a research perspective, qualitative data can sometimes be useful in identifying salient experiences that can then help ground or inform the development of more structured questionnaires (Pound et al., 1998a).

Methodology

Both qualitative and quantitative approaches have much to contribute to our understanding and some authors advocate combining approaches (for example, Clarke, 2003). However the exploratory nature of the study together with its focus on personal experiences and meaning-making indicated the use of qualitative methodology (Willig, 2001). It was hoped that semi-structured interviews would allow participants to pursue the salient aspects of their own experiences and allow for exploration of thoughts, feelings, interpretations and links between concepts. Since the timeframe did not allow for a longitudinal design, the study aimed to gain personal accounts through one-off interviews with stroke-survivors who had attended NHS services in the UK.

Areas Of Exploration

1. What changes do stroke-survivors face following a first stroke?
2. How do stroke-survivors attempt to make sense of, or find meaning in, their experiences?
3. What behavioural and psychological strategies are used to cope with stroke-related changes?

METHOD

Ethical Approval

Before commencing this study, ethical approval was sought and granted by the local NHS Trust and University of Surrey Ethics Committees (Appendix One). Approval was also granted by the local PCT Research and Development Committee (Appendix Two) and recruitment sites. Protocol amendments were later agreed by the ethical committee (Appendix Three) to overcome difficulties obtaining sufficient interviews due to clinic cancellation at the original study site following staff sickness. Agreed changes comprised of extending (a) exclusion criteria, (b) data collection to a second location within the same NHS trust and (c) interviews to participants’ own homes (discussed further in the Method and Discussion).
Design
This was a retrospective semi-structured interview study.

The Sample
Inclusion Criteria
IPA employs purposive sampling and is concerned with selecting a homogenous sample for whom the research question is relevant (Willig, 2001). Therefore in order to obtain a broadly homogenous sample in terms of life-stage, type of and time after stroke, patients were invited to participate if they were over the age of 65 years and had experienced a first-time right-sided stroke six months previously. This timeframe was chosen to allow time for participants to have experienced and begun to reflect upon changes, while also not being too far in the past to inhibit recall (or significantly suffer from reconstruction). For ethical reasons it was also agreed that suitable participants should be able to give informed consent. In order that patients could participate in an interview, they were considered eligible if they lacked expressive or receptive language difficulties, were able to concentrate for a 60-minute face-to-face interview and were deemed appropriate by the Clinic Convenor.

However due to cancellation of Clinic A (initially over January and February 2004, and later from mid-March to July 2004), the recruitment criteria were amended to allow patients at a second location (Site B) to be invited to participate in the study. This was to maximise participant numbers in order to meet the study timeframe. Criteria were subsequently amended to a) include diagnoses of left-sided stroke, b) include patients aged 50 years and over and c) increase the interval after stroke to include patients being reviewed up to two years post-stroke. While the revised inclusion criteria were broader than originally intended, the sampling remained relevant to the research inquiry.

The first two participants fulfilled the original criteria, the remaining participants met the amended criteria.

Recruitment
Participants were recruited from two specialist Review Clinics within the same NHS Trust. Patients had previously received in-patient treatment from the local specialist Stroke Units and were then offered out-patient review appointments at six-monthly intervals following stroke-onset.
Permission to review medical notes in order to identify and approach suitable participants was gained from the Consultant Physicians responsible for their care. Patient notes were screened by the Nurse Consultant coordinating the Stroke Review Clinic (Site A) and the Consultant Clinical Psychologist or Assistant Psychologist at the Disability Clinic (Site B). The Nurse Consultant at Site A and the Medical Secretary at Site B forwarded with the clinic appointment letter, a letter inviting patients to participate in the research (Appendix Four) and Participant Information Sheet (Appendix Five). When confirming their review appointment, patients were also asked to show their interest in participating in the research – procedures to indicate interest differed at each study site in keeping with current clinic procedures:

1. Initially, participants at Site A were asked to indicate their consent when telephoning to confirm their appointment. When the clinic was later re-instated, participants were asked to confirm via a ‘tear-off’ response slip returned to the Assistant Psychologist (“I AM / AM NOT interested in being interviewed as part of the ‘Life After Stroke’ research study”) (Appendix Six).

2. Participants at Site B were asked to confirm via a ‘tear-off’ response slip added to the existing clinic appointment letter and returned to the Medical Secretary (Appendix Six).

Participation Rate

Of the twenty-one participants who were invited to take part in the study, a total of eleven interviews were conducted. Interviews were conducted over the period of October 2003 to August 2004.

Site A

Five out of eight eligible participants agreed to be interviewed (62.5%). Both eligible participants consented during October and December 2003 (P1 and P2) and two weeks of March 2004 (P4 and P5); One out of four agreed to take part during August 2004 (P11); another did not wish to participate and a further two did not respond to mailed invitations.

Site B

Between March and August 2004, six out of eleven possible participants (54.5%) agreed to take part (P3, P6-P10; P9 was later excluded due to ineligibility). Of the five that did not participate in the study, one cancelled their review appointment, one telephoned to say she did
not wish to take part and another three did not respond to invitations. Appointments were
often scheduled for early morning.

Data Collection
The present study wished to explore and gain an insight into the personal experiences of
stroke-survivors after a stroke. Therefore semi-structured interviews were selected since
these allow participants "to raise their own concerns and priorities" (Page 339; Pound et al.,
1998a) rather than have questions imposed from a researcher. Semi-structured interviews
also allow greater flexibility than structured interviews to explore and follow-up on
interesting issues and gain a fuller understanding of participants’ experiences (Smith &
Osborn, 2003). In the present study, an interview guide was developed from a number of key
open-ended questions and prompts based around the main areas of inquiry (Willig, 2001;
Appendix Seven). Questions were informed by related research and discussed with experts in
the stroke-field and in qualitative methodology. However the guide did not dictate the
interview areas but rather acted as a guide, with the interviewer following up on areas that
arose spontaneously. The interview guide did not substantially change following the first two
pilot interviews.

Key interview areas included in the interview guide were as follow:

1. Set the scene – recall of stroke-onset and, hospital/discharge
   experiences
2. Life changes since stroke (positive/negative) and impact on self,
   relationships and lifestyle
3. Personal meaning given to stroke experiences and subsequent
   changes – ways that participants think and feel about changes, ideas
   about causes, personal meaning found in their experiences
4. Process of adjusting to and coping with stroke-related changes – ways
   that participants learned to cope with changes

Background information was obtained from the medical notes so that experiences could be
placed within a socio-demographic and medical context (Appendix Eight). The researcher
kept a research diary recording thoughts about the interview process, themes and links
between themes.
Conducting The Interviews

Written informed consent was obtained prior to interviewing (*Appendix Nine*). This entailed a full explanation of the study, participants’ right to withdraw at any time and the limits of confidentiality such that if serious concerns arose, these would be discussed during the interview and passed onto relevant services. Concerns arose during two interviews (P4 and P11) and were passed onto the multi-disciplinary review team; information regarding psychological support was forwarded to P7.

Consenting participants were interviewed once; eight interviews took place prior to their review appointment and two in participants’ own home (P10 and P11; due to further clinic cancellation). The interviewer, who was of the same ethnic origin as participants, had not previously met participants and made every effort to establish a rapport and help them feel at ease and relaxed.

Interviews lasted up to 70 minutes. They were tape-recorded and transcribed verbatim for analysis and included non-verbal expressions such as pauses, silences and laughter (See *Appendix Ten* for a transcript selected for its richness). Recordings were stored in a secure place and destroyed following transcription; transcripts were anonymised to ensure confidentiality and pseudonyms used to protect their anonymity. All identifying material was kept secure and only accessed by the trainee. Participants’ G.P.’s were sent a Participant Information Sheet and a letter informing of their study participation (*Appendix Eleven*).

Feedback To Participants

All participants will be sent a letter thanking them for their participation together with a summary of the main findings and conclusions. Participants will also be able to contact the researcher to discuss findings or request a full research report. Participants’ G.P.’s, the Specialist Stroke wards and Clinics will also be sent summaries.

Analytic Strategy

The ten transcripts were analysed using Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith, Flowers & Osborn, 1997; Smith, Jarman & Osborn, 1999; Willig, 2001). The two initial pilot interviews were included in the main study. An eleventh participant (P9) was excluded from the main analysis since she had been erroneously screened as eligible to participate. While admitted six-months previously for recurrence of stroke
symptoms, during the interview it became apparent that stroke onset had been thirteen years previously and that themes reflected transition over a longer period of time.

**Description Of IPA**

IPA is a qualitative analytic method. It offers a systematic method by which to analyse transcripts generated from semi-structured interviews. It takes an idiographic approach, such that the insights from intensive and detailed engagement with individual transcripts are integrated only in the later research stages (Willig, 2001). It is based on two theoretical epistemologies - phenomenology and symbolic interactionism (Smith, 1996). Phenomenology concerns itself with the individual’s personal perceptions and accounts of an object or event (versus attempts to obtain an objective statement). Symbolic interactionism is concerned with the meanings individuals attach to events. It recognises that meanings arise, and are made sense of, through a process of interpretation and, or social interaction (Smith, 1996). Hence as far as is possible, IPA is concerned with gaining an “insider’s perspective” (Conrad, 1987; cited-in Smith, 1996; Page 264) while also recognising that accounts are influenced by the researcher’s interaction and interpretative framework (i.e. values, beliefs and assumptions; Smith, 1996).

**Rationale For Using IPA**

Since IPA provides a systematic way to gain detailed accounts of participants’ experiences from their perspectives and to explore cognition and meaning-making (Smith, 1996; Coyle & Rafalin, 2000; Willig, 2001), this was selected for the current inquiry. Unlike other analytic methods such as Discourse Analysis, IPA shares the social-cognitive paradigm’s interest in cognition and acceptance of a chain of connection between account, cognition and psychological/ physical state (Smith, 1996). This opens up the possibility that a participant’s internal and external world may be explored through language (i.e. talk relates in some way to events and thoughts). IPA is therefore likely to be a valuable approach for health psychology research, and more specifically for the current inquiry, through its ability to allow detailed exploration of the participant’s views of an illness experience and relationships between cognition and behaviour (Smith, 1996). However in contrast to Grounded Theory, IPA importantly recognises the interviewer’s role and own interpretative framework in shaping the interview process and analysis (Smith 1996; Willig, 2001). Access to the participant’s view is “both dependent on, and complicated by, the researcher’s own conceptions” (Smith, 1996; Page 264). Hence any analysis is a product of the researcher’s interpretation of the participants’ experience (Willig, 2001).
Analytic Process

Individual transcripts were repeatedly read and key phrases, associations, connections, feelings and preliminary interpretations were noted in the left-hand margin of the transcript. This was followed up by further readings of individual transcripts to develop themes that both interpreted and summarised preliminary notes and captured the meaning represented in the text (noted in the right-hand margin). Where new themes emerged in subsequent transcripts, previous transcripts were re-read and checked for examples or dis-confirmations. Themes were compared across transcripts to identify those that were consistent across participants or particular to individuals. Themes were listed on a separate piece of paper and links identified to generate clusters of themes. Themes considered to be similar were combined. Finally, it was checked that themes were illustrated in the transcripts and that they were at a similar level of interpretation across all transcripts (Willig, 2001).

A table of major themes and sub-themes that were recurrent across and summarised all transcripts was then developed. Again links between themes and the transcripts were repeatedly checked (Willig, 2001). Themes were then ordered to "produce a logical and coherent research narrative" (Page 26; Coyle & Rafalin, 2000). While themes were generated from the data, some of these did reflect areas covered in the interview guide.

Researcher's Interpretative Framework

Analysis of this nature is shaped by the researchers' interpretative framework. The interviewer recognised how her personal experience of a close family member suffering a mild stroke as well as previous employment on a specialist Stroke Unit made her aware of the potentially wide-ranging psycho-social impact of stroke. This also stimulated her interest in exploring stroke experiences and how stroke-survivors made sense of and coped with these. While the researcher endeavoured to remain open and receptive throughout the research process, she recognised how prior educational and clinical experiences influenced the choice of theoretical frameworks that were used to frame interview questions and follow-up on participant responses and later to ground the findings. Experiences included an MSc in Health Psychology that focused on understanding aspects of health and illness using social-cognition models, and, a six-month specialist placement in psycho-oncology during which clinical supervision was from a predominantly cognitive-behavioural perspective (CBT). These experiences encouraged the researcher to understand chronic illness from social-cognition and CBT perspectives and also generated a belief that talk relates to cognition and, that cognition is meaningfully related to emotional states and coping behaviours. While not deliberately
excluded, other theoretical orientations such as psychoanalysis, humanism and existentialism were subsequently considered less.

**Evaluative Criteria**
Differences in the epistemological underpinnings make criteria traditionally used to evaluate quantitative research inappropriate for qualitative research. Small numbers of participants are interviewed for their special attributes rather than representativeness, outcomes may not be replicable or considered ‘objective’ due to the dynamic process between interviewer and participant as well as the interpretative framework of the researcher (Yardley, 2000). Hence some of the alternative evaluative criteria suggested by Elliot, Fischer and Rennie (1999) and Yardley (2000) were used for the present study:

1. *'Owning one's own perspective'*: The researcher hoped to show transparency by detailing the data collection and analytic process, and acknowledging the impact of her own experiences, values and beliefs on her interview style and interpretative analysis. This has been disclosed to help readers understand the researcher’s account.

2. *'Grounding in examples', 'Coherence' and 'Resonating with readers'*: All interpretations were illustrated by and ‘grounded in’ examples from transcripts so that readers could assess the meaningfulness and persuasiveness of the researcher’s interpretations (Coyle & Rafalin, 2000). It was hoped that themes were presented in a coherent story that resonated with readers to expand their understanding of the research area.

3. *'Providing credibility checks'*: Several methods of checks were conducted. The research supervisor independently generated themes for P3 and P4’s transcripts that were discussed in detail and checked against the researcher’s themes to provide credibility for her interpretations and ensure that themes were illustrated in the data. Themes generated from the first six transcripts were also discussed in detail with the research supervisor. Further checks were conducted through peer-group analysis and discussion of P3’s transcript, thereby enhancing confidence that themes were grounded in the data.

4. *'Commitment and rigour'*: The researcher engaged in an in-depth reading and re-reading of the transcripts. She became familiar with the research topic by reading
relevant material and drew upon her previous clinical and personal experiences with stroke-survivors.

ANALYSIS

Introduction To The ‘Analysis’
The ‘Analysis’ begins with a description of participants and their experiences of the stroke onset and aftermath, followed by an outline of the two super-ordinate themes and eleven sub-themes. Each of the super-ordinate and sub-themes are then described in turn, followed by a discussion of the ways in which participants expressed these. The ‘Analysis’ concludes by exploring tentative links between the main themes for two contrasting accounts.

The following conventions were used to display participant quotations:

<table>
<thead>
<tr>
<th>Alfred</th>
<th>Participant</th>
</tr>
</thead>
<tbody>
<tr>
<td>IVR</td>
<td>Refers to Interviewer</td>
</tr>
<tr>
<td>&quot;Text&quot;</td>
<td>Direct quotation</td>
</tr>
<tr>
<td>'Text'</td>
<td>Summary of participant’s words/ Indirect quotation</td>
</tr>
<tr>
<td>&quot;Text&quot; (in bold)</td>
<td>Indicates word emphasis</td>
</tr>
<tr>
<td>&quot;...&quot;</td>
<td>Omitted material</td>
</tr>
<tr>
<td>[text]</td>
<td>Text added by researcher to clarify meaning or add anonymity</td>
</tr>
<tr>
<td>(unintelligible)</td>
<td>Speech that could not be transcribed</td>
</tr>
</tbody>
</table>

Description Of Participants
The sample consisted of ten white British participants, five men and five women, aged 54-90 (mean=67.6; s.d.=11.5). Half the sample were under the age of 65. Five participants (50%) were married and living with their spouses, the remainder lived alone and were either widowed (2, 20%), divorced (2, 20%) or separated from their spouses (1, 10%). All participants had experienced a first-time stroke between 6-22 months previously (mean=10.1; s.d.=4.8) and had been living back at home for 2-18 months since discharge from hospital (mean=6.0; s.d.=4.6). Participants had experienced a range of strokes and subsequent physical, cognitive and emotional difficulties (See Table 1 for participant characteristics). At the time of their stroke, five were employed in a range of jobs (Lorry Driver, Taxi Driver, Secretary, Landscape Gardener and Auditor). Five were retired, formerly working as Civil Servants, Administrators and a Cook.
Setting The Scene

In order to set the scene for the interview, participants were asked to retrospectively recall the stroke onset and describe how life had since changed for them. While some recalled warning signs such as headaches and feeling unwell, others experienced sudden symptoms such as severe headaches, legs giving way, losing physical balance, and unconsciousness. Some used prior knowledge of stroke to make sense of these symptoms, others were diagnosed by medical professionals. Those that were unable to clearly recall the initial days talked about this as being “a bit vague” (Elsie); “a different world, a twilight zone” (Cliff). They relied on others’ accounts to make sense of this period. While later discussed in relation to the themes, many recalled the early days as a period of uncertainty and described feeling frightened, worried and anxious at realising a diagnosis of stroke.

Consistent with existing literature, participants described a range of physical, cognitive and emotional changes that resulted in an even wider range of personal consequences. Words like “standstill” (Frances) and “transformation” (Cliff) were used to describe their new situation. Physical changes like hemiplegia brought changed abilities for ‘doing’, ‘getting around’ and ‘looking after oneself’. This was meaningful for participants’ self-concept, sense of security, control and autonomy, and also continuation of pre-stroke roles, social relationships and leisure activities. Cognitive changes in memory, concentration and dysphasia also brought changes in self-concept, as well as abilities to communicate, and pursue social and leisure activities. Emotionalism triggered frustration and embarrassment; depression or hopelessness seemed detrimental for self-concept, quality of life, active coping and future hope. Several participants spoke of coping with ‘invisible’ effects, such as unpredictable and profound fatigue, loss of confidence, lost vision and altered body sensation. While some expressed predominantly sad and angry feelings at the time of their interview, participants more commonly expressed a range of emotions that included sadness, anger/frustration, worry/uncertainty, thankfulness, hope, ‘fighting spirit’ and acceptance. Three participants became tearful or angry when reliving their hospital experiences; one of whom found that memories were triggered by everyday reminders. It seemed that for many, the impact of the stroke had unfolded over time.
<table>
<thead>
<tr>
<th>Pseudo-nym</th>
<th>Age</th>
<th>Sex</th>
<th>Marital Status</th>
<th>Months since stroke</th>
<th>Type of stroke</th>
<th>Residual impairment &amp; stroke consequences</th>
<th>Living circumstances &amp; formal support</th>
<th>Present during interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>P1</td>
<td>74</td>
<td>Male</td>
<td>Married</td>
<td>6</td>
<td>Right-sided thalamic CVA</td>
<td>Left-sided paralysis (arm/hand), memory deficits &amp; some dysphasia. Walks with stick &amp; supervision (wheelchair outside)</td>
<td>Lives with wife in own house. PT &amp; OT</td>
<td>Wife</td>
</tr>
<tr>
<td>P2</td>
<td>90</td>
<td>Female</td>
<td>Widowed</td>
<td>6</td>
<td>Right CVA</td>
<td>Left-sided weakness (arm/hand). Incontinence. Walks with frame (wheelchair outside)</td>
<td>Lives alone in warden-assisted flat. HH</td>
<td>Daughter</td>
</tr>
<tr>
<td>P3</td>
<td>55</td>
<td>Male</td>
<td>Divorced</td>
<td>8</td>
<td>Sub-arachnoid haemorrhage</td>
<td>Right-sided hemiparesis (arm/ hand)</td>
<td>Lives alone in ground floor flat</td>
<td>Alone</td>
</tr>
<tr>
<td>P4</td>
<td>54</td>
<td>Female</td>
<td>Divorced</td>
<td>6</td>
<td>Right-sided infarction in basal ganglia</td>
<td>Left-sided weakness (arm/leg) &amp; depression</td>
<td>Lives alone in own house. PT &amp; ADI</td>
<td>PT</td>
</tr>
<tr>
<td>P5</td>
<td>74</td>
<td>Female</td>
<td>Married</td>
<td>8</td>
<td>Left CVA</td>
<td>Right-sided hemiplegia &amp; memory loss</td>
<td>Lives with husband in bungalow</td>
<td>Husband</td>
</tr>
<tr>
<td>P6</td>
<td>66</td>
<td>Female</td>
<td>Married</td>
<td>11</td>
<td>Cerebellar haemorrhage</td>
<td>Left-sided weakness &amp; impaired balance. Walks with stick (short distances)</td>
<td>Lives with husband in own house</td>
<td>Husband</td>
</tr>
<tr>
<td>P7</td>
<td>64</td>
<td>Male</td>
<td>Married</td>
<td>12</td>
<td>Sub-ischaemic right parietal infarction</td>
<td>Left-sided weakness, temperature &amp; noise sensitivity, blindness in left eye, reduced concentration</td>
<td>Lives with wife in own house</td>
<td>Wife</td>
</tr>
<tr>
<td>P8</td>
<td>60</td>
<td>Male</td>
<td>Separated</td>
<td>11</td>
<td>Intra-cranial haemorrhage</td>
<td>Right-sided weakness, mild dysphasia, memory problems &amp; depression. Walks with stick</td>
<td>Lives alone in warden controlled flat. PT, SLT, Psych &amp; ADI</td>
<td>Alone</td>
</tr>
<tr>
<td>P9</td>
<td>58</td>
<td>Female</td>
<td>Separated</td>
<td>155²</td>
<td>Left parietal infarction</td>
<td>Right-sided weakness, dysphasia. Wheelchair for mobility</td>
<td>Lives alone in bungalow, HH</td>
<td>Alone</td>
</tr>
<tr>
<td>P10</td>
<td>60</td>
<td>Male</td>
<td>Married</td>
<td>11</td>
<td>Right CVA</td>
<td>Left-sided weakness (arm/leg). Some dysphasia.</td>
<td>Lives with wife in house</td>
<td>Alone</td>
</tr>
<tr>
<td>P11</td>
<td>79</td>
<td>Female</td>
<td>Widowed</td>
<td>22</td>
<td>Right CVA</td>
<td>Left-sided hemiplegia, depression. Uses tripod inside home</td>
<td>Lives alone in bungalow, HH &amp; ADI</td>
<td>Alone</td>
</tr>
</tbody>
</table>

NOTES: 1 = Medical notes varied in level of stroke classification; 2 = P9 was excluded from the analysis
KEY: CVA = Cerebrovascular Accident (Stroke); PT = Physiotherapy; Psych = Psychological support; OT = Occupational Therapy; SLT = Speech & Language Therapy; HH = Home Help input; ADI = anti-depressants
Description Of Main Themes

Two super-ordinate themes emerged from the analysis that appeared to capture participants' unique and shared ways of making sense of the stroke's occurrence and impact on their lives, as well as describing how stroke-related experiences were coped with. These were entitled 'Making sense of the stroke' and 'Managing life after the stroke', and encompassed a range of sub-themes that are listed in Table 2. There appeared to be links between the manner in which participants made sense of their stroke and their emotional responses and coping. However the two main themes were not entirely distinct, since sub-themes under 'Making sense of the stroke' also served to manage post-stroke experiences and changes. Accounts demonstrated how both meaning-making and managing were dynamic processes that evolved over the course of recovery.

<table>
<thead>
<tr>
<th>Super-ordinate themes</th>
<th>Sub-themes</th>
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<tbody>
<tr>
<td>1. 'Making sense of the stroke'</td>
<td>1.1 'Meaning within life narrative'</td>
</tr>
<tr>
<td></td>
<td>1.2 'Searching for an explanation'</td>
</tr>
<tr>
<td></td>
<td>1.3 'Comparing this self with other selves'</td>
</tr>
<tr>
<td></td>
<td>1.4 'Meeting with new life perspectives'</td>
</tr>
<tr>
<td></td>
<td>1.5 'The uncertain journey'</td>
</tr>
<tr>
<td>2. 'Managing life after the stroke'</td>
<td>2.1 'Making the most of support from others'</td>
</tr>
<tr>
<td></td>
<td>2.2 'Drawing on inner resources'</td>
</tr>
<tr>
<td></td>
<td>2.3 'Finding new ways of doing things'</td>
</tr>
<tr>
<td></td>
<td>2.4 'Setting goals'</td>
</tr>
<tr>
<td></td>
<td>2.5 'Using thoughts to cope'</td>
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<tr>
<td></td>
<td>2.6 'Managing emotions'</td>
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</tbody>
</table>

1 'MAKING SENSE OF THE STROKE'

1.1 'Meaning within life narrative'

In making sense of the stroke's occurrence and impact, many participants talked about how they had placed the stroke within the context of their life-history and current situation. While emotional responses appeared to be linked with expressed meanings, they also seemed to be determined by an interaction between this sub-theme and other sub-themes.
Life Stage/ Life Review

Some placed their stroke within the context of older age. This appeared to normalise the stroke as an expected event during older age and as one of many illnesses that peers were currently experiencing. Post-stroke changes were also normalised by being partly attributed to old age, and for Elsie, familiarised through drawing similarities with her mother’s behaviour.

Elsie: “I know its annoying [repeating questions] ... but that comes with old age anyway ... I remember my Mother doing that”.

However similar attributions also caused Elsie to negatively evaluate her emotional response to forgetfulness:

Elsie: “I shouldn’t do [lose temper/ weep], a woman my age, you know ... I should be taking it in my stride”.

Others appraised the stroke as being easier to cope with when older due to benefiting from abilities learned over the life-course, such as controlling unhelpful thoughts. Some participants also showed a process of life review. Their subsequent ability to positively evaluate past achievements and feel as though they had ‘lived life’ appeared to facilitate acceptance of the stroke’s timing.

Alfred: “Because I think that er (pause) I don’t have any moral complaints about it. As far as I’m concerned its come at the time of my life when I’ve done all the things that I’ve wanted to do.”

Cliff: “I mean I’m 55 so, I’m sort of different from a bloke of say 30 who’s had a stroke, who’s got a lot of life ahead of him and a lot of things that probably he wants to do.”

Previous Life-Events

Understanding where the stroke came within participants’ personal histories helped explain their appraisal of its occurrence and impact. For others the ability to locate the stroke as another life-event or illness encountered over the course of their lives re-framed the stroke as a challenge to be overcome.
Elsie: "Oh this is just something else that life has thrown at us"

Previous life-events or illness appeared to promote a positive appraisal of personal coping resources, minimise the stroke’s significance and/or facilitate acceptance and adjustment. There was no evidence of participants feeling victimised by a series of illnesses or life events.

Cliff: "...I think as I've always tried to be self-sufficient and survived one thing and another. And this is just another sort of, (pause) lump out of the gravestone, ain't it, you know, as you look at it, you know, its something that's happened. Yes, I'm still kicking, so, you make the best of what you can do and hope to get back as best you can, that's it."

In contrast, previous good health endowed Alfred's stroke with a sudden and unexpected quality, an event that he wasn’t prepared for.

Alfred: "I've had a whole lifetime without, nearly a whole lifetime, without any problems at all, then (claps hands) boom all of sudden all of this."

Henry reluctantly perceived the stroke to have rescued him from a risky pre-stroke lifestyle, although his overall account suggested difficulty adjusting to his stroke.

Henry: "I suppose in some ways the stroke has been quite useful because it probably, stupidly, saved my life ... only because the way I was going, I was going to kill myself anyway ... [a warning sign] to get a grip of my life somehow."

For Delia, Henry and Kate the stroke occurred in the context of previous losses or significant life stressors. Although it was hard to untangle the relative impact of the stroke from that of previous or concurrent life-situations, the stroke did appear to add further demands to already strained coping resources and to compound previous emotional responses. These participants expressed a high level of emotion that predominantly related to loss and regret; all were diagnosed with depression (no other participants were similarly diagnosed).

In talking about how the stroke had affected her, Kate made immediate links to the loss of her husband ten years earlier. Stroke consequences, such as needing to accept help from formal support persons, restricted social activities and loss of cherished routines associated with her marriage, had emphasised her bereavement.
Kate: "And of course, I lost my husband in 1992 ... which left me right down ... my husband's not here, and I thought he would have done everything"

For Delia, the stroke was meaningful in jeopardising 'new beginnings' after a difficult year; for Henry it was meaningful in jeopardising his ability to repair a strained marital relationship.

Life Values/Scripts
The impact of the stroke was also made sense of in relation to participants’ values. For example, the stroke was appraised to have a larger impact where it threatened ‘connectivity’ with others or most commonly, a long-standing and valued sense of self-sufficiency and independence. Kate initially appraised her stroke as “the end of life” and “one of the worst things” that could have happened to her; two years later she described feeling “Just fed-up”. Her response appeared to be compounded by her previous bereavement but also by her appraisal of relying on others.

Kate: “I was such an independent person (pause), now I’m not, I can’t go out in my car, I can’t do anything. [Before the stroke] I did everything, my own shopping everything ... I have to rely on people now.”

A strong sense of independence appeared to both promote and hinder coping. Similarly, the meaning of the stroke for life values was re-appraised following subsequent coping and recovery.

1.2 ‘Searching for an explanation’
Another way that participants made sense of why the stroke had happened to them was through searching for a cause of their stroke. Although causal attributions were an anticipated area of exploration, ideas mostly arose spontaneously from participants suggesting that these were personally salient. Notwithstanding, participants did vary in how actively they had searched for causes, the perceived validity and importance of this search, and attributed causes. While for some the search was over, for others this was an on-going activity.

Causal Attributions
While majority considered causes to be knowable and identifiable, a few disregarded this possibility and tended to express stoic acceptance of the stroke’s occurrence.
Brenda: "No. I mean, you can’t figure that out really, can you? ... Well you think, ‘Its happened and that’s it!’ really. I mean its not as though you’ve done something to cause it, have you? They’ve no idea why you have a stroke, do they? They don’t seem to."

Attributed causes included lifestyle factors such as stress, insufficient exercise, working too hard, smoking and alcohol consumption. Others spoke of uncontrolled blood pressure, stroke as a modern illness or chance event with no known cause. It was not uncommon for participants to hold multiple causal ideas. Other participants believed that causes were knowable but had not yet been able to personally identify these. They showed an active process of considering and excluding possible causes, with associated feelings that ranged from anger and frustration to stoic acceptance:

Jon: "its an unsolved mystery but an irritation, if you like, that’s still here to this day."

However lack of identified cause ultimately resulted in uncertainty over how best to reduce risks of recurrence:

Elsie: "I don’t worry about it. If it happens, it happens. I mean, there’s nothing I can do about. I don’t know what caused the other one, so, you know."

Finding a cause may have been linked with exerting control over an uncertain situation, in terms of understanding why it had happened (i.e. creating order and predictability) and preventing it from happening again. Inability to make sense of the stroke in the context of known behavioural risk factors lead some to express frustration and disbelief at the lack of available medical knowledge. George felt particularly angry that an unfortunate, and as such random, chance event had effected significant life changes.

George: "...its more than annoying its uh, you know you feel (pause) angry, I think, angry um because I can’t do the things that I used to do, right?"

He also expressed anger at the common assumption that stroke results from lifestyle choice, since he took responsibility to live healthily and didn’t escape a stroke:

George: "So it makes me furious when I read all these things about
your diet, if you have this diet you will, prevent you from having strokes and ... it didn’t help me at all.”

He talked about stigma and fears of negative appraisal, and demonstrated how this particular appraisal influenced his subsequent coping behaviours and choices (discussed later):

George: “You see there’s a public conception that stroke is, is a product of lifestyle ... Because these, um blooming newspapers keep on coming up with this same old thing. Like you know, low fat diet, exercise, everything, and you know its just not true. And the result is, that you just won’t tell anybody that you’ve had a stroke now because its either, its your fault, its your lifestyle, which of course it was not.”

Responsibility Attributions
While some participants denied or were unaware of any personal responsibility for their stroke, others expressed ‘behavioural self-blame’ (Shaver & Drown, 1986).

Cliff: “Yes, I assumed, I accepted that something had happened and that was it. But I can’t say I was totally overwhelmed by, what’s the word, by panic or anything like that. ... I was more resolute to, i.e. something had, had happened. I probably blamed myself for it ... You know, smoking, driving, you know, under stress all the time, that something was going to happen one day and that was it. It was obviously a shock but not an initial heart-rending sort of thing.”

In some cases ‘behavioural self-blame’ helpfully moderated negative emotional responses, however for others it brought negative self-evaluation and regret:

Henry: “I brought this stroke upon myself really, by being stupid ... Because I was working too much and I wasn’t getting enough rest, I was burning the candle at both ends, I suppose. And something had to give. But at the time it didn’t seem that way. It’s only looking back now I can see just how stupid I was. Now its too late to do anything about it.”

Those that had attributed their stroke to personal behaviours or lifestyle factors, reported subsequent changes based on their identified causes. These included quitting smoking and eating more healthily as well as active attempts to worry less and avoid stress.
Selective Incidence ("Why me?")

Four participants had asked 'Why me?'. Perceived causes ranged from physical factors such as uncontrolled high blood pressure to more psychological ideas such as personal punishment for past misdemeanors. Those continuing to ask 'Why me?' at the time of the interview demonstrated tearfulness, negative thinking, and a diagnosis of depression; one participant expressed suicidal ideation. Jon recalled having questioned 'Why me?' during the earlier days of his recovery but had been left with unanswerable questions, as well as a 'terrible sense of unfairness and frustration'. 'Why me' had elicited questioning about risk factors and unchangeable medical decisions.

Jon: “I think, this was an extreme frustration of the fact it had happened at all. Because as far as I was concerned, I’d been signed off by a doctor as ‘A1’ fit, I didn’t smoke, I hardly drank at all and er, and I also played sport, so, I was the last person who was likely to have a stroke. So the question mark was always, well, why has it happened to me? And the only question I had was, well was it the blood pressure? And if so, would I have avoided it if I had been medicated?”

Others described actively avoided such questions since they considered these unhelpful or had been advised against asking this by professionals.

George: “Just ignore that... if you start thinking like that... then that’s it, you’ve had it.”

Questions of selective incidence frequently led to participants who had not yet identified a personal cause or who considered that causes were unknowable to rhetorically asking unanswerable questions about why injustices happened at all.

1.3 ‘Comparing this self with other selves’

All accounts showed an active process of making sense of the stroke’s impact through comparison of their present self with other selves. Different selves were used as a comparison point, namely, themselves before the stroke, themselves after the stroke, other stroke-survivors, selves with different illnesses/disabilities and the general public. Each comparison appeared to have a different function and associated emotional response.
Before And After The Stroke

Participants gained an idea of the ‘discontinuities’ and ‘continuities’ resulting from their stroke through comparing themselves before and after the stroke – comparisons were drawn between pre- and post-stroke abilities, ways of doing and self-concept. The magnitude of perceived pre- and post-stroke differences, appraisal of differences and subsequent emotional responses varied across participants. However the extent to which the stroke restricted salient aspects of self-identity and valued abilities made sense of the stroke’s impact. It also indicated personal areas of adjustment and goals for recovery. Some, like Brenda, appraised herself to be lucky since she had retained valued abilities such as her speech. She simultaneously downplayed lost body functioning and perceived “no real life changes”.

Another participant, Elsie, expressed significant distress at her changed memory functioning, a salient aspect of her self-identity.

Elsie: “I always prided myself on a very good memory. The kids always say ‘Ask Mum, she’ll know when it was’.”

There were also links between emotional responses and the extent to which stroke changes threatened previous values such as autonomy and independence.

George: “That’s another thing that makes me angry, for relying on [wife] for everything ... I never used to before, did I? ... She used to rely on me ... and I like to be the boss, you know ... Its just, you know, I mean I was, I was in charge of people when I was still well and I don’t want to be dependent on people.”

Post-Stroke Selves Over Time

Comparing the present self with previous post-stroke selves had a positive effect in demonstrating progress and recovery. This was also a way of coping that fed into subsequent goal-setting. Participants monitored their own improvements but typically found feedback from others helpful.

Frances: “now I’ll go out the back door and walk around the back garden, don’t I? I did that the other day, I walked into a different corner of the back garden and he said to me ‘Do you realise something?’ and I went ‘No, what?’ , ‘You haven’t walked across that garden since before last year’ (laughs). Yes not since I went into hospital, and I did it, didn’t I? ‘Cos we got some flowers that have come out in the corner”
However for some this comparison also marked the unfolding impact of the stroke. Alfred talked about realising restraints over time and conjured up the image of an evolving “hell”; Cliff talked about “The way things have hit [him]”. Comparison over time also brought ongoing re-appraisal of what had been lost as well as ideas about future recovery.

**Henry:** “And I know you get spots of improvement, I mean, I just feel that time is passing, and my big improvements ... have all happened ...[from now on] its slower. Less improvement ... I can’t make my mind work any better.”

Jon had initially considered the stroke to be a “recoverable situation”. However “slow progress” recovering his physical abilities and setbacks with services brought frustration and renewed questioning of causes and previous medical decisions, as well as a new perspective of recovery as more difficult than initially anticipated.

**Jon:** “I think every day, a little bit more dawned onto me, on, on the fact, ‘er that this was not going to be as easy a thing as I thought”.

**Social Comparison**

Many participants made sense of the stroke’s impact through comparing themselves against more badly affected stroke-survivors or against a worst-case scenario (‘downward social comparison’). This typically resulted in a positive appraisal of their personal circumstances, and a sense of relief or being fortunate at having escaped worse effects. (This also constituted a way of ‘Using thoughts to cope’).

**Brenda:** “Like some that had a stroke, it was dreadful ... You see, I’m lucky that I haven’t had those severe after-effects.”

**Jon:** “you think, there but for the grace of God, go I”

Delia provided an exception to this during the early days after her stroke when she described great distress at seeing others more badly affected than herself since this meant for her “That [she] could have been a lot worse”.

While the majority only used ‘downward social comparison’, Cliff and George were unusual in engaging in multiple self-other comparisons with varying emotional responses. Cliff
questioned the speed of his recovery in comparison to media representations of stroke-survivors in television soap-operas, and experienced longing yet relief when comparing his unmarried circumstances against those of married survivors. Both participants highlighted the continued timeline of stroke through drawing comparisons between ‘this self with a stroke’ and ‘selves with other illness’. Cliff reflected that the stroke was “a totally different kettle of fish” in comparison to his previous experiences of a heart attack and broken back due to its long-term recovery. George expressed frustration with others’ expectation for his rapid and complete return to pre-stroke life. This fuelled his experience of “ploughing a lone furrow” and his belief that others did not understand. He contrasted the position of someone with a stroke against that of a footballer with a broken leg.

George: “if I was a footballer and I broke my leg ...there will be light at the end of the tunnel...With stroke, the light at the end of the tunnel is usually, it’s a train (Sigh). You don’t know if its going to happen again. Whereas with a footballer, it probably won’t, you know”.

He appraised society to perceive stroke as a self-induced disability and therefore avoided disclosing his diagnosis, preferring others to attribute difficulties to other illnesses, such as arthritis. He also considered that he would have been better off with a heart attack since this would bring better understanding from others and a more certain course of recovery. George however reassured himself of retained cognitive abilities through personal comparison with television quiz contestants.

1.4 ‘Meeting with new life perspectives’
Another way that participants talked about and made sense of the impact of their stroke was through describing changes in their self- and world-view. Participants encountered new life perspectives that were both positive and less positive.

Vulnerability, Insecurity And Mistrust
Since the stroke, participants spoke of how changed abilities, self-concept and autonomy brought a sense of vulnerability, insecurity over whether basic needs would be met and significant others could be trusted. Several spoke of post-stroke life focusing on survival rather than enjoyment. Participants also experienced doubt over their ability to cope with previously managed circumstances.
Henry: “I’m dysfunctional, basically. My body doesn’t do what I want it to do half the time. I’m not sure whether to trust my mind, is it right or is it wrong? ... I just feel very lonely and vulnerable”

Stroke is a potentially life-threatening event and indeed some participants spoke of a new awareness of personal mortality. This brought mixed emotional responses. Some expressed struggling with “unanswerable questions” (Alfred) and uncertainty over their future; others expressed gratitude at having survived and enriched life perspectives.

*Enriched Life Perspectives/ New Learning*

Participants used words like ‘enlightened’, ‘enriched’ and ‘appreciation’ to express how they had encountered new ways of viewing themselves, others or life since the stroke. Many participants had gained a new appreciation of relationships, of both others’ love and kindness, but also how much they were valued by others. They also spoke of a new appreciation of the smaller things in life, life in general and specific changes to have come from the stroke.

Frances: “you take it [life] for-granted ... I now appreciate each day more.”

Through ‘surviving a narrow escape’, Elsie had been able to gain a new perspective on her former tendency to worry.

Elsie: “The great reaper didn’t get me that time, so, so I’m not going to worry about anything ... I used to worry quite a lot about things and, I don’t now. I sort of take a ‘What will be, will be’ attitude now”.

One participant, Cliff showed numerous and striking new life perspectives that related to the ways in which he viewed himself, others and life in general. Although positive changes were weighed up against losses, Cliff described a “transformation” from a stressful, aggressive, work-oriented and isolated lifestyle, to a more relaxed, “placid” and happier lifestyle with greater social participation and openness to others.

Cliff: “the way I feel and the way I look at things, and the way I talk about things and talk to people, then I’m a totally different person”.

Jon spoke of having learned from his “extraordinary experience” in terms of being “more open emotionally” and having greater awareness and empathy for others experiencing
illnesses. He also perceived the stroke experience to have helped him cope with the recent loss of his father:

Jon: “having gone through these emotions, most probably, made me tougher ... when my father died ... it was a tremendous shock, but at the same time, I was able to accept that he'd had a good life and um, its been easier to deal with, you know, his death, than before”

For Henry, new perspectives about the meaning of love, new understandings of his pre-stroke behaviour and beliefs, were tinged with regret since he expressed a wish that he had realised these before the stroke, and frustration at inability to take benefit from these due to stroke-related restrictions. However not all participants had experienced enriched life perspectives – both Alfred and Brenda recognised this possibility but had not experienced it personally.

1.5 ‘The uncertain journey’
Accounts were dominated by questioning and uncertainty such that stroke appeared to be made sense of as an uncertain journey. Participants were faced with making sense of significant areas of uncertainty throughout all stages of their stroke – from realising the diagnosis to looking forward into the future. On hearing the diagnosis there were common themes of worry and uncertainty about how much the stroke would jeopardise valued abilities, independence and freedom. Later on, participants were faced with uncertainty over what the future might hold in terms of recurrence and/or how much further recovery might be possible. Uncertainty created worry, anxiety and a sense of waiting; it also clouded hopefulness and confidence in future recovery. Cliff talked about uncertainty and being in “no man’s land” following a ‘plateau’ in his recovery:

Cliff: “So, at the moment I’m in a (pause) vex, sort of, er (pause), an in-between time, you know, sort of”

IVR: “Limbo?”

Cliff: “Yes, waiting for the next stage to sort of erupt to, or if it don’t, you know, at least I know where I stand sort of thing”.

Many spoke of how insufficient and contradictory information triggered and perpetuated uncertainty. This related to identifying causes, reducing future recurrence, being prepared to
return home from hospital, knowing where to gain support and how to make sense of body symptoms.

Alfred: "Nobody’s explained anything, nobody has said, ‘Well this is what’s has happened, and this is what you should expect to happen, and what might happen’.

Jon’s account showed a sense of he and his family battling against services to gain rehabilitation input and uncertainty over whether different medical decisions both before and after the stroke would have brought better outcomes.

2 ‘MANAGING LIFE AFTER THE STROKE’

The accounts reflected a second super-ordinate theme (‘Managing life after the stroke’) that described how participants coped with stroke-related changes. Accounts showed a wide range of coping strategies, including psychological processes and practical strategies that exerted changes on external circumstances as well as internal appraisals and emotions. Sub-themes of ‘Making sense of the stroke’ that also constituted coping will be referred to but not re-examined.

2.1 ‘Making the most of support from others’

This sub-theme described the type of support provided by informal and formal relationships and how participants found ways to make the most of help.

Support To Facilitate Everyday Life

Support was directed towards physical, cognitive, emotional and social changes. Instrumental support such as home help, transportation, and assistance with self-care helped to manage physical changes. Relationships provided help with cognitive difficulties such as memory, concentration and dysphasia through acting as substitute ‘memories’ or diaries’, and providing encouragement and humour to minimise associated emotional responses. Fears of recurrence, worry, distress, and frustration were moderated through reassurance, encouragement and the supportive presence of others. Support appeared to facilitate participation in ‘everyday life’ and maintain roles and relationships. It was meaningful in allowing participants to resume some level of normality, satisfaction, well-being and quality of life. Married participants questioned how single survivors coped living alone.
Elsie: “how these people go out on their own and manage, because there are times when you do need somebody there ... I wouldn’t have done it on my own.”

Overcoming Difficulties Accepting Help
Although support often played an important role in day-to-day living, half the accounts described how accepting help had been a significant area of adjustment, requiring changes in their perspectives on life, themselves and relationships. Accepting help had represented, and in some cases threatened, a long-standing sense of autonomy, independence, and control. This was made more difficult by strong schemas about independence, unfamiliarity with receiving help, needing to fit in around others’ lifestyles, having insufficient control over help and guilt over taking up others’ leisure time. Some perceived accepting help as risky since it might induce apathy, laziness and ultimately jeopardise recovery, or because people might not always be available to help.

George: “If you allow yourself, yourself to be waited on hand and foot ...you would never get anywhere would you? You would never achieve anything ... your mind would get used to that ... you would accept that as the norm you see... so you would have to beat that.”

These participants described a variety of ways that, over time, they had begun to feel more comfortable with accepting help. These included recognising the necessity of accepting help:

Brenda: “you sort of get used to accepting it I s’pose. At first it’s a bit irksome in that you can’t be independent but ‘er, then you sort of think ‘Well, I’ve got to accept it and that’s it’ ... But I think I’ve got used to it now ... Its something I’ve got to accept.”

And, recognising that help opened up more rewarding activities, such as social activities and feeling secure to go abroad on holiday.

Brenda: “You’d just sit there all the time. That would be a bit boring wouldn’t it?”

Accounts described how it was easier to accept help when formal support systems had taken participants’ personalities and needs into consideration and participants were able to develop friendly relations with formal support persons. Use of humour by both parties also contributed
to developing good working relations and overcoming the potential indignity of accepting help with personal care.

Kate: "[The ambulance men say] 'Hello [Kate], what are you doing down there?' And I say, 'I'm having a rest', [They say] 'Well, you're not going to rest much longer, come on girl', you know, and they get you up"

Accepting help was facilitated by open communication with support persons, as well as their sensitivity and respectfulness of participants' need to maintain a sense of control. Participants found ways to maintain control through supervising help, asserting personal opinions, and being able to use support to continue in previous roles, albeit in a modified form.

Brenda: "my son takes me shopping which is a great help because he takes me around in the wheelchair so I can see what to buy".

Such strategies appeared useful in protecting participants' self-esteem and a positive, 'autonomous' self-concept. However some support was viewed in an unhelpful light, due to others not acknowledging personal frustrations or respecting participants' needs to continue in activities. Developing some sense of reciprocation with support persons also facilitated accepting help, presumably in equalising power and maintaining a sense of self-worth in relation to others. Reciprocation included writing letters of praise to support agencies, providing food and gifts to support persons and finding ways to make carers' tasks easier or doing household duties.

2.2 'Drawing on inner resources'
Nearly all participants spoke of how they drew from inner strengths and previous experiences, coping strategies or areas of expertise to cope with stroke-related changes. Many of these inner resources had been part of pre-stroke life but appeared to have taken on a greater prominence since the stroke. Half the participants demonstrated the importance of mental energy, effort, persistence and determination in overcoming stroke effects. This seemed similar to the concept of 'fighting spirit' described by those coping with cancer (Greer, Moorey & Watson, 1989) and appeared to mediate emotional responses and facilitate coping efforts.
Cliff: “I’ve been like that [determined and self-sufficient] all my life, if you can understand me, so, yeah, maybe that’s why the transition of the stroke, i.e. after the hospital, ... so and so, that it didn’t affect me too whatcha-me-call-it. ... You’ve got to have it in you to fight for it”.

Others talked about using humour to make light of otherwise distressing situations. Several participants spoke of having re-directed a long-standing drive towards ‘self-sufficiency’ and ‘achievement’ into their recovery. However for a couple of participants these standards also made it hard for them to accept help and feel pleased or encouraged by small improvements or a partial return to previous activities.

Four participants talked about how they had drawn from previous illness experiences to cope with the present stressor, either through accepting the disability or developing coping strategies.

Cliff: “[you know] how to counteract, or what you can do, what you compensate for.”

Others spoke of applying previous areas of expertise such as lateral thinking to solve problems, organisational skills to plan ahead and exert control, and secretarial skills to type rather than laboriously hand-write letters.

2.3 ‘Finding new ways of doing things’
Participants described numerous ways in which they had experimented to find new ways to carry out everyday tasks that took into account their post-stroke abilities or made adaptive use of changed body functions.

Jon: “as I eat a grapefruit in the morning ... and I use the bottom of a plastic bottle, er, to contain it, to hold it, ... So then scraping the grapefruit out, I try and utilise the left [affected] hand in some functional mode, so I grip the fingers and the thumbs round it [the bottle]. Best done using sort of excessive tone to hold the grapefruit, but at least its performing a function.”

Problem-solving and experimentation were key elements of this sub-theme. However participants also described using external aids, adapting vehicles and household appliances/furniture, accepting help from others, planning, slowing down, resting when tired,
risk-taking, taking a day-by-day approach and modifying previous roles or activities to fit within present stroke-related constraints. Many of these ‘new ways’ were also supported by cognitive strategies in order that changes were viewed in a positive light and achievements rather than losses focused on (described further in ‘Using thoughts to cope’). Experimentation was also supported by cognitive strategies and ‘inner resources’ to persist in the light of setbacks. Successful experimentation appeared to foster mastery, self-efficacy and motivation to persist.

Cliff: “I tend to, in all sort of consequences, try to work out something one way or the other, whether its just opening a tin, or whether its anything as basic as that. It might look awkward, it might look totally dangerous ... but if I can achieve it and get away with it, then its mentally done me the world of good. I can open a tin, I can do this.”

Some emphasised how everyday activities had been endowed with a new quality of challenge, threat, or uncertainty since the stroke. While formerly taken for-granted, activities such as getting out of bed, showering, carrying a cup of tea, crossing a road were now approached with caution and consideration. Participants described a process of planning ahead and problem-solving how tasks could be adjusted for new post-stroke abilities, followed by weighing up the risks and benefits of undertaking tasks. This seemed to be an on-going process involving continual appraisal and re-appraisal of abilities against the environment.

2.4 ‘Setting goals’
While many participants described a process of goal-setting, and its multiple coping functions, this was particularly salient in Cliff and Jon’s accounts, and least expressed in Henry’s account.

Types Of Goals
Goals mainly related to resuming some level of previous abilities or activities, or identifying new activities that were manageable within present physical capabilities. Goals appeared to create continuity between the past and present, re-define the self (Becker and Kaufman, 1995; cited in Kirkevold, 2002) and represented the road to ‘normality’. ‘Normality’ constituted resumption of basic self-care abilities, getting around and returning to valued leisure activities.
Cliff: “Determined to get back to normality, or what I classify as normality, you know ... to get back to basics really, of survival more than (pause). Does that sound a bit harsh to you? Its not so much dancing and enjoying life, as getting back to a basics where you can grab hold of something, do something for your best, walk, climb up stairs. As I said the basics, getting back to as near to normality as you can. And that’s it.”

However he and other participants spoke of their uncertainty over what constituted their final goal.

Cliff: “There’s nobody telling you at the end of the tunnel, that you’re going to be back to 100%, do you understand? So you can only go as far as you can go... getting back to the best normality you can”.

**Significance Of Goals**

For some having objectives to aim for provided a key source of motivation and were crucial in measuring and demonstrating progress. For others, goals were valuable in occupying time and thoughts in order to provide focus to the day and distract from negative rumination. Goals were often significant in moderating emotional responses. Meeting goals was met with elation, encouragement, happiness and a sense of achievement. It signified reduced doubt about abilities, progress and moving closer to normality. However not meeting goals resulted in disappointment, frustration, dashed hopes about returning to valued activities and often a re-evaluation of strategies and/or goals.

**Goal-Setting As A Dynamic, On-Going Process**

Goal-setting was a dynamic process for many participants, with goals evolving over time and involving behavioural, cognitive and affective processes. Accounts demonstrated how the feasibility of goals were evaluated in light of present abilities and feedback from experimentation. Some talked about meeting smaller goals to gradually accomplish a larger goal. Where goals were unmet or later considered unmanageable, there was a subsequent realisation of the unfolding impact of the stroke, cognitive re-appraisal of possible outcomes, cognitive shift to positively reframe the changed goal as well as strategies to manage emotional responses (‘secondary control processes’; Rothbaum, Weisz and Snyder, 1982). Cliff speaks of re-adjusted goals after a ‘plateau’ in his recovery:
Cliff: “if driving never comes up and I never drive again, all I want to do, it to physically be able to get to and from places without too much, you know, whatchame-call it [hassle]”

Help And Hindrances In Meeting Goals
While supportive others and inner resources helped participants to meet goals, progress was hindered by several professional and systemic factors. Participants talked about ‘struggling’ with lack of timely, on-going rehabilitation input and planning, poor multi-disciplinary communication, inconsistent or absent informational and emotional support, as well as negativity by professionals. Some described their distress at personal needs being dismissed due to rules and regulations. The following instance by Jon describes his personal experiences of negativity when requesting extra physiotherapy from a rehabilitation doctor.

Jon: “He said, ‘Oh, forget the arm, you’re brain damaged, you’ve lost the arm, you’ll never get that back’. And I couldn’t believe it. ... And it wasn’t just me, it was other patients as well, another patient was told he would never walk again. He’s now walking.”

While Jon was able to view unhelpful professionals as “a barrier and someone to fight”, such negativity was frustrating and distressing. He could see his potential to continue making improvements but was frustrated by lack of professional input; he viewed that many patients may not be realising their full potential.

2.5 ‘Using thoughts to cope’
Participants described using a rich variety of cognitive strategies that helped them to re-evaluate their experience in a positive light or make the most of their changed situation. These were often used in combination with other coping efforts, e.g. accepting help, goal-setting, new ways of doing things, and managing emotions. At times these strategies could be conceptualised as ‘secondary control processes’ (Rothbaum, Weisz & Snyder, 1982) in order to exert control within unchangeable circumstances through bringing the self into line with the environment.

Cognitive strategies included positive self-talk, focusing attention on the positives of their situation and/or downplaying negative aspects. Social comparison played an important role in downplaying negative aspects, through comparing themselves against stroke-survivors who
were more badly affected or a worst-case scenario, then feeling lucky and grateful that this did not occur to them.

Elsie: “It happened. I mean I’m very glad it didn’t leave me [with worse effects], because I know a lady I was friendly with in hospital and she couldn’t speak and the difficulty talking to her. I’m glad I didn’t have any of that. They said it was a mild stroke. So I’m grateful. I’m grateful that we caught it very quickly and that it didn’t go on and get worse.”

Despite continuing changes in independence and mobility, Frances found it helpful to remind herself of the significant improvements she had made in recovering from her stroke:

Frances: “I’m lucky, I know that I’m lucky, in what happened, to be here really, doing this, so that’s the thing I remember”.

Participants also talked about revising goals and redefining what they wanted from their situation so that their expectations did not exceed possible outcomes. While Cliff’s account demonstrated significant post-stroke changes, he expressed numerous ways in which he was able to adapt to these. He was able to see positives in his new situation (public transport) and weigh these up against the disadvantages of his former situation (driving); he also drew positive similarities between his new and former modes of transport.

Cliff: ‘I’ve been using public transport and I’ve adapted to it ... I’m sitting on that bus and I don’t get no stresses and strains ... But in theory you just get on the bus and somebody else has got to worry, somebody else has got the problems and I’m only going from A to B, which you would even if you were in the car but I don’t have to worry about parking, I don’t have to do this. And suddenly its, it’s a total transformation, from what I used to do. I drove from 17. I had a car or a lorry ever since then. I always drove everywhere, done this, done that and suddenly this is a different world for me ... Yeah, I’ve adapted to it, put it that way ... I probably do enjoy it in a way”

Participants demonstrated appreciation that they could ‘at least still do activities’ albeit in a modified form or at a lower standard.
Jon: “we went snorkeling ... because it's always one the things I've always done, and um, I found with a mask on and snorkel, I could snorkel. But it wasn't always in a straight line, but at least I could move around.”

2.6 ‘Managing emotions’
Participants also described how they fostered a positive attitude and used avoidance strategies to cope with emotional responses to the stroke and/or related changes.

Fostering A Positive Attitude
While this also linked to ‘Using thoughts to cope’, fostering a positive attitude encompassed positive thinking, hopefulness, patience and seeing the ‘funny side’ and ‘positives’ in post-stroke situations. Participants often gave the sense that having a positive attitude resulted from a conscious decision that necessitated sustained mental energy. Participants talked about accepting that they ‘had to get on with it’.

Jon: “you can’t turn the clock back, you learn how to deal with it.”

Accounts described how having a positive attitude allowed participants to make the most of difficult and unchangeable situations; humour also minimised negative emotional responses and drew support in.

Jon: “...if you didn't have a positive attitude, you’d get very depressed, but um, generally speaking, um, the sense of humour is the saving grace, honestly, it's the thing that bonds you to other people.”

Cliff found focusing attention on his ‘abilities’ rather than ‘disabilities’ cultivated a greater sense of normality. Several participants talked about praising, encouraging and reassuring themselves:

Delia: “And then when I do it, I think, ‘There you go, you knew you knew how to do it’”

Frances: “Well I can’t do it like I used to do it so, I’ve just got to wait in there for as long as it takes (chuckles)”
While positive self-talk can provide a valuable source of energy and self-support, negative self-talk can become draining and self-defeating (Lyon, 2002). Henry used ‘self-flagellation’ to atone for past behaviour, however rumination may have perpetuated his depression.

Henry: “A bit like the guys who beat themselves up, ‘self-flagellation guys’. Going back to biblical times I think”.

Avoidance/ Distraction

Many participants talked about using some form of avoidance or distraction to minimise negative emotions. One way in which participants demonstrated avoidance was through actively avoiding (or limiting) sharing their worries and feelings with others. This appeared to stem from fears of burdening others or being perceived as ‘complainers’. George’s appraisal of stroke as a self-induced illness caused him to avoid sharing his diagnosis and symptoms with others for fear of negative evaluation. However such beliefs seemed likely to have maintained his (and other’s) sense of isolation and may have perpetuated his perception that others did not understand his experience. Several faced practical barriers such as social isolation and difficulty expressing feelings in words. Emotional ventilation was relatively under-reported in the accounts.

Participants also talked about avoiding painful emotions or maintaining a sense of self-worth through physically avoiding situations and people that would emphasise changed physical abilities.

Cliff: “I think there’s obviously an element of pride and er (pause) I could say prestige, you know sort of self, whatcha-me-call-it. So I’m not going to walk around blokes I’ve worked with for years, like walking around like a useless what-me-call-it. There’s a bit of pressure and pride, self-esteem. So when I go back there, I will want to go physically knowing I can do that job”.

Others ‘kept busy’ or ‘mentally occupied’ to distract from negative rumination, and prevent their dwelling on losses and worries.

George: “I try not to, uh, be on my own and thinking too much ... What I try to do, is put other things in, in my head ... I plan ahead ... it makes me try and forget about these other things”.

234
This appeared to be supported by a belief that thinking about his treatment experiences and life changes would lead to insanity or bitterness:

George: “I think if you think too much about things, then ... it would make you bitter and twisted ... I know that I have to protect my mind, I'd lose my marbles if I started thinking about these things”.

Although avoidance and distraction may be functional at certain time points, their longer-term use may not allow mastery of difficult situations or resolution of painful emotions.

Tentative Links Between ‘Making sense of the stroke’ And ‘Managing life after the stroke’
Participants varied in their expression of meaning-making, relative use of internal/external coping strategies, recovery self-efficacy, and emotional responses. While theoretical understandings are considered in the ‘Discussion’, two contrasting accounts are now considered in order to illuminate possible links between the super-ordinate themes and sub-themes.

Henry had found personal meaning in the stroke having happened (Searching for an explanation’) and made constructive behaviour changes to reduce risk of recurrence. However his appraisal of the stroke in conjunction with concurrent life-events (‘Meaning within life narrative’) brought a sense of regret, vulernability, ‘learned helplessness’ and ‘it all being too late to matter’ (‘Meeting with new life perspectives’). Comparison of life before and after the stroke lead to his appraising significant losses (‘Comparing this self with other selves’). He reported “I'm not the same person at all” and described difficulties communicating, remembering and walking. These had resulted in his feeling “dysfunctional” and unable to control external or internal events (“there's nothing I can do about it, it's like my whole life is out of my control”). He viewed the stroke to have jeopardised reparation of his marital relationship (‘Meaning within life narrative’). In comparison to other accounts, Henry showed fewer attempts at coping and appraised himself as 'not coping'. He appeared to rely on help from one other person with little use of internal resources or wider social support. Comparing himself over time since the stroke led to hopelessness about further possible improvements and he showed little experimentation and goal-setting (aside from wishing for marital reconciliation). Henry's perception of his having ‘plateaued’, in conjunction with depression, were likely to have engendered low motivation and energy for experimentation.
The negative self- and world-views found in Henry's account were characteristic of someone experiencing depression.

Cliff's account showed extensive, active and successful attempts to make sense of the stroke's having happened to him. This included using previous life experiences to reframe the stroke as another challenge (a manageable stressor) and an ability to appraise himself as having sufficient coping resources due to successful coping with other illnesses ('Meaning within life narrative'). He had also found personal meaning in its happening ('Searching for an explanation') and encountered new and positive life perspectives ('Meeting with new life perspectives'). While the stroke potentially jeopardised Cliff's long-standing and valued sense of self-sufficiency, these became valuable coping assets. Cliff's account reflected resilience, 'fighting spirit' and extensive coping activity. He used behavioural and psychological strategies to directly address post-stroke demands and secondary control processes to manage unchangeable situations. He predominantly relied on internal resources and expressed a sense of autonomy and self-efficacy about his ability to effect changes. He demonstrated a high level of persistence ('Drawing on inner strengths') that supported experimentation and goal-setting. Successful progress was likely to have brought mastery, self-efficacy and motivation to continue experimenting.

**DISCUSSION**

**Overview**

There has been little systematic study of the psychological process of meaning-making among stroke-survivors using qualitative methodology. Furthermore while coping has been researched using both quantitative and qualitative methods, much qualitative analysis has been descriptive and lacking in theoretical grounding. The current study therefore took a systematic, interpretative-phenomenological approach to exploring these areas, aiming to incorporate a psychological perspective to the experience and where possible, management, of stroke. It conducted semi-structured interviews with ten stroke-survivors at 6-22 months post-stroke. Their accounts of post-stroke changes and how these were made sense of and managed were analysed using IPA.

**Reflections On The Research Process**

Attempts were made to address issues of relevance, meaningfulness, persuasiveness and credibility through describing the participants' circumstances, grounding interpretations in
examples, reflexivity and peer-discussion of transcripts. However the following section reflects on the possible impact of a number of implementation difficulties.

**Clinic Cancellation**

While qualitative methodology does not seek ‘representativeness’ and ‘generalisability’ in the quantitative sense, homogeneity was initially considered important so that accounts reflected similar life-stages, stroke-type and stage of stroke. However clinic cancellation at the original study location necessitated amendments to the inclusion criteria. All participants were relevant participants by virtue of their experience of a first-time stroke, however the sample subsequently included a wider range of ages, stroke-types, and time since stroke than originally planned. The most significant change was the inclusion of participants aged 50-64 years who were employed at the time of their stroke. However despite the more heterogeneous sample profile, participants notably described similar ways of making sense of and coping with their stroke experience and homogenous themes emerged from the analysis. For example, participants who were younger and employed at the time of the stroke, as well as those who were older and retired, positively framed having a stroke at their current life-stage against the potential impact for ‘younger’ people and showed a sense of life-review and satisfaction with their ‘lived life’. It might be interesting to explore how those under 50 years of age might perceive a stroke, especially with regard to life-stage. Clinic cancellation and subsequently long intervals between interviews also felt unhelpful for developing interview style.

The present study also provided an interesting insight into carrying out research from outside a system. The researcher received and appreciated invaluable support from individuals within the NHS trust, for example in accessing an additional recruitment clinic, screening notes and mailing invitation letters. However due to on-going clinic cancellation, the researcher faced uncertainty, repeated re-adjustment of the study time-frame, and reliance on others within the system for essential information and ultimately for convening clinics. This seemed an interesting parallel to themes emerging from the present accounts. With hindsight, home visits would have overcome difficulties with clinic cancellation.

**Interview Process**

While all participants were screened as free of significant communication difficulties, the researcher learned to be responsive to varied levels of communication and emotion – particularly in striking a balance between open-ended and specific prompts, and managing
emotional lability. These variations also added time to transcribing which was later helped by capturing interviews with two tape-recorders. Some participants chose to have significant others present during the interview and their contributions were valuable in for example providing details forgotten by participants, or clarifying speech difficulties. However it was necessary to differentiate participants' own views from those of their significant others.

The researcher evaluated whether accounts could be considered private and meaningful. However for the most part, accounts were not overly concerned with favourable self-presentation and contained embarrassing episodes, negative and positive experiences, and personal family information (Perry & McLaren, 2003), and were therefore considered predominantly private. For some participants, the researcher’s independent position provided anonymity to speak freely and frankly. However the lack of prior (and on-going) relationship made it necessary to consider how to ethically and sensitively establish rapport and safely explore deeper thoughts and feelings. While the study explanation may have inadvertently emphasised coping, accounts did describe both ‘coping’ and ‘not coping’.

Clinical skills were useful in prompting responses, conveying empathy and exploring underlying meanings. However there was often a tension between fulfilling a research agenda and taking a more clinical role, for example, recognising opportunities for cognitive restructuring or problem-solving, and conducting a risk assessment for suicidal ideation and feeding back concerns to the clinic convenor. Indeed de-briefing became an important part of the interview structure.

**Analytic Method**

While IPA provides a systematic method to analyse experiences and meanings, it does rely on language to capture participants' experiences. Other epistemological perspectives, such as discourse analysis, would argue that language constructs rather than describes reality (Willig, 2001). There are also questions about how successfully people are able, and accustomed, to communicating their experiences with words (Willig, 2001). Survivors with significant communication difficulties were excluded from the present study. Nevertheless participants did vary in their willingness and ability to talk psychologically and access thoughts and feelings. Some like Alfred required great effort to speak and produced briefer accounts, others like Brenda and Frances talked more about practical, behavioural strategies. George and Henry explained how they were not used to expressing their thoughts and feelings to others, and Cliff showed word-finding difficulties, yet all three produced eloquent accounts. Overall
however, participants were able to provide rich descriptions of their experiences that were amenable to IPA, confirming that stroke-survivors are able to participate in research exploring their perspective.

The initial participant invitation letter, information sheet and questions posed during the interview set out the focus of the research, however participants' willingness to explore these areas may suggest their meaningfulness and salience within the stroke experience. Furthermore, while the two super-ordinate themes reflected the initial research questions, the sub-themes were generated from an interpretation of participants' accounts and were therefore novel; these add to our understanding of how stroke is made sense of and coped with. The analysis did however present challenges in clustering sub-themes since these often seemed inter-linked and to serve multiple functions. This may reflect that the richness of human experience cannot always be 'categorised'. It is also acknowledged that, IPA is one of range of possible analytic methods and mainly social-cognition and cognitive-behavioural models were used to ground findings. Other methods, models and researchers may elicit different perspectives. However the main strengths of the study were its rich personal descriptions of meaning-making and coping from a sample of ten stroke-survivors, together with its interpretative analysis, consideration of theory and suggestions for clinical practice. Findings will now be summarised and grounded in the context of existing research and psychological theory, followed by suggestions for further research and clinical practice.

Making Sense Of Themes In The Light Of Existing Research And Theory

'Making sense of the stroke'

'Making sense of the stroke', encompassed five sub-themes that expressed how participants' actively sought to make sense of why the stroke happened and its impact. Participants expressed this through placing the stroke in the context of their life narrative, seeking causal explanations, drawing comparisons of the self against other selves, and encountering an uncertain journey and new life perspectives.

Seeking meaning has commonly been observed among those coping with loss, traumatic life-events and significant illness (Davis, Wortman, Lehman & Silver, 2000; Rothbaum, Weisz & Snyder, 1982). This may reflect an inherent motivation to make sense of, and maintain a view of, the world as 'stable', 'predictable' and 'controllable' (Heider, 1944). Seeking a causal explanation may provide one way of realising this (Heider, 1944). Some theorists have considered meaning-making critical to successful adjustment, perhaps through helping to
assimilate the stressor into the individual’s world-view (Davis et al., 2000). For example, Taylor’s (1983; cited-in Ogden, 2000) interviews with rape-victims, and cardiac and cancer patients lead her to identify ‘finding personal meaning’ as the first of three processes in a model of cognitive adaptation. Davis et al. (2000), however, described studies exploring bereavement that refuted a relationship between coping and meaning-making and discussed how events that profoundly challenged deeply held views may not yield meaning. While causal attributions have been widely used to understand emotional responses, response to treatment and coping behaviours in illness (Brewin, 1985), there is no conclusive evidence associating positive illness adjustment with establishing a cause. Turnquist, Harvey and Anderson (1988) found positive relationships while Downey, Cohen-Silver and Wortman (1990) did not. Nevertheless, a considerable proportion of those experiencing life-threatening illness seek causal attributions (Turnquist et al., 1988) and the little work conducted with stroke-survivors found a positive relationship between adjustment and finding meaning (Thompson, 1991).

‘Coming up with an explanation’ was a salient part of many of the present accounts, incorporating ideas about cause, responsibility and less frequently selective incidence (‘Why me?’). Although behavioural risk factors for stroke have been established, a few participants did not believe that causes were linked to personal behaviours; they tended to express stoic acceptance of its occurrence. Inability to attribute a cause was associated with significant negative emotions and on-going cognitive effort to find this. Causes seemed important for re-establishing order and control, particularly in reducing uncertainty and future recurrence (Thompson, 1991). Indeed attributed causes often lead to corresponding behaviour changes.

Accounts highlighted the importance of contextualising illness within the individual’s life narrative (Carricaburu & Pierret, 1995; cited in Pound et al., 1998b) since participants of all ages evaluated the stroke’s personal meaning in terms of life-stage, previous life-events and life values. For example, placing stroke in the context of older age helped normalise it (also found by Pound et al., 1998b) and previous life-events or illness familiarised and re-framed the stroke as another ‘challenge’. These appraisals might be considered ‘vulnerability’ or ‘protective’ factors in a psychological formulation of emotional responses and coping behaviours. Some, but by no means not all, of the accounts supported the common idea of stroke as a ‘biographical disruption’. This reflected existing variations in the literature (discussed by Pound et al., 1998b).
Accounts showed searches to make sense of the initial, evolving and possible future impact of the stroke. All appraised the stroke as a ‘uncertain journey’. Participants were faced with the hard emotional challenge of making sense of uncertainty in an unfamiliar, unspecified life situation (Dowswell et al., 2000). Uncertainty appeared meaningful in jeopardising participants’ ability to exert control and re-establish their world as predictable and controllable (Heider, 1944). Personal meaning was also achieved through drawing self-other comparisons. Downward social comparison helped participants feel better about their own situation (Thompson, 1991) and comparison of ‘post-stroke selves over time’ marked forward progress (Dowswell et al., 2000). The stroke also brought meaning through new life perspectives. For some the stroke brought vulnerability, insecurity, and mistrust that resulted in worry, low mood and self-efficacy. These resonated with life-stage developmental crises such as for example, ‘Trust vs. mistrust’ and ‘Autonomy vs. shame, doubt’ (Erikson, 1982; cited-in Nilsson et al., 1997) and were similarly reflected in Nilsson et al.’s (1997) interviews with survivors three-months post-stroke. Their analysis viewed the stroke as a “crisis” that could be turned “into a positive or negative direction” (Page 995). Indeed accounts showed a movement from ‘narrowly escaping death’ to enriched life perspectives that appeared to minimise the stroke’s negative impact and thereby constitute a way of coping. Finding new appreciation has also been reported by populations diagnosed with cancer and found beneficial for adjustment (Fromm & Andrykowski, 1990).

‘Managing the effects of the stroke’

Accounts demonstrated the numerous, creative and resourceful ways in which participants had learned to cope, many of which are already described in the current literature (Cox et al., 1998; Pound et al., 1999; Alaszewski et al., 2003). The present analysis therefore explores coping sub-themes using existing models and as a process.

Sub-themes expressed how participants made the most of social support, experimented to find new ways around everyday activities, drew from inner resources, set goals, used thoughts to cope and strategies to manage emotions. Sub-themes varied in whether they incorporated strategies that brought about a shared coping outcome (e.g. ‘Managing emotions’) or expressed a similar process of coping (e.g. ‘Using thoughts to cope’). While categorisations by Lazarus and Folkman (1984) and Rothbaum, Weisz and Snyder (1982) of coping into ‘emotion-focused vs. problem-focused coping’ and primary and secondary control processes were useful for considering accounts of coping, not all sub-themes could be neatly categorised since they incorporated elements of both coping categories. For example, ‘Goal-setting’
involved emotion-focused strategies to manage distress when goals were not met, problem-focused strategies to plan a new goal or tactic, followed by emotion-focused strategies to positively appraise revised goals. ‘Finding new ways to do things’ incorporated primary control processes in actively changing the environment to meet personal needs (e.g. aids and adaptations) as well as secondary control processes to bring the self in line with the environment (e.g. positive appraisal of ‘new ways’). Coping thereby involved a combination of complementary strategies.

Sub-themes showed use of both ‘trait-like’ coping, such as using previous strengths or expertise to minimise, adjust to and overcome stroke effects, as well as strategies that were more specific to the current stressor (Lazarus, 1993). Successful use of previous skills may have enhanced self-efficacy and created continuity between pre- and post-stroke selves. Consistent with other qualitative explorations (e.g. Pound et al., 1999), active attempts were made to cope with stroke effects; indeed active coping strategies were more apparent than avoidant coping in terms of both proportion of sub-themes and overall coping repertoires. ‘Avoidance’ mainly related to managing emotions with accounts showing relatively little use of emotional ventilation due to practical and attitudinal barriers.

In keeping with the extensive literature on social support, present accounts suggested how support often played a significant role in day-to-day living and recovery. However accounts valuably described how they overcame difficulties with accepting help that arose from lifelong schemas of independence and self-sufficiency. One such method, reciprocation, has been reported previously by Cox et al. (1998). Other methods included positively appraising support (an emotion-focused strategy) and maintaining perceived control over help (a problem-focused strategy). Indeed maintaining perceived control in an illness context that results in lost control over significant areas of the self or life has positive effects for well-being, quality of life and self-esteem (Miller, 1992 & Pollock, 1987; cited-in Lyon, 2002).

Social-Cognition Models Of Coping

Findings showed some consistencies with a transactional model of stress (Lazarus, 1966) and the self-regulatory model (Levanthal, Nerenz & Steele, 1984). Firstly, meaning-making may be likened to a process of ‘primary appraisal’, and at times ‘secondary appraisal’ of coping resources (Lazarus, 1966). Accounts showed some support for the model’s assumption that appraisal (‘Making sense of the stroke’) determines coping (‘Managing life after the stroke’). However although secondary appraisal was apparent in the accounts, it did not emerge as a
salient theme. Consistent with Folkman (1997), meaning-making also provided a means of coping. Tentative support was found for the self-regulatory model’s assumptions that cognitive representations (‘Making sense of the stroke’) influence coping behaviours (‘Managing life after the stroke’), cognitions and emotions interact, and cognitive representations are updated in the light of feedback from coping. While accounts also incorporated ideas that related to dimensions of cause, consequences, timeline, cure/control, coherence and emotional response, it is unclear where the saliency of life narrative might be incorporated.

**Research Implications**

The present findings highlight the salience of cognition in the experience of stroke and therefore its relevance in clinical practice and future research. Further quantitative and qualitative studies will be important in adding to the small amount of existing work of meaning-making and coping and providing more in-depth exploration of these processes. They might seek to firstly, better understand these processes and secondly evaluate their impact on emotional adjustment. The current inquiry generated specific ideas such as exploring individual differences in meaning-making, the impact of not finding meaning, and factors that promote/hinder this (as well as coping). Exploration of coping related to specific problems areas might add specificity to our understanding.

If a search for meaning constitutes part of cognitive adaptation and therefore coping (Taylor, 1983; cited-in Ogden, 2000), further studies will help inform how clinicians might best support this. Qualitative explorations might be valuably complemented by a quantitative outcome measure of adjustment. Further the present sub-themes might be developed into a more structured questionnaire of meaning-making (Pound et al., 1998a) for clinical and research use. Open-ended questions about for example, the meaning of the stroke in light of prior crises or illnesses, current life circumstances, previously valued activities/abilities, anticipated stroke-induced changes, comparison with other stroke-survivors might help understand the stroke’s personal relevance and thereby emotional and coping responses.

While the present accounts were cross-sectional and retrospective, they confirmed that meaning-making, coping and emotional responses evolved over time. However serial interviews conducted over a longer time frame would provide valuable exploration of how these might unfold along the illness trajectory. This might expand understanding of how
challenges vary at different time-points and accordingly how support might be timed and tailored.

The self-regulatory model (Leventhal, Nerenz & Steele, 1984) has been useful in explaining coping and outcome in illnesses such as Chronic Fatigue Syndrome (Moss-Morris, Petrie & Weinman, 1996) and myocardial infarction (Petrie, Weinman, Sharpe & Buckley, 1996) but little applied to stroke. However present accounts suggested the potential usefulness of this model and relevance of the Illness Perception Questionnaire (Weinman, Petrie, Moss-Morris & Horne, 1996) in future research of adjustment and coping after stroke. Greater exploration of these inter-relationships might be useful in identifying beliefs linked with poor emotional adjustment and coping, that might subsequently be targeted through cognitive intervention.

**Clinical Implications**

It is well established that stroke-survivors face significant adjustment tasks following a stroke. However current accounts suggest the importance of meaning-making within adjustment and further how clinicians might facilitate or hinder this - most significantly through communication “the overlooked rehabilitation tool” (Page 400; Anderson & Marlett, 2004). Accounts were dominated by ‘uncertainty’ and described how lack of information at all times since stroke-onset contributed to this. Unfortunately, this is not an uncommon experience and is frequently reported (Anderson & Marlett, 2004; Hoffman, McKenna, Worrall & Read, 2004). However lack of information and avoidance of emotional issues by health-care professionals creates distress, which is in turn associated with poorer recovery (Nichols, 1993). Although anxiety and cognitive difficulties do interfere with the ability to process information (Ley, 1989), accounts nevertheless reflected the importance of on-going opportunities to discuss concerns face-to-face together with appropriately presented written information (Nichols, 1993; Anderson & Marlett, 2004; Hoffman et al., 2004). Written information can be referred to when needed and promotes recall (Bernier, 1993; cited-in Hoffman et al., 2004). Areas of uncertainty and therefore opportunities for enhanced communication, included causes, risk factors, preventing further strokes, recovery and where to access further information or support (also reported by Hoffman et al., 2004). Communication might include educational support together with emotional support to explore the personal impact of the stroke.

It is important that survivors have the opportunity to realistically appraise the stroke’s impact and grieve over experienced losses (Personal Communication; Kneebone, 2004). Some may
Many participants naturally identified goals for themselves and goal-setting played an important part in motivating and structuring their recovery (Hafsteinsdottir & Grypdonck, 1997; Alaszewski et al., 2003). However they highlighted the importance of not having possibilities for future recovery removed or belittled by professionals, and the benefit of having goals to strive for. Participants did not typically wish for a 100% return to valued pre-stroke abilities, but rather aimed for ‘good enough’. Professionals can help survivors in setting meaningful rehabilitation goals, such that professional goals have everyday validity. They may also help through avoiding unnecessary negativism about future recovery and
supporting survivors in co-ordinating aftercare on a longer-term basis to help fulfil their recovery potential.

Appendix Twelve shows how sub-themes were matched to suggestions for adaptation and interventions. Participants’ reflections also allowed for specific opportunities for cognitive interventions; an idea that may be pursued in a later publication. Accounts specifically showed the benefit of adapting previous skills as well as using a wide range of coping skills, particularly goal-setting, experimentation, problem-solving, goal-directed activity, adaptive self-other comparisons and positive appraisals.

Final Words
Participants described varied experiences and meanings, and great strength and resourcefulness in managing after their strokes. Their descriptions emphasised the importance of person-centred care (Standard Two) and supported the need for continuing rehabilitation and longer-term support (Standard Five, Department of Health, 2001). However these areas require greater in-depth exploration. Services may better support stroke-survivors through understanding the personal meaning of the stroke, and offering improved emotional and informational support to “shape their lives in a meaningful and fulfilling way” (Page 309, Burton, 2000).
REFERENCES


APPENDIX ONE

Letters of ethical approval from (a) local NHS Trust and (b) University of Surrey Ethics Committees
Dear Ms Harris

Life after stroke: from experiences of stroke-survivors to the development of psychological care

I am pleased to be able to inform you that at its meeting held on 22 July 2003 the Ethics Committee approved the above study.

The Committee's decision was based on its review of the LREC Application Form including appendices (i)-(x) which you submitted to the Committee.

The Committee's approval is subject to the following conditions:

(i) No changes should be made to the documents listed above or the procedures set out in them without prior written approval of the Committee.
(ii) The project must be started within three years of the date on which the Committee approved the study. If the study is delayed it is your responsibility to ensure that due account is taken of any new research information or developments which might affect the design or conduct of the study. Any amendments arising from this would need to be approved by the Committee before commencement of the study.
(iii) The Committee should be provided with a copy of a report on the outcome of the study or a copy of any published document.

Yours sincerely,

[Signature]

Co-ordinator
06 October 2003

Ms Jennifer Harris
Trainee Clinical Psychologist
Department of Psychology
School of Human Sciences

Dear Ms Harris

Life after stroke: From experiences of stroke survivors to the development of psychological care (EC/2003/101/Psych) - FAST TRACK

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

This letter of approval relates only to the study specified in your research protocol (EC/2003/101/Psych) - Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

Date of approval by the Ethics Committee: 06 October 2003
Date of expiry of approval by the Ethics Committee: 05 October 2008

Please inform me when the research has been completed.

Yours sincerely

Secretary, University Ethics Committee
Registry

cc:
APPENDIX TWO

Letter of approval by the local PCT Research and Development Committee
Dear Jennifer

Re: Life After Stroke: from experiences of stroke survivors to the development of psychological care.

I am pleased to inform you that the PCT have agreed that the above research study can be conducted and I apologise for the delay in formally writing to you. Thank you for enclosing a copy of the letter of ethical approval from Local research Ethics Committee.

If the project results in a report, publication or dissertation/thesis, I would be grateful to receive a copy as it would be beneficial to share within the PCT as part of the Clinical & Research Governance agendas.

Yours sincerely
APPENDIX THREE

Letters from local NHS Trust approving later protocol amendments
Dear Ms Harris

Life after stroke: from experiences of stroke-survivors to the development of psychological care

I am pleased to be able to confirm that at its meeting held on 6 April the Ethics Committee ratified the Chairman’s decision to approve the changes and revised documents details of which were set out in my letter dated 10 March 2004.

Yours sincerely

Co-ordinator
August 2004

Ms Jennifer Harris

Dear Ms Harris

‘Life After Stroke’ research study

Thank you for your letter dated 26 July about amendments you are proposing to the above study.

Your letter enclosed a copy of a letter from the Associate Director, authorising you to visit patients at home to complete interviews for your research. You also enclosed a revised information sheet (version 4, dated 26 July 2004) and invitation letter (version 3).

I am pleased to be able to confirm that a Sub-Committee of the Local Research Ethics Committee has approved the protocol changes and supporting documents.

Yours sincerely

Co-ordinator

262
APPENDIX FOUR

Invitation Letter
Dear [Patient name],

Re: LIFE AFTER STROKE
(RESEARCH STUDY)

We are writing to invite you to take part in the above research when you attend for your appointment with the Stroke Review Clinic (see attached letter). In this research we are interested in hearing how life has been for you since your stroke and how you have coped with any changes that you have faced. By talking with you, we hope to better understand the issues faced by people who have experienced a stroke and to improve future services.

Agreeing to take part in the research will involve up to an extra hour of your time before you attend for your appointment at the Stroke Review Clinic when you will be interviewed by [Name], Trainee Clinical Psychologist. The interview will be tape-recorded but will remain confidential. Fuller details of the research are given in the enclosed Participant Information Sheet.

You are not obliged to take part in this research and deciding not to participate will not affect your care in anyway. However if you would like to take part then please telephone [Name], Nurse Consultant, on [telephone number] to let her know that you are interested in being interviewed. Please remember that agreeing now does not commit you to being interviewed later - you are free to change your mind at any time without needing to give a reason.

With all best wishes and looking forward to meeting you.

Yours sincerely,

[Name]
[Name]
Lead Researcher
Trainee Clinical Psychologist
Convenor of Stroke Review Clinic
Nurse Consultant

(Enclosed Participant Information Sheet)
APPENDIX FIVE

(Anonymised) Participant Information Sheet

This was printed in size 14 font and produced as a double-sided A3 leaflet
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?
The purpose of the study is to find out more about how people cope with life after a stroke. Other studies have interviewed people involved in caring for survivors of stroke. But not many studies have been conducted with the people themselves who have experienced a stroke. By talking with you face-to-face, we hope to better understand the experiences of people affected by stroke and to improve future services.

Why have I been chosen?
You have been invited to take part in this study because you have recently experienced a stroke and received care from the [Name] Hospital. We are interested in how people cope with life after a stroke and are hoping to interview ten people in total.
Do I have to take part?
NOT AT ALL. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. Even if you agree to take part you are still free to change your mind later and will not need to give a reason for withdrawing. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

What will happen to me if I take part?
If you agree to take part in the study, we will interview you when you attend for your appointment at the Stroke Review Clinic. The interview will take place before your appointment and may take up to one hour. We will ask if we can tape-record the interview and also whether we can obtain background information from your hospital medical notes. Information such as your age, marital status and type of stroke allows us to describe the people who have taken part in the study.

Is the study confidential?
YES. If you do agree to take part, we will let your family and hospital doctors know that you are a participant in the research. However the content of your interview and medical notes will remain confidential within the research team. The audio-tape and transcript of your interview will be kept secure and will only be used for research purposes. Any information that could be used to identify you from the
transcript will be removed. However, if you were to tell us something that caused us to be concerned about your safety, then it would be our duty to discuss our concerns with you and pass these onto the relevant authority.

**What will happen to the results of the study?**
The results will be produced in a report. This will be circulated to the teams working on the Specialist Stroke Unit and the Stroke Review Clinic and if possible, published in a journal specialising in stroke-related research. All information that could be used to identify you will be removed and pseudonyms used. Once the study has been completed, you will be sent a summary of the findings and conclusions. You will also be given the opportunity to discuss the findings and receive a copy of the full report.

**Who is organising the research?**
The research is being co-ordinated by psychologists and nurses working at the University of Surrey and the [Name] NHS Trust. A Trainee Clinical Psychologist not involved in your care will be interviewing you.

**Who has reviewed the study?**
Three ethics committees have reviewed the study and given their approval for the study to take place. These are: The [Name of NHS] Local Research Ethics Committee, the [Name of] Research and Development Committee and the University of Surrey Research Ethics Committee. The clinicians responsible for your care during
your recent admission to [Name] Hospital and the Clinic Convenor are also satisfied with the study and have given their permission for you to be invited to take part.

What should I do now?
Think about whether you would like to take part in the study.

Once you have decided, please telephone [NAME] (Convenor of the Stroke Review Clinic)
[Telephone number]
to let her know that you are interested in being interviewed for the Life After Stroke research.
And we will look forward to meeting you when you attend for your appointment.

If you have any questions about this study now then please do contact any of the following members of the research team:

[Name] (Interviewer) – [Telephone number]
[Name] (Clinic Convenor & Nurse Consultant) - [Telephone number]
Dr [Name] (Consultant Clinical Psychologist) - [Telephone number]

Thank you very much for taking time to read and consider this information. With all best wishes.
APPENDIX SIX

"Tear-off" response slip
Dear [Patient name]

You have an appointment to see the Disability Medicine Consultant and the multi-disciplinary team at [Name] Hospital on Monday 8th March 2004 at 11.30 a.m. If you have been an in-patient on the [specialist stroke unit] please bring your yellow Patient Held Records folder with you.

I would be most grateful if you or your carer could complete the attached note and return it so that we are able to give your appointment to another patient if you are unable to attend. I must point out that if you cancel this appointment, the waiting list for another is between 5-6 months.

Yours sincerely,

[Name]
Secretary to the Consultant in Rehabilitation Medicine

I am / am not able to keep my appointment for the Disability Clinic on Monday 8th March 2004 at 11.30 a.m. I would / would not like another appointment.

Signed: .................................. Date: .......................

Research Statement

Please circle below to indicate your interest in taking part in the ‘Life After Stroke’ research study (described in the enclosed Invitation Letter). Thank you.

I AM / AM NOT interested in being interviewed as part of the ‘Life After Stroke’ research study. I understand that the interview will take place one hour before my appointment with the Disability Clinic (i.e. at 10.30 a.m.).

Signed: .................................. Date: .......................
APPENDIX SEVEN

Interview Guide
LIFE AFTER STROKE: INTERVIEW AREAS

A. Introduction to the interview: Summarise research aims and structure of interview

B. Set the scene
1. When did the stroke happen
2. Did the participant go into hospital, how were they admitted and how long did they stay
3. What like realising diagnosis of stroke
4. When was the participant discharged and did they return to their own home
5. How long have they been at home (residence) now

C. Stroke consequences, implications for day-to-day life and coping strategies
1. How has the stroke affected the participant
2. How do they think having a stroke has affected their life (what stop, how differ from pre-stroke life, hardest changes to adjust to)
3. Have there been any positive changes for participant (and family) that have come from the stroke
4. Thoughts and feelings about changes
5. How are changes coped with (what helps, makes coping difficult, professional help)
6. How have thoughts, feelings, ways of coping changed over the time since stroke (‘journey’)
7. What is their view of (thoughts and feelings about) the future

D. Causal attributions: Understanding of what caused the stroke
1. Causal attributions for stroke (what do they see the as having caused the stroke)
2. Basis for explanations

E. Selective Incidence: Ideas about why this happened to them
1. Questions about why the stroke happened to them (frequency think about this, ideas, feelings about, discussed with others)
2. Ideas about ‘why them?’

F. Personal Meaning
1. Have they found any personal meaning in their experience of a stroke (what, how develop, when develop, effect of)

G. De-briefing and End of Interview
1. Summarise the areas talked about
2. Give an opportunity to say how feel having talked about their experiences
3. Identify main issues of concern and remind of option to discuss with review team and G.P.
4. Thank participant and remind will send feed back from the study
LIFE AFTER STROKE: INTERVIEW GUIDE

A. Introduction to the interview: Summarise research aims and structure of interview.

B. Set the scene
1. First of all I'd like to set the scene and get an idea of when the stroke happened. When did you have your stroke? What was it like for you realising you'd had a stroke?
2. How did you come to go into hospital?
3. How long did you stay there?
4. How long been home now? How has being at home been for you?

C. Stroke consequences, implications for day-to-day life and coping strategies
1. What changes have you noticed in yourself since the stroke? / How has the stroke affected you?
2. What changes have you noticed in your life since the stroke?
3. What's that been like for you?
4. How does that make you feel (about self, life, future, relationships)?
5. What has that meant for you? What does that mean for you?
6. How has this changed since the stroke?
7. How do you cope with that/ manage that?
8. What has helped you cope with this? / What do you think might help?
9. What has made it difficult to cope? / What hasn't helped?
10. How do you feel about the future?
11. Has this changed since the stroke?
12. Have there been any positive changes or good things to have come out of the stroke?
   a) Can you tell me more about that?
   b) What makes you say/ think/ feel that?

D. Causal attributions: Understanding of what caused the stroke
Some people have thought about what caused the stroke, others haven't. Have you?
   a) What ideas have you come up with?
   b) What makes you say this?
   c) How does that make you feel?
   d) What did the doctors tell you about the causes of stroke?

E. Selective Incidence: Ideas about why this happened to them
Have you ever thought "Why me?", "Why did this happen to me?"
   a) What ideas have you come up with?
   b) How does this make you feel?
   c) What makes you say that?
   d) How often do you think about this?
   e) How you talked about these questions with anyone else? Do you think it might help?
   f) How do you cope with these questions?

F. Personal Meaning
Another area I was interested in was whether people find personal meaning in the stroke, like a different way of looking at life? (If necessary, appreciate life or other people more). Some people say that they find meaning, others don't. Have you found any meaning in your stroke?
   a) What sort of meaning have you found?
b) What makes you say that? How did you come to think about the stroke like this?
c) How soon after the stroke did you begin to think like this? What happened at this time?
d) What sort of effect does this have on your life? How does this make you feel?

G. **End of Interview**
1. So today we've talked about the ways in which the stroke has affected your life and how you've learned to cope with these changes. Summarise what helped and not helped
2. How have you found it talking about the stroke?
3. Do you feel there are things that you would like to talk more about or have more support with?
4. You mentioned that you were finding it difficult to cope with X, Y, Z. I know that the review team would be very happy to discuss ways that might help with this. Or if you feel happier you could talk with your GP about extra help or counselling if you'd like to talk more.
5. Thank you very much. It's been very interesting for me to talk to you and I appreciate you giving up your time and for being so open in talking about your experiences. I'm hoping to complete this research by [month] of next year and will send you a summary of the main findings after then.
APPENDIX EIGHT

Demographic Form
LIFE AFTER STROKE
Demographic Information

1. Date of Birth __________________________

2. Age: __________________________________

3. Hospital Number ________________________

4. Marital Status:  
   - Single □ 1
   - Married □ 2
   - Divorced □ 3
   - Widowed □ 4
   - Not Stated □ 9

5. Pre-admission living arrangements:  
   - Own Home □ 1
   - Flat □ 2
   - Warden Assisted □ 3
   - Nursing Home □ 4
   - Not Stated □ 9

6. Current living arrangements:  
   - Own Home □ 1
   - Flat □ 2
   - Warden Assisted □ 3
   - Nursing Home □ 4
   - Not Stated □ 9

7. Ethnic Origin:  
   - White British □ 1
   - White Irish □ 2
   - Any other White □ 4
   - White & Black Caribbean □ 5
   - White & Black African □ 6
   - White & Asian □ 7
   - Any other mixed background □ 8
   - Indian □ 9
   - Pakistani □ 10
   - Bangladeshi □ 11
   - Any other Asian background □ 12
   - Black Caribbean □ 13
   - Black African □ 14
   - Any other black background □ 15
   - Chinese □ 16
   - Any other ethnic group □ 17
   - Not Stated □ 99
8. Previous occupation

9. Level of education (years)

10. Stroke Classification

11. Date of Stroke

12. Date of Admission

13. Date of Discharge

12. List stroke consequences documented in the medical notes:

13. Services/treatment facilities/ follow-up therapies involved since stroke (home care, day care, psychology, physiotherapy, occupational therapy etc)

14. List other current medical problems documented in the medical notes

15. List day-to-day problems/concerns documented in the medical notes
16. Describe past mental health problems documented in the medical notes

17. Describe current mental health problems documented in the medical notes

18. List current medication (name/ dose/ frequency/ purpose)

19. Describe social support & perceived helpfulness documented in the medical notes

20. Describe any major life events noted in the year prior to stroke
APPENDIX NINE

Consent Form
1. I confirm that I have read and understood the Participant Information Sheet dated 17.09.03 (Version 2) for the above study and have had the opportunity to ask questions.

(PLEASE INITIAL BOX) 

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

(PLEASE INITIAL BOX) 

3. I understand that participation will involve being interviewed prior to my appointment for the Stroke Review Clinic and that this interview will be tape-recorded and transcribed for analysis. I give permission for the interview to be tape-recorded and transcribed for analysis.

(PLEASE INITIAL BOX) 

Please turn over page →
4. I understand that sections of my medical notes may be looked at by responsible individuals from / NHS Trust where it is relevant to my taking part in the research. I give permission for these individuals to have access to my records.

(PLEASE INITIAL BOX) ☐

5. I understand that all information will remain confidential but will included in an anonymised form in a written report. The only exception to confidentiality is where serious concerns are raised during the interview.

(PLEASE INITIAL BOX) ☐

6. I understand that my G.P. will be contacted and informed of my participation in this research study.

(PLEASE INITIAL BOX) ☐

7. Are you involved in any other research studies? YES / NO
   If YES please state: .................................................................

8. I agree to take part in the above study.
   (PLEASE INITIAL BOX) ☐

_________________________
Name of patient (CAPITALS)  Date  Signature

_________________________
Researcher (CAPITALS)  Date  Signature

THANK YOU FOR PARTICIPATING
APPENDIX TEN

Example Transcript
TRANSCRIPT OF INTERVIEW WITH CLIFF (P3)
A 55 year old White UK man with right weakness

1. IVR: Okay, thank you for agreeing to take part. (Explanation of study) First of all I'd like to look at when you what it was like for you when you first went into hospital. So it was a year ago that you had your stroke?

2. P3: Yep, yep, March (pause)

3. IVR: March time. And what was that like for you realising you had a stroke?

4. P3: I didn't know anything about it. I actually (pause) come to a month later, at the hospital

5. IVR: Right

6. P3: Whereas up until then, up until then, I didn't know up anything

7. IVR: So did you have any warning, were you having headaches, dizziness or anything then?

8. P3: What prior to the stroke?

9. IVR: Mmm

10. P3: Oh yes, I just felt rough on the Wednesday (pause), headaches, so and so.

11. And then on the Sunday I went over to my daughter's, said I felt a rough still

12. IVR: Sat down, I didn't know nothing, I was out for a month, that was it, ended up in A intensive care/must have had an operation and that was it

13. IVR: Yes

14. P3: Didnt really come to, as I said, until about a month later. And then they moved me from there out to B (next hospital), then moved me three days later over to here, and that was it

15. IVR: So when did you realise what had gone on?

16. P3: Couple of weeks after I got to C (stroke unit). I was aware that something had gone wrong, but, you know, I was still, sort of in a different world, a twilight zone. I remember certain bits of A, bit very, very vaguely. My daughter reminds me, more of everything. Like I said, B was a bit of a shambles, and I seemed to come together after a week here, so. Up to then, anything, you know, my daughter sort of talked about how abusive I was and how I was doing this and doing that but as I said, I have no real memory of it. And in truth I probably remember the last couple of days prior to actually moving from A

17. IVR: And then when you did realise what was going on, was it a shock, or did you think 'Well what does that mean??' [Better – how did you feel?]

18. P3: I think basically, er how can I put it? (Pause) Once I realised that obviously something, had gone, you know, to pot (yes), I didn't realise the severity of it until I was more
aware of me, of bodily functions so and so, so and so. And yes then, it sort of hit me. But
you know I didn't feel, I don't feel, over, what's the word?, you know other than that, sort of
surprised. I don't know, I was quite (pause)

IVR: Quite accepting?
P3 Yes, I assumed, I accepted that something had happened and that was it, but I
can't say I was totally overwhelmed by what's the word, by panic or anything like that. As I
said you know, I was more resolute to, i.e. something had had happened. I probably blamed
myself for it

IVR: Did you?
P3 You know, smoking, driving you know, under stress all the time, that something
was going to happen one day and that was it. It was obviously a shock but not an initial
heart-rending sort of thing.

IVR: So, you were sort of accepting of it, had ideas about what had caused it
P3 I obviously blamed it on smoking, or well a mixture of both, the stress

IVR: What job was that?
P3 I was only a skip driver, lorry driver, HGV. I've driven HGVs all my life, Arctics,
you name it. Some jobs are more stressful than others. If there's a bonus and other
attributes in it, then it creates a bit more stress to earn so and so, so and so, you know. And
I've got to admit, the way of life, I've sort of, not really worried about anything as such you
know, I was just merrily going through a daily basis, routine, so and so, so and so, you know,
so.

IVR: Sounds like you were very focused on doing well in your job?
P3 Yes, I think the job was the main focus of my existence, you know at the time
(Yes). Obviously I'm single so you know, there was no other sort of, immediate factions
around, sort of thing. Yeah. Like I say, that was the period, after I started getting my head
together, I was more concerned about that than I was, initially, in my own physical what-you-
ma-call-it.

IVR: So, when you said you were worried about your job, whether you would be going
back to it, or whether?
P3 Yes, that was the funny part. The governor had, sort of obviously, you know
heard by then, and he phoned me up and already said, that I was guaranteed my job
whenever and so and so, and so and so.

IVR: So they were supportive?
P3 Yeah. And that was also a mental instigation to try and get as well as I could,
you know, as soon as, as fast as I could, sort of thing
Major Research Project - Appendices

71. IVR: You had that goal to work towards
72. P3: Yeah, that was it, that more of an incentive as such to get back to a basic
73. normality which was my basic normality than it was any other factions.
74. IVR: Yes, yes
75. P3: It might sound strange, I dunno.
76. IVR: No, no
77. P3: I mean I used to drink, but I couldn't see any glory in sitting at the bar, night after
78. night. I mean if I had the choice, I'd sooner go to work than sit there decked lager all day.
79. I'm not saying I didn't at the weekends, but you know there's a different category, you know.
80. At the end of the week that was the end of the week, the working week, you grab what you
81. could then you went back to work and that was it. You know, maybe mentally, that was more
82. geared up work-wise than it was social-wise
83. IVR: Yes (pause). Have you gone back to working at all?
84. P3: No
85. IVR: How's that been? Knowing that that was the thing that was motivating you?
86. P3: Mentally, I'll be honest, since, er, how can I put it? When I was in here, I was
87. improving and then and they let me out in September and I still carried on, you know, even
88. on my own, with exercising, pushing myself and improving myself
89. IVR: Very determined
90. P3: Yes, I was improving all the way through until sort of prior, to when the cold
91. weather came in at Christmas. And then I suddenly starting going backwards and I think,
92. then it sort of hit me that this wasn't going to er (pause) be the ultimate sort of situation. My
93. arm never came up to what I wanted it to be, in that I couldn't grab a steering wheel or you
94. know, move it. I can't even drive a car at the moment so, you know. And that suddenly did
95. start dragging me back down. And like I say, there were other complications with the knee
96. and so and so. So, at the moment I'm in a (pause) vex, sort of, er (pause), an in-between
97. time, you know, sort of
98. IVR: Limbo?
99. P3: Yes, waiting for the next stage to sort of erupt to, or if it don't, you know, at least I
100. know where I stand sort of thing. I'm reasonably aware that, how can I put it, in the words of
101. legality that there's no way that I'm going to drive an Arctic again
102. IVR: Right (would have been better to follow up the 'limbo' feeling)
103. P3: You know, for the fact is medical wise they wouldn't even entertain me, you
104. know, so
105. IVR: When did you find that out?
106. P3: You don't have to. I had a heart attack, er, bout five years ago and then I had to
107. have a medical every three years and that was hard, tough enough. For what they wanted
108. then, there’s no way that I’d ever, well they wouldn’t do it, you wouldn’t get, the moment my aneurism come up, that’s it, you know twice bitten

110. IVR: Right

111. P3 You know, its bad enough with a heart attack. But with an actual stroke as well. They’re not going to let me loose on a blooming 8-ton lorry are they? Coughs

113. IVR: Do you think you’ll be able to drive your car again?

114. P3 I think that’s one of my goals, to actually but, I don’t know, you know, it sort of goes by the way because (pause) obviously for the last few months, I’ve been using public transport and I’ve adapted to it

117. IVR: Oh right? Good

118. P3 I’m sitting on that bus and I don’t get no stresses and strains

119. IVR: That’s true, unless they’re late!

120. P3 Laughs, well even if they are, I still get there, I had a bit of a flutter coming over here today. But in theory you just get on the bus and somebody else has got to worry, somebody else has got the problems and I’m only going from A to B, which you would even if you were in the car but I don’t have to worry about parking, I don’t have to do this. And suddenly its, it’s a total transformation, from what I used to do. I drove from 17. I always drove everywhere, done this, done that and suddenly this is a different world for me.

127. IVR: It sounds like a world (public transport) that you’re actually quite enjoying in a way?

129. P3 Yeah.

130. IVR: That there are benefits to?

131. P3 Yeah. I’ve adapted to it, put it that way. I wouldn’t say I (pause), no I can’t really lie, you know, I probably do enjoy it in a way. But I’m not over engrossed with getting a car, if you can understand me. That isn’t one of my main priorities. And I sort of, I tended to sort of, er, whichever way the wind blows in that aspect, i.e. because I can’t get to a certain position, i.e. where you just jump in the car and go, its not the end of the world. If you can understand me, you know. I can go shopping, I go and do this, go and do that

137. IVR: Mmm

138. P3 Admittedly, I’ve got me mates that come and pick me up. But other than that, if I sort of, touch wood, and went down the thing, it wouldn’t worry me if I never drove in my life, again, you know

141. IVR: Right, right

142. P3 Does that sound weird to you?

143. IVR: No, you used the word adapt, and it sounds like you’ve adapted. You’ve looked at the situation and realised that maybe that’s not going to happen and then that you’ve
Major Research Project - Appendices

145. found other ways to get round that, like by using public transport, friends

146. P3 Yes. It's a mixture of both. Because there is this er, mental block, call it, that you
147. reflect back and you think. There ain't no hassle on the bus whereas there's hassle, you
148. know, in driving your own car, your own vehicle, so and so. But maybe there was in driving
149. (a lorry) but once again that was a totally different combination. Now that's mental as well,
150. admittedly. When you was in the lorry you felt different from when you was in the car. Does
151. that sound totally weird to you?

152. IVR: I was just thinking that I'd never been in a lorry, and was thinking what it must be
153. like, that its such a bigger to manouevre around

154. P3 You get a mental, obviously you cope with moving it around physically and er
155. (pause). But mentally you have this sort of er, step above, if you can understand me, than a
156. normal car driver. Suddenly you're looking down on and you're not that worried

157. IVR: About safety?

158. P3 Yes, your safety factor is none, you don't even worry about it, you know
159. because you're that much higher, that much bigger, so and so, and so. I'm not saying that
160. you're not worried about other people outside you know, that safety factor's there, but there
161. is a mental jump between a car and a lorry, you know. Very hard to describe. But it also
162. works in the same position when I get on the bus. Suddenly, I ain't got to worry about a 40-
163. foot truck, all I got to worry about is sitting down here waiting for the bus to get to so and so.
164. Now that's a total difference, you know

165. IVR: And did you think, did you adapt very quickly to that, or did it take a longer time?

166. P3 No, I adapted, reasonably quick, obviously because of the sheer fact of having
167. to, I had no other what-d'ya-me-call-it. Now I've got to admit, I was cacooned very much in
168. here. The fact is that I was unable to go anywhere really other than around the hospital
169. bounds, if you can understand, so I didn't have that element of, you know, vision of, or
170. whatever, of transport, you name it. And, yeah, it was only when I got home on my own that
171. suddenly, the awareness of need. <Nosebleed starts> "It'll stop, its alright, it happens to me
172. now and again"

173. IVR: Are you okay, do you need any more tissues?

174. P3 No, I'm alright. But, how can I put it, you know, basically, all it really boiled down
175. to was, it was a total transformation from my day-to-day life. Everything run on wheels,
176. whereas now, and the annoying part is, if I could walk better, I would probably, you know

177. IVR: That's one thing you would like to be different?

178. P3: The walking pattern yes, without the (pause), its still going (nosebleed)

179. IVR: Do you want to, is there anything that will help?

180. P3: No. It just happens. I described it to the doctor, he thought I was an idiot.
181. There's no reason for it, just, you know

182. IVR: How long does it usually last?

183. P3 A couple of minutes. How can I put it? When I was walking alright, I wouldn't
184. walk. The only time I walked was when I was on holiday, you know. But now, I just want to
185. mainly for freedom and access, sort of get out rather than sitting there, i.e. staring at four
186. walls, looking through a window, reading (Mmm) or something like that. But once again, 
187. that's a total transformation from my normal way of life.

188. IVR: Well (pause), before you're normal way of life was?

189. P3 I used to get up, breakfast, cup of tea and so forth, wash, shave, in the car, 
190. boom, into work, into the lorry, and boom that was that. The boom, in the car, and drive 
191. home and boom, end of story, go back, day after day, day after day. So it was a total 
192. transformation.

193. IVR: So it's quite important for you at the moment to get your knee (interrupted)

194. P3 Yes, as physically as well as I can, to sort of go into a different world.

195. IVR: Yes?

196. P3 I don't mean to say it like that, I s'pose. You know, it's, getting back to a bit of a 
197. normality, where I can actually move physically around and to see things like I used to but 
198. without rushing about. As I said, if driving never comes up and I never drive again, all I want 
199. to do, is to physically be able to get to and from places without too much, you know, whacha-
200. me-call it

201. IVR: Difficulties, hassles, or getting stressed?

202. P3 I very rarely get stressed now, I've got to admit that. But you do get tangled up in 
203. your own troubles, you know, walking-wise. You're tired, you stumble. As you get tired-er, 
204. you stumble more and suddenly you're in this er dodgy period, you know, where if you do 
205. sort of happen to fall over or something like that, so and so, so. You're, that's your sort o f 
206. safety line run down.

207. IVR: Do you know when that's, do you know your limits, in a way, of how much you 
208. can do?

209. P3 I don't think you can know your limits totally. But you know them roughly, for the 
210. fact is, it's very hard because I suffer with, I don't know if you know, fatigue?

211. IVR: You suffer from tiredness?

212. P3 Yes, but when you have a stroke, fatigue comes into it. Its more than tiredness, 
213. its not like sort of working all day and then going home feeling tired. You can get up and 
214. walk, right? (Right). Be as right as rain, have a cup of tea and sit down and then feel totally 
215. shot away. That's where the fatigue comes in. And it can come on in theory, at any time, you 
216. can be out walking, sit down and within a couple of minutes, feel 'Phew'

217. IVR: It sounds very unpredictable, that you don't know when its going to happen 

218. P3 Yes, it is unpredictable, in many aspects. You get a slight feeling of what's 
219. happening but by that time if you're in no man's land, i.e. shopping or doing this and doing 
220. that, then you've only got an avoidance (unclear word: 17.8) i.e. to get back to square one, 
221. sort of thing, or back home and that's it

222. IVR: Mmm
223. P3 And I've been caught out a couple of times in the last six months but
224. IVR: What happens when you get caught out?
225. P3 Well you, basically, I can get home but you're stumbling, your foot's curving up, your arm's up here (showed high tone arm), you know, all the attributes of the stroke suddenly start (pause)
228. IVR: Are much more marked?
229. P3 More prevalent, you know. Like I was saying the arm, I can normally hold it down there but it would sort of be up here and sort of, you know start clawing. And the foot, it's a mixture of both. If its cold, the foot will not only just drop but it will claw
232. IVR: Right
233. P3 So your toes will be like that (shows) and so and so. Yes, and so it's a combination of really knowing when the whole can fold, you know. Its not very often now but it happens.
236. IVR: Did it happen more?
237. P3 Yes in the early stages, yes, and obviously as the months have gone on I've sort of, probably been aware of it more and sort of know when to pull the plug. You know, even indoors, it might sound silly, but you feel knackered and just go and lie down for ten minutes and then be as right at rain again
241. IVR: Right, so you've found a good way of coping with it?
242. P3 Oh yes, you know, but even outside you can do the same as long as you've got the physical awareness or, the capability of getting somewhere to like sit down, you know, give yourself a rest for five minutes
245. IVR: Have cup of tea
246. P3 Have a cup of tea if you can, or have a fag, so and so, so and so, you know, yes.
247. IVR: And when this starts happening, when you start to get really fatigued, how do you feel about it, do you get bothered by it?
249. P3 Frustrated
250. IVR: Yes
251. P3 But its er (Pause), I don't know what the word really. It's a combination of sort of, you know or you feel that suddenly you might have improved, that you may be walking better, so and so, so and so but then it hits you and then you're back to square one again, you know, you get sort of (pause)
256. IVR: Disappointed?
257. P3 Yes. For the fact is, you sort of look at things, and how can I describe it? You can mentally, if you were thinking, "Fuck, I felt 100% better yesterday so and so, so and so. I completely could start going into work"
260. IVR: Mmm

261. P3 And then, something like that, the fatigue comes down on you

262. IVR: Yes

263. P3 And it hits you and then you're sort of, afterwards you start thinking about "What if it'd had been at work?" you know

264. IVR: What would have happened?

265. P3 Yes. What would have happened? What would have not? I would have just sat in that chair, I wouldn't have been of any help, you know, I wouldn't have been doing this and doing that, I wouldn't have been doing the job I should do so and so, and so and so. And then it hit you because you probe back and sort of think well, I've got to get out of this, you know. How can I ever go for a job if I can't last a day, you know? Its no use going up to the governor and saying 'Well yes I'll be alright, as long as I don't get fatigued or I don't get this and don't get that. Well if I do, it means I can't do this and I can't do that until I feel better and so and so.' So it does you know, really sort of mentally, throw you about and confuse you.

266. P3 Yes. And then do you stay, kind of thinking about the work still, well that would mean that I can't do that then and I can't do that, but there's a way I could do

267. P3 Yes, I categorise jobs down. I mean, the job I was in, it was a skip driver, its in a er (pause) I forget what the word is, it's a big concern and its got every different type of vehicle, er, ways and modes of waste, salvage and so and so, and so and so. So there's always a job in one form and another for me (Right). And I've always tried to categorise meself, going up stages to when I can go back to work. So I look at say the bottom stage was 'pickerel'. I've got one hand so and so, so and so. And then up to the next stage which would be so and so, and so and so. And er, I might get a 'loading shovel' driver or you name it, even down to a 'weigh bridge operator'. But once again, if I'm sort of knackered and I'm one-handed trying to operate the weigh-bridge and doing this and doing that and suddenly I can't turn around and tell half a dozen lorry drivers that they've got to wait because you know (pause)

268. IVR: You need a rest?

269. P3 Yes, so and so. Or grab someone from somewhere else to take over my role while I sit there

270. IVR: Have you discussed that with your governor?

271. P3 Not yet, no. I always thought, I won't go back to him until I know that I'm physically capable of doing i.e. a certain type of job. He has been reasonable, you know, he has said come in for a couple of days, but in truth, at the moment the way things have hit me, I'm not even ready for that, you know

272. IVR: And it doesn't suit you at the moment?

273. P3 Well, it's a mixture of both, you know, I'm sort of. I think there's obviously an element of pride and er (pause) I could say prestige, you know sort of self, whatcha-me-call-it. So I'm not going to walk around blokes I've worked with for years, like walking around like a useless what-me-call-it. There's a bit of pressure and pride, self-esteem. So when I go
301. back there, I will want to go physically knowing I can do that job, I'm capable of doing it, and
302. yes, I can settle for that. But I'm not going to go and do a job and suddenly, two hours later,
303. I need a rest so and so, so and so, or physically I can't do it

304. IVR: What do you think people will think of you then, when you talk about, you know,
305. pride and wanting to do a good job?

306. P3 Well, I don't know, I sort of (pause). I think, you get the same sort of impression
307. off some people when you're, even on a bus. They look at you like you're, you know you
308. sort of hobble up to the thing, and they're looking at you like you're some kind of, er, what's
309. the word, species (slight grin). You know, it won't take long to notice, so yeah, its no
310. different at work, I should imagine, because everybody's different. Somebody's going to say
311. something. They'll probably say in, not trying to upset me but, I'll probably bite on it or it they
312. do get upset, I won't bite on it, and they'll, you know, so I don't know. But I sort of (pause)
313. always try to eliminate the situations that create that sort of thing, you know. I would want
314. to be in that situation where I'm in parity with the job that I'm going to do and then I can sort
315. of say 'Well (pause)

316. IVR: 'I can do the job'

317. P3 Yeah, that's it. There's no, you can't get me. That sounds a bit weird. But in that
318. aspect, you know, you can't pick fault with what I can do or I can only do that, I ain't going to
319. drive no more. But at least I'm sort of, I can do this (Yes), and that's it. So there's a bit of
320. self-esteem mentally and physically as well.

321. IVR: Yes (pause). Have you found that people have actually treated you differently
322. then since you had the stroke?

323. P3 Ye-ah, I mean, its, its hard to say because obviously it's a new, it's a new world
324. for me, being sort of like this. I was always, alright I've had a heart attack but I was out of
325. hospital within three days

326. IVR: Quite different to this? (would have been interesting to explore this 'new world',
327. what 'being like this' was)

328. P3 I've smashed my legs up, I've broken my back, I've done this, I've done that. But
329. you know once again they're all physical injuries that you sort of, can shake off and carry on
330. with life (Right). And suddenly this is a totally different kettle of fish.

331. IVR: In that its taken you a bit longer?

332. P3 Yes, er, it also produces you, (pause) out into, yes, I could stay at home and sit
333. indoors and let the world go on around me and get the home help, or whatever, to do this
334. and do that. But I've always been the opposite, I've always (pause), I would go shopping
335. (unclear: 25.1), so and so

336. IVR: Determined to keep your independence?

337. P3 Yes, and that's, I've always been like that and I'm sort of adamant of actually
338. trying to maintain the best independence or something like that. And yeah you do, how can
339. you put it, er (pause) even friends (pause) sometimes feel that they're over, what's the word,
340. they're over-compensating for your injuries. They're worried in some aspects but in others
341. you get the impression that, you know, you're a pain in the arse to them, do you know what I
341. mean?

342. IVR: Is that what you think, or somebody (interrupted!)

343. P3 It's a mixture of both. You, you, its what happens to everyone, but you do, you
344. know, I mean you disrupt other people's lives and I don't like doing that. That's something
345. about me on an individual basis

346. IVR: It makes you feel uncomfortable?

347. P3 Yes. So you know, somebody else might be totally different, mentally or
348. physically in that aspect to me. But you know, I sort of, I've always been, what's the word,
349. you know, self-sufficient as such, from an early age.

350. IVR: Yes

351. P3 And I've always, like, the majority of the time I've been on business driving so
352. I've been on my own, I've had to fend for myself, sort my own troubles out, so and so, so
353. and so. Nothing has changed in that category. The only thing that has is that inability, i.e. to
354. do certain things. Other than that, nothing in my eye has changed.

355. IVR: Would you say that you find it quite (pause) difficult to accept help from your
356. friends?

357. P3 Yes, quite truthfully.

358. IVR: Mmm

359. P3 I, how can I put it, I don't want to consider, they might do it, for instance, my mate
360. he always comes over on a Sunday to take me shopping at Tescos. Well in the early days,
361. yeah, quite truthfully, I was down on one hand, I could hardly walk, right, so yeah, I needed
362. somebody initially just to drive me there. I wouldn't sit on my arse, I would hobble around
363. Tescos and get the shopping right. And hobble back and I would really ache but you know

364. IVR: It felt like a real achievement?

365. P3 Yeah, but it solved a problem, i.e. I got my food, so and so, so and so

366. IVR: Do you think some part of you was reluctant to accept that help?

367. P3 Yes, in the early days, I don't think it entered my head, that's being truthful

368. IVR: Yes

369. P3 I sort of accepted it

370. IVR: A means to an end

371. P3 Yeah, in that aspect. But now, like I was saying, in the last couple of weeks, I've
372. tended to try and do it on my own, on my own, work it out to suit how I can do it physically,
373. so and so, so and so. And I sort of called up him and said 'X, don't bother coming over so
374. and so, so and so. And I sort of accepted it

375. thinking I don't want you to, why get up on a Sunday morning when you don't have to, just to
376. come and run me to Tescos you know? So and so. So I feel a bit beholden to him, perhaps
for doing that. Do you understand me?

IVR: Right, yes.

P3 So I try to eliminate that side, and that works, as I said, that's me as an individual. But I might be a bloody cuss (laughs)

IVR: No, I don't know but perhaps there's also a part of you, that you've worked out a way of doing it so you can be self-sufficient and you want to try that out. But if you're friend's there, it's a bit difficult to try out?

P3 No, that aspect, for the fact, I tend to, in all sort of consequences, try to work out something one way or the other, whether its just opening a tin, or whether its anything, as basic as that. It might look awkward, it might look totally dangerous, so and so, so and so, but if I can achieve it and get away with it, then its mentally done me the world of good. I can open a tin, I can do this, so and so, and so and so

IVR: You feel good about it

P3 Yeah. So that doesn't come into his sort of category. I just felt, er slightly, guilty, for the fact is, he's only got a day and a half off, the same as I used to. And er, he doesn't want to spend the rest of his, I mean we're talking months now, I don't think he wants to spend every weekend or every Sunday morning coming over to me, to run me to Tescos. So, you know, if there's ways and means of me getting it, I'd sooner do it that way and be once again self-sufficient on myself. As I said, it stems from the past, so

IVR: So that's part of you being normal and being you

P3 Yes, that's it, that's it

IVR: And I'm just interested have you had a conversation with friends about feeling guilty

P3 Yes, and they do the normal stature thing of 'Oh, no, no. We wouldn't do it if we didn't want to do it'.

IVR: You don't believe them?

P3 Laughs. No as I say, I've been around fifty odd years and I've looked at the times. I've said that to people, and yet in truth, you know, yes while you were doing it, I'm not saying you don't sort of mind doing so and so, but you know, you've got other things in mind to do than wipe my bum sort of thing, you know what I mean? If there's a line between you and as I've said, it stems back to me as an individual, I'd sooner not, I wouldn't say its beholden, I'd sooner not be beholden to anyone. If I can do it, I will do it. But that's me, call that me being self-sufficient, so, yes, there is a category of that. But I've never, I never sort of, I daresay there are times when I do need help

IVR: And do you ask for it then?

P3 On the odd occasion. But I'll have a few attempts before I do (laughs), you know

IVR: Right. Yes. It sounds like your determination and your strength and your self-sufficiency have got you to where you are, overcoming difficulties. Its been helpful
415. P3 Yes, but I've been like that all my life, if you can understand me, so, yeah, maybe
416. that's why the transition of the stroke, i.e. after the hospital, initial A, so and so, that it didn't
417. affect me too whatcha-me-call-it. I'm still sort of gibbering on things like that, obviously I still
418. sit down and think about things, certain things, but yes, I think as I've always tried to be self-
419. sufficient and survived one thing and another. And this is just another sort of, (pause) lump
420. out of the gravestone, ain't it, you know, as you look at it, you know, its something that's
421. happened. Yes, I'm still kicking, so, you make the best of what you can do and hope to get
422. back as best you can, that's it

423. IVR: Sounds a very constructive, helpful way
424. P3 Oh you've got to be, you know. What's the alternative? The alternative is to sit
425. there
426. IVR: Look at the four walls?
427. P3 Yep, look at the four walls and let somebody do everything for you, and for what?
428. But like I say, some people are probably, I'm not being nasty or detractive, but some people
429. probably are better off, being nursemaiden and so and so, but, me as an individual I'm the
430. opposite so. Laughs. I'm not sure how I'm going to help your study on that!
431. IVR: It does. Maybe as you say, its down to the individual. I was interested in whether
432. people used similar strategies before and after a stroke, and how these change in the early
433. days and over time. And if some people aren't able to say I'm going to make the most of it,
434. what happens
435. P3 There is an element of er mental or psychology or whatever that creates, certain
436. things. But I mean there also is an element of physicality that, you know, i.e. with a stroke,
437. they are all totally different to each other. I'll tell you a quite frustrating scenario. This might
438. sound terribly absurd to you but on the telly, you've got Neighbours and Harold's just had a
439. stroke and
440. IVR: Oh yes
441. P3 And also you've got
442. IVR: Emmerdale
443. P3 And he's had a stroke. And when you've had a stroke yourself and you're
444. looking at them, its so farcical
445. IVR: Its not believable?
446. P3 No. There's no conviction whatsoever, you know. You see certain aspects come
447. up and you think 'Yeah' and then you look at it ten seconds later and its totally different.
448. Then you look at it the next day and he's improved where its took you a month and a half in
449. here, its took him a day
450. IVR: They've speeded it up big time
451. P3 And that is a mental, you know, effect
452. IVR: (I should have asked, can you tell me more about that? How does that make you
453. feel?) Did that make you compare yourself with it, I mean you just did compare it but more
453. did it make you think, oh, should I have gone faster or do you think other people think that?

454. P3 Yeah, I should imagine that everyone does, they look at it and think ‘Oh’. I look at it on the fact that, somebody must have wrote it, somebody must have read about it

456. IVR: You hope (laughs)

457. P3 Laughs. Well, you assume that the writer on the TV programme, sort of, get their facts right first. And you look and think ‘Really?’. Then you look at some of the astounding things that he’s doing and suddenly, if you look at it, I mean, that’s the terrible part about it. Because you’re so aware of it, you look at things and you wait for them. You know its like, up-teen times Terry will get up with his bad hand, on there (shows one hand), right, and be walking down the road with his stick in his hand. Which is farcical. And the next time you see him on the next cut, he’s got it in that hand (shows opposite hand) and he’s doing the opposite. And you think ‘Yeah, right’, but you know, that’s

465. IVR: Maybe they haven’t got their facts right?! Laughs

466. P3 Laughs. Yes, that’s, they spend, its five minutes out of your life, that you’re observing something that, you know

468. IVR: (I should have asked, how does that make you feel?) That made me think, where do you get extra information from?

470. P3 On what aspect?

471. IVR: Knowing how you’re doing, to get extra support, or physio

472. P3 There’s a sort of, er, chain gang, no what’s the word, er, basically when I started over here, it was a total difference between this and the other hospital, this is the disability thing so they are geared up to that aspect. We used to do physio everyday, OT some days so and so, so and so. And they judged you on how you went in, assessed you, so and so so and so, and build you up throughout the months

477. IVR: Was that helpful?

478. P3 Yeah. And you initially had goals, looked at every month

479. IVR: Was that helpful for you to work towards goals?

480. P3 Yes because I always did beat the goals, get there before so and so, and that does give you a mental incentive and also you can see it for the fact is, you are improving

482. IVR: Yes

483. P3 So that is an uplift as well as you know, it increases your mentality

484. IVR: Encouragement?

485. P3 Yeah encouragement, so and so and so and so. Then you obviously got well enough to leave (pause) which (pause) you can’t stay in here all your life. But you can understand they could have had me in here another year, or another six months. There’s, what’s the word, there’s nobody telling you at the end of tunnel, that you’re going to be back to 100%, do you understand? So you can only go as far as you can go, sort of thing, you
490. know, physically, mentally, making goals and trying to improve or get back to the best
491. normality you can. And its very hard to sort of jump through them barriers. You sort of, you
492. can get to a certain stage, like when I left hospital, yeah, but when I got out in the big
493. world it was a totally different situation

494. IVR: How did you feel about leaving, I know you just said 'I know I couldn't stay there
495. forever'  

496. P3 I was glad in one aspect to actually leave, mainly for the fact that I had been in
497. here for so many months. But it was a total eye-opener as such to be out in the big wide
498. world and you're not getting the support, get your cup of tea, cook your dinner or do any of
499. them things. You've got to do everything for yourself.

500. IVR: You didn't have any meals delivered?
501. P3 No, no. From day one, I was sort of had to fend, basically, for myself

502. IVR: So how were you feeling? (Pause) Nervous, scared, worried, happy (pause),
503. mixed emotions perhaps?

504. P3 Yes, mixed emotions, I mean, because, yes, obviously going back to the past, I
505. was, I've been self-sufficient. But I found it frustrating and hard because certain things,
506. seemingly little things, you know were (pause)

507. IVR: Were frustrating?
508. P3 Yes, were frustrating. The fact is whereas you took going like that, so and so, so
509. and so, a simple thing would be an enormity

510. IVR: How did you keep yourself going, keep encouraging yourself?
511. P3 Pause. I've never really asked myself that one (laughs). I think you do it on a
512. day-to-day sort of existence

513. IVR: Take each day as it comes?
514. P3 Yes, you've got to, you know

515. IVR: I s'pose I was thinking, that if you were talking to somebody else who'd just had a
516. stroke and who was finding it really hard, and as you said, was finding everything an
517. enormity, how would you encourage them, I wonder from what you've done for yourself?

518. P3 I do, I come and see people on the ward every week. They're obviously chopping
519. and changing people. And if they want to listen and then, you know, I do try to help them. I
520. can't give them no pitfalls, I just tell them, you know, what's what and that's it. You've got to
521. have it in you to fight for it, sort of thing. Make sure you want to get yourself better but if you
522. don't and you want to sit down and do nothing, then fair enough. It gives them that sort of,
523. bit of stimulus. It does help, I've got to admit. They say after a couple of weeks, you know,
524. what you said to me 'That was helpful'. That helps me mentally in one aspect, but sort of,
525. yeah.

526. IVR: Yes

527. P3 In theory, the same reason for this (the interview), you know, if I can help
somebody else. But don't get me wrong, I'm not a goody-goody or anything like that. I'm realistic enough to know this has been a nightmare for me, and I can understand other people, you know, in the same aspect. It does, it brings you down to a different parity of life and minds. You know, you haven't got this high esteem, you sort of. I have, I can help somebody up there, with no hesitation, I'll do it in an instant and without even questioning why I'm doing it. And that is a total different aspect to what you get out in the big wide world sort of thing.

IVR: Yes. Thank you. Another aspect I was interested in was (pause), the personal meaning of having a stroke. Some people say that they have learned to look at life differently, appreciate other people more or they can take it easier, they have a different perception on things. Would you say you have? In that you think about life differently?

P3 Yeah, I do, but I'm slightly adverse because I had a heart attack and that sort of twisted me off the realms a little bit, to mentally to sort of, how can I put it, not to worry too much. You know, sort of, you know, what was the point of all those years worrying about bringing the kids up, of doing this, of doing that and of doing this, of doing that. And suddenly you end up like this, and suddenly it was a big eye-opener. And I think its done, because I had a heart attack prior to this, this didn't effect me too bad. It did change me, I do look at things and I obviously take one day at a time. I'm not saying I'm try, I s'pose I try to drive the best I can out of a day and that's it. I'm sort of, a lot happier er, obviously because I haven't got work problems or anxieties or stress or anything. Yeah I am a lot better in that aspect. But then when you throw in all the other attributes it evens itself out, you know because you're walking around like an 'hopidoo' and so and so, so and so. I s'pose, on a parity, it has changed a lot. You accept things a lot easier, you sort of, I don't know, that's me. I'm only going on me. You can look at other things and I've been up on the ward for 8 months. I've different attitudes from different people that were there, noisy, aggressive, so and so, so and so. So I can only go on my initial thing, in that aspect.

IVR: How do you drive the most out of each day?

P3 Yes, its hard to sort of say. Its not a lot. It's a combination of you wake up. I don't know if you want to know the medical side of it?

IVR: Well, I was thinking because you said that one of the ways you cope is to get the most out of each day and I wondered how you did that?

P3 Its within your own physicality, that, how can I put it. I mean, I'm quite sort of occupied? Enjoying?

IVR: Occupied? Enjoying?

P3 Yes, yes. Actually, I can sort of derive pleasure out of going into Woking, just looking around, talking to a couple of people, having a chat, so and so. And you go through your day and it doesn't have to be anything other than that, you know. You go out, you go home, have something to eat, have a cup of tea, sit down and watch a bit of telly. That's in theory, is the end of day, bed, so and so. But you know, you have mentally achieved something, you've kept yourself occupied

IVR: You've met people

P3 You're not sitting there like a numbly and yeah, you do go through sort of mental physicalities, of you know, doing the garden or something like that. Then you look at it, and you know, I can do certain things down there with one hand, like the pruning and so and so,
but on the other hand, I can't dig it

IVR: No

Do you understand me?

IVR: Yes

So suddenly its sort of, you can get so far then yeah but I can manage to prune the rose trees and do this and do that. So I've done something, you know. And all the time I can keep myself occupied in one form or another, you know I think, you know, I'm sort of driving the day. Now, how can I explain. I went to Cyprus in January and physically wise, because its warmer, it opened me up that much more and I could walk a lot further. I looked at things. Like when I'm on holiday I always like to try walk around. I used to walk miles but obviously I can't. So I used to drive rather, sorry I mean I got on a bus. Honestly it was quite an eye-opener for the fact is, that over there it was only 50p or something to get on the bus, that's your initial price, total price. So I'd get on a bus, sit on it, I'd be looking at everything and if I saw something, I'd get to the end and wait and get off within distance of seeing that place and be able see it and then be able to come back. And so yeah, you use a mental but physical so and so, you use everything to work to that sort of thing. Whereas before you walked all the way up there or used transport to get to the nearest point as I can. And yes, I adapt to that situation. And it is a reward mentally and so and so, it stimulates the dead cells. Laughs.

IVR: Laughs, yes

Numb cells. Yes you do tend to get into a numb cell stage while you're in hospital, you know, because you're geared up to one, Physio, two, OT

I bet the physio stimulates your cells.

Yes, you know, you do, from when you wake up initially in the morning, so and so, you go through every category on a day-to-day basis other than at the weekend. And so, you do get sort of hospitalised. Laughs. As such. So yeah. Obviously the weather is a distraction, if its wet, windy, cold. That affects the stroke

How does that affect you?

The cold is the greatest whatcha-me-call it. If its cold, initially, you are cold anyway physically, right, although you can't actually feel the freezing cold on me, if you touched it with that hand it is cold. Everything tends to sluggish off, like your leg, your arm, so and so, and then obviously you in the end, it does drop you down

So keeping warm's really important

I had an eye-opener didn't I, in the fact that I went to Cyprus in January. And it was cold prior to going and when I got over there, it wasn't 100%, it rained and so and so, but it was something like it is now, about this temperature. But it physically improved and when the sun really came out, then I knew, I felt, no was physically top-knot all the time sort of things. So the cold does create some problems

Do you manage to keep warm at home?

Ye-ah, in a round about way. I've got storage heaters in the house, you've got to
612. set them up on a day in advance. I switched one off last night, because it was supposed to
613. be nice, up-teen degrees today but look at this and it will be cold tonight. I can switch it on
614. now, but it won't come on until midnight tonight, so. I've got a back up, little watcha-me-call-
615. it

616. IVR: Heater?
617. P3 Yes
618. IVR: Oh good.
619. P3 But it's a bit of a judgement act to work it out. I'm terrible, for the fact that I smoke
620. and I don't like to sit in a hot room smoking

621. IVR: So you have the windows open?
622. P3 Yes. So you've either got to have the windows open or the door. And the more
623. air that's in the room, I mean I sit there with the door open and smoke quite merrily you know
624. without any sort of thing. But if I sit in a warm room without any windows open, my eyes are
625. streaming. But this is another thing that has happened since the stroke rather than before

626. IVR: It didn't happen before?
627. P3 No. I used to smoke all day in the truck.
628. IVR: With the window down?
629. P3 Yes. And at nights, I'd have the window open in the flat. It would be warm but
630. with the stroke, that's affected some parts of me

631. IVR: Did you start cutting down on smoking?
632. P3 Yes and no. I mean, you get bored, frustrated, or I either sit there
633. munching sweets or something. So you know. I told Dr X that I've cut down to 15 a day now
634. but it's very hard to go below that. Because one thing affects the other, if I stop, I start eating
635. and stuffing sweets. If I'm going out, like now, physically I don't mind, it's just through
636. boredom that you're doing it.

637. IVR: Have you tried patches?
638. P3 I've tried things like that, and then suddenly you've got this £18 box of them and
639. then they don't work too well

640. IVR: That's a lot of money. Do GPs prescribe them now? It makes sense if they're
641. encouraging people to quit

642. P3 Initially when I got here, the sister said something. I got the impression that they
643. were supplying patches here. There were initially five smokers on the ward so whether
644. they'd had been offered the same sort of thing but nobody'd ever took it up. I wasn't 100%
645. accurate about what was said to me in those days

646. IVR: That's very usual in the early days. I've just going to check my interview guide,
647. Um, I'm, I think you've been, you've been hitting all of the areas
648. P3 All of the questions that you wanted

649. IVR: Yes, fantastic. (looking through guide) Because you’ve talked about what you
650. think caused the stroke, the sort of meaning that you gave to it

651. P3 Basically, I think stress. Stress mixed with everything, old age, smoking, stress,
652. drinking

653. IVR: Was that based on what the doctors told you or something you had been
654. reading?

655. P3 No, I don’t really look at things like that

656. IVR: When did you start thinking about causes?

657. P3 I don’t think there is any initial cause to something, they will always put
658. something down won’t they? I mean if you break your arm, the first they do is argue is
659. whether you smoke as if that did anything. They do. So that side of it I’ve never looked at,
660. I’ve just looked at i.e. what I was like when it happened and then reflected back to what sort
661. of situations I was in. So yeah. It was obviously the job, otherwise I wouldn’t have had it. I
662. wouldn’t have had the stroke if I hadn’t have been doing this and doing that for the last year
663. prior to that

664. IVR: So that’s how you made sense of it, by looking back

665. P3 By reflecting back and sort of saying well I was drinking a little too much on the
666. weekends, very stressful, this and that, working too long hours, smoking, so and so, so one
667. of them from there to there. If it wasn’t that, then it was a medical thing that could have
668. happened when you was 15 or so

669. IVR: Thank you (pause). We’ve, I think you’ve also talked about some of the positive
670. things. I was wondering whether there’s anything else that the stroke had added to your life,
671. positive things? I mean, you talked about, you don’t have the same amount of stress and
672. you take things easier

673. P3 I’m more awareness of, yeah, its very hard to say relaxing, because you can’t
674. physically relax as such, but you know, you do get a mental sort of, parity, or a lower level of
675. er, its not stress

676. IVR: Tension?

677. P3 Yeah, you know, you’re sort of, you’re not so tense, you’re not so worked up.

678. IVR: A-ha

679. P3 Things have totally changed, I mean, I used to be fairly aggressive, I wouldn’t
680. say punchy or anything like that but, because of the type of the work, driving, so and so, so
681. and so, I was always verbally aggressive. I would be driving so and so, so and so, now
682. none of that, now bearing in mind I’m not driving, so and so, so I don’t know whether it was
683. total or not, but the way I feel and the way I look at things, and the way I talk about things
684. and talk to people, then I’m a totally different person. I would say I have changed that much,
685. you know. Does that sound absurd to you, you know, but I have, I sort of look at things, I
686. look at things in a totally different way to what I did prior to that
687. IVR: And do you like that?

688. P3 Yeah. Its sort of, yeah, in a sense that sort of things (pause) around you are more sort of (pause), what's the word, are sort of, are more like placid. You're not in this ripple of so and so, yeah.

691. IVR: A kind of calmer, placid, gentler way of being?

692. P3 Yeah. You're going into things. I mean I'm friendly, reasonably friendly or was reasonably friendly with i.e. with my good mates, but I wouldn't say that I would be in any other way sort of be. Whereas now I would talk to anyone, so and so, so and so, which has been totally different. Where I was more isolated when I was driving so and so, so and so, I didn't have, well I suppose I did have the opportunity, but I'd sort of just have a quick chat and go. Now I'd talk about anything and everything and so and so, yeah, and that's another thing. That's going from, stemming from babies to sort of things, to older people and that was an aspect that was never in that line before.

700. IVR: Yeah, sounds like its opened up conversations, part of your social world

707. P3 From them and me. You know, you'd sort of. Somebody would say something to me and before, you know, I'd look at them and think 'Phaaa'. But now, there's that tolerance, parity that's dropped down, so you can accept an awful lot more, you know, in that sort of aspect. Yeah, so, yeah, things have changed.

711. IVR: How has that benefited your friendships then, or your family?

712. P3 Well, I've only got a daughter, so. Yeah, I s'pose, you know in some aspects, I'm outside, cos I only see her, not all that often, but I've got time and I can talk and discuss anything and anything you know. And as I said, from one level, from a baby, tod, to a thing, and whatever their discussion is, you know, I can sort of come in and sort of. If I dunno, there's something there that wasn't there. There was always this 'hello mate' and be gone. Whereas now I've got that sort of, alright, well yeah, things have changed in my life that allow me to do that. Whether it was there prior to that, I don't know, so

720. IVR: And you were very busy with work

721. P3 Yeah. Like I say, I was always going about, getting from A to B, and back to so and so. Maybe I didn't have that element time or place in my life to do it.

723. IVR: Yeah, yeah. That's interesting.

724. P3 But it is quite absurd, you know. Like I say, I sit there, with a kid of four or so, and just sort of sit there and converse with them. They do admittedly, they're more honest than adults, you know?
IVR: What, in terms of noticing things?

P3 Yeah, like when you get up and you sort of start walking, ‘Have you hurt yourself?’ You know, they’ll come out with it. And I’ll say ‘Yeah, but I’m getting better’. But they converse with you but that’s it, that’s an innocent thing. There’s no (pause), I don’t feel any (pause), if they tell me I do walk funny or something like that, that doesn’t (pause)

IVR: That doesn’t make you feel?

P3 That doesn’t hurt me, or what’s the word, you know. I don’t get frustrated by it, or I don’t get upset by it, or anything like that, you know. So and so.

IVR: Yeah

P3 And how you put it. I can also talk to an old girl and sort of explain it and she can say, ‘Oh my husband had one and so and so, so and so’. And you can converse with that side as well, you know, cos you’ve been through something their old man or she’s witnessed, so and so, so and so. So yeah, there’s a new expanse (pause)

IVR: Understanding?

P3 Yeah. And the only time you come to a dis-understanding, is when you are obviously mixed up with the social, Woking, shopping so and so, so and so. Where everyone’s in their own little world, or their own big world, trying to get from A to B, or going in shop to shop. And so, I wouldn’t say its (pause) deliberate. They’re doing it, in a, to (pause)

IVR: They’re just focused?

P3 Yeah, they’re focused on their shopping. You, often and often, can’t, don’t, sort of, they’re in a totally different world to you, sort of thing. So, yeah, that’s the only time when you do sort of suddenly, detract off it. Where you’re sort of trying to duck and weave between them and they’re the able-bodied ones. In truth, you know, I’d say 50% are aware and will move and some will obviously catch you and they’ll say sorry. Others will just walk past you like you never existed. So yeah, there is that air of frustration.

IVR: Does that make you want to say something or do you just pass it off?

P3 Yeah, I do say something

IVR: You do, yeah?

P3 Yeah. If you sort of think its blatant. I’m bloody-minded, you know, I’ll just deliberately stand there and let them realise and then suddenly, they’ve got to go round me. And it works both ways. Cos the majority of the danger ones are the ones (laughs) in wheelchairs, ironically enough (laughs)

IVR: Laughs

P3 Yeah, I mean, but they’re in the same, how can I put it, they’re on the same mental wavelength as me. You know, you’re expecting them to get out the way,

IVR: And they’re thinking I’ll just go straight through
764. P3 (Laughing) Yeah, and I'm thinking 'Well, he's portable, at least he can move' different to me and then he's looking around and thinking 'Why doesn't he move out the way' and I'm thinking 'Why don't you bloody?' Yeah, sort of, but, that's serious. Alright, it's what I fair enough, experience on a day-to-day basis, you have accept it and that's it, you know.

768. IVR: Mmm

769. P3 Its quite funny really. You know, you sort of, you look at it. And then they'll suddenly realise, you know (laughs)

771. IVR: And then do you both laugh about it?

772. P3 I laugh sometimes, and other times, I sort of, I do get frustrated. I've got to admit, I don't like swearing, but sometimes I think 'You've got a wheelchair and I need it more than you', you know. Especially when you get into a context where they've sort of, you've met them in the town before and then suddenly you've gone up to D (local place) and that, and they're getting out of their chair, their electric chair and getting into a proper seat, and you think (pause). And that tends to sort of frustrate, for the fact is, that you've been hobbling around, probably, three times the length that they've rolled past you in their electric wheelchair. But its my fault in that I should have gone and got my own electric wheelchair, you know, so, its, its half and half.

781. IVR: Mmmm. Do you want to get an electric wheelchair?

782. P3 No. If I can't walk, then well I'll have one, but you know

783. IVR: But you can walk?

784. P3 Well, that's what I mean. It would be detractive mentally for me to actually use an electric wheelchair. I had an electric wheelchair in here.

786. IVR: Did you run people over?

787. P3 Laughs. I used to get close but no, cracking the walls quite a few times.

788. IVR: But at the moment having a wheelchair might mean for you that you weren't so self-sufficient in a way?

790. P3 Yeah, I think that works in that aspect. Yeah you do tend to, er (pause), look at people sometimes, especially your own disabled. You know, sort of look, and think, well. Especially when they're doing things and you think, all of a sudden you're in a different category than they. I s'pose that's just an individual, sort of, whatcha-me-call it.

794. IVR: Is it kind of looking to see how people manage or what goes on for other people? (=leading question, better 'What are you looking at?')

795. P3 Well I'm in a sort of terrible vex for the fact that I'm on my own. So, how can I put it, so by talking to even people that were up here, while I was in hospital, they've come out with a different sort of, answer to things for the fact is that they have got somebody there to help them, to sort their business out for them. So yeah, some of the pressure, or some of the things, are different for the fact is they have instant help as such. But some of their problems are against for the fact is they aren't doing it themselves, you know, if you can understand me.
802. IVR: And there may be changes in their relationships as well?

803. P3 Oh yes, there's bound to be. Well let's be truthful, I mean. The creation of stress in situations like this, you know, must be, for a woman, you know who's got to tend to after her husband after so many years and so and so. It must be a nightmare, to have their whole lives transformed, you know, into certain categories of what you can do and what you can't do, so and so, and so on. And know that it's not going to go away, its going to be there for up-teen years, or months, you know. So yeah, I'm glad in a way that I didn't have any of that side of it. So. Maybe it would have helped me in some aspects, made some of the things a bit more open and clearer. But yeah.

811. IVR: As you were saying, maybe, part of their problems may be that they have somebody to do things for them, whereas you were determined to, you were going to do it. So that's got you on a good road to recovery

814. P3 Yeah. You can always get yourself in a position where one day, that person ain't going to be there, to do that, you know. So you've got to do it. It might be something simple like getting a glass off the table, unless you were initially going to sit there and ring the bell all day, you know, what's the other part going to be, you know? Do you understand me, so I don't know, that's in, er (pause) no man's land there, I think. One that I didn't go through but I actually sat there and looked at people snapping and snarling at each other while we've been on the ward you know. Its very hard, you know. Everyone's different, every marriage is different, so and so. So yeah, its very, like I say, it's a sort of context that I'm glad, in one aspect, that I wasn't it. But in other way, you know I do, I've got to admit, I sort of look back and think 'Oh yeah, it would have been nice to have somebody sit with me for an hour and do this and do that' but you know

825. IVR: Yes (pause). And do you think, how do you think about relationships in the future then?

827. P3 For what? Women?

828. IVR: Well, relationships, yes.

829. P3 I don't know, I'm terrible like that, I sort of, er (pause)

830. IVR: Is it something that you've thought about or not really?

831. P3 It's not an importance, as such, no. I mean going to Crete in a couple of weeks, in about three weeks time. I went to Cyprus at Christmas and I found I was slightly isolated, so I did ask somebody to go with me, not sexually but, just for the fact of somebody there, as somebody to talk to. But in theory, I've been on my own quite a few times and never, never got to that sort of stage. By ironically going with somebody, it creates its own sort of problems, suddenly you're not an individual, there's two of you. She might want to do something or he might want to do something that's totally different from you. Whereas if you go on your own, you've only got to worry about yourself

839. IVR: You can do the things you really love doing

840. P3 It took me 46 years of marriage and God knows what to actually realise, you know, that you actually can enjoy a holiday on your own. You know, and actually do it when and when you please. That's obviously a nice place out in Crete to do it, you get up when you want, sit in the sun when you want, have a drink when you want, go to sleep when you want, so and so. With a, with a woman wanting to go shopping, or a bloke, you know
845. IVR: Whichever

846. P3 Whichever, sort of partner, or anybody wants to do, so yeah. I only took this partner, not a partner, this girl with me for the fact is if something did happen, at least I've got somebody there. So it was worth buying, just paying for her holiday as such and at least know that that safe pot is there

850. IVR: Security?

851. P3 Yes, that was it. That was the only reason. It was totally different in Cyprus, I was in a self, hotel accommodation. There was nowhere else to go other than on the bus, so there I was alright. But its different when you're in a sort of chalet and when you're in the middle of a town.

855. IVR: Mmmm. I guess, I only asked about relationships, because you were talking seeing other people's relationships, part of what you missed and also thinking about (interrupted)

858. P3 No, no, I haven't got any detractions or worries about that side of things. I daresay that if I met the right person, that, you know, I wouldn't even hesitate. No, you know, its sort of, its hard enough as it is, without all the other little, sort of, complications in life. And its, from a stroke person to, whether its husband, wife or what, its very hard to define or to describe to someone, to the other, what's going through your mind at the time, you know. You do tend to get frustrated, and you do get tired, and you do get irritable, and you do get this, so and so. But on the other hand, you could be perfectly normal without the stroke and be exactly the same, so.

866. IVR: Yes

867. P3 But, I'm actually from what I've seen, its got to be really hard to, actually, go from one extreme to another, where from one minute where you're whole, so and so, and then the wife

870. IVR: Did you say whole?

871. P3 Yes, as in physically whole you know. And then suddenly, the next time she gets him out of hospital, he's needing assistance, needing you know this and that

873. IVR: So it would be different in your case meeting somebody, they would

874. P3 Yes, they would accept me for what I am.

875. IVR: Yes

876. P3 Like I say, at least they're straightaway, into that.

877. IVR: And you also know about them as well, about how they are and are with you

878. P3 I haven't, didn't even consider that side of it. I'm not saying that I don't get lonely sometimes but you know, there's an element to both sides of the fence, you know. When you look at them and maybe sometimes you're better off, not being. You know I'm not anti-royalist or anti-marriage or anything, I'm sort of just quite rational and sort of look at things.
883. IVR: It sounds like a very balanced way of looking at things

884. P3 I think you've got to in some aspects, you know. Alright, this has obviously 885. sorted out a lot in my mind but you know even in the past I've sort of looked at things. You 886. know I was married, I've been married twice but I sort of look at things. Alright this has 887. affected it, but it hasn't affected me in that stimulus that way. You know, I sort of look at 888. things, and I accept it. As I said, if I meet somebody and that's the right thing, then fair 889. enough, but as I said, at least you meet on open ground, on equal ground. And that's a total 890. effect. As I said it must be hard to have a young healthy bloke, so and so, so and so. And 891. then bang! But no.

892. IVR: There's lots of thoughts going through my head from all the things you've said 893. that are very relevant to what I'm researching. Apart from what you've already told me, is 894. there anything that we haven't covered about what it's been like, how your life has changed 895. since the stroke?

896. P3 I think being negative down one side of your body does play you 100% round, 897. you know. You get this mixture of what you can achieve and what you can't achieve, and try 898. to do and that's what you can't do. And you get an air of frustration. But on the other hand, 899. you get elation when you can do something.

900. IVR: What do you do with the frustration? Does it last long?

901. P3 No, it all really depends on what you're trying to do in the first place. Because, 902. you get to a certain degree where you obviously can't do it and that's a no-man's lands, as 903. such. Where you sort of, you might swear, you might kick, or stumble at something or just 904. sit down and have a fag and think about it, think another way around it. And then try again. 905. Other than that, I wouldn't say you have the frustration all the time cos lots of times, if you're 906. doing things or doing something, you don't sort of dwell on it. Can you understand?

907. IVR: Yes

908. P3 Lets to say, just to sit down and you read a book and then its only when you want 909. to turn the page over that its suddenly it's a different category. But up to then, you know, it 910. hasn't entered your head

911. IVR: You're enjoying your book?

912. P3 Yeah, and so and so. So you do this and you then obviously you go through the 913. rigmarole and the bloody book'll go somewhere and then its poignant. But up until then, 914. you're trying to get back to as best a normality as you can, you know. And I think that works. 915. And as I said, I think that works out in the same way as frustration wise, you know. You'll 916. do something or go to do something and you can't do it. Alright some way or the other, you'll 917. get round it. Whether its i.e. leave it or try another different angle. That's it.

918. IVR: And there's the elation as well?

919. P3 Yeah. Whether its kack-handed or thing, you know. I mean, I sat down and put 920. a table and chairs together, a set of four chairs, you know screwing them

921. IVR: Wow!

922. P3 I had them, God knows where, you know. Tucked up around my knees, around 923. my head, with one screw-driver in this hand, but you know, I done it. I looked at it, whereas
924. it'd probably take half an hour with normal factions, it probably took me all afternoon

925. IVR: Determination?

926. P3 Yes, I done it. And then you have a word with somebody and look at you like 927. you're a total idiot. That's the way to do that. But I done it. And that's it. So that does build 928. up an air of whatcha-me-call-it

929. IVR: Confidence and pride?

930. P3 Yeah. Like I say, its just having that sort of, to do it, you know. And I've got to be 931. truthful its not in everybody who's had a stroke. Different people are in different situations 932. but also every stroke's different anyway. So I don't know

933. IVR: Yes, Thank you

934. P3 Does that help you?

935. IVR: Very much so (Pause). There seems to be a strong theme, that you're a 936. determined person

937. P3 Yes, I've always been a sort of, although I wouldn't say determined, although I 938. have been since the stroke. Determined to get back to normality, or what I classify as 939. normality, you know.

940. IVR: Enough of normality?

941. P3 Enough of, yes, to sort of (pause)

942. IVR: Enough to enjoy life?

943. P3 No, to get back to basics really, of survival more than. Does that sound a bit 944. harsh to you? Its not so much dancing and enjoying life, as getting back to a basic where 945. you can grab hold of something, do something for your best, walk, climb up stairs. As I said 946. the basics, getting back to as near to normality as you can. And that's it. Now fair enough, I 947. can accept that this arm never comes back to full percentage, I can adapt. And the same in 948. one aspect to the leg. But there's always that thing that you want it to get as well as and as 949. good as it can. I mean I'm 55 so, I'm sort of different from a bloke of say 30 who's had a 950. stroke, who's got a lot of life ahead of him and a lot of things that probably he wants to do. 951. Whereas me, I'm sort of, well, I'm not active as such. I've always kept myself healthy and run 952. round. But I only run around in between the skips and the lorries and so and so. But I use 953. physical strength to off-load and so and so. I always kept my weight down, I was never 954. certainly obese, but I never put on more than a stone at any one time. And I've always been 955. reasonably fit, so. It mixes both ways

956. IVR: So when you said, like a younger person might have things they won't be able to 957. do. Is there a sense for you, that you've done the things you wanted to do?

958. P3 Yes. Alright, admittedly I done my back in, so and so. So that did bring me down 959. certain points that I could, what I obviously could do and what I couldn't do. The same 960. sports-wise, and, but I sort of compensated for that through walking. By going on holiday. 961. Right, doing things up to a certain, that you could achieve, so and so. So I knew my sort of 962. what's the word, I knew how far I could go. Whereas, somebody who is younger is only 963. going through that stage, things like golf, so and so
964. IVR: So you've learned through being ill, what you've got to do, how to help yourself?

965. P3 Yeah, yeah, how to counteract, or what you can do, what you compensate for, so and so, and so and so. Whereas somebody younger, alright they might be 30, but there's such things in life, i.e. building, home building. When I was 30 (Somebody came into room, needing to use it in 5 minutes, therefore agreed to wind up interview!) To compensate for things, when I was 30, I was building me own house, had two kids, so and so. If they're going through that stage and a stroke happens, it's the biggest drawback physically, and financially and everything. There's so many attributes to it.

972. IVR: Sounds like you're placing the stroke into where people are at in their life, at that time? Who they've been, what they've done, what they've got left to do?

974. P3 That does affect everybody in that aspect, it must do. As I said, there's been a girl in here who's 17 years old. And the poor cow she's been frustrated for the fact is she should be dancing, she should be doing this, she should be doing that.

977. IVR: And you feel that there are fewer 'shoulds' for you at the moment?

978. P3 Yeah, I look at things, as I was a lot older and wiser, I've done an awful lot of things, so and so, and so and so. Whereas, its even harder for them that haven't got to that stage or been through that stage.

981. IVR: That sounds very important. Also that there's not one good way of coping, but its down to the individual

983. P3 Yes, its on an individual basis, on what they're life is around at that time, more than anything

985. IVR: Thank you, thank you

986. P3 If you want to talk again, I mean that, you've got my phone number, I can always come to, you are stationed at Guildford?

988. IVR: Yes

989. P3 If you give me a few days notice, then I will happily come and talk again

990. IVR: Its been very interesting, thank you for your time.

Summarising and debriefing...
APPENDIX ELEVEN

Letter to GP informing of patient's participation
Dear Dr [Name],

RE: [Participant Name] (D.O.B - )

I am writing to inform you that the above patient kindly agreed to be interviewed in [Month/ Year] as part of our research investigating life after stroke. This research is being carried out as part of my clinical psychology training at the University of Surrey and has the support of the Consultant Clinical Psychologist and Nurse Consultant at [Name] Hospital. Approval has also been granted by the Research and Development Committee, the local NHS ethics committee and the University of Surrey Ethics Committee. I have enclosed a Participant Information Leaflet for your information. Please do not hesitate to contact me on [telephone number] or by email [Email address] should you like any further information about the study.

With best wishes,

Yours sincerely,

Ms [Name]
Lead Researcher & Trainee Clinical Psychologist
APPENDIX TWELVE

Table matching sub-themes to suggested opportunities for adaptation and intervention
Table 2: Table matching sub-themes to suggested opportunities for adaptation and intervention

<table>
<thead>
<tr>
<th>SUPERORDINATE &amp; Sub-themes</th>
<th>Suggestion for adaptation and intervention (based on participants' accounts and relevant literature)</th>
</tr>
</thead>
<tbody>
<tr>
<td>'MAKING SENSE OF THE STROKE': To promote adaptive meaning-making</td>
<td></td>
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</tbody>
</table>
| 'Meaning within life narrative' | 1. Positive appraisal of stroke within life-narrative  
2. Consider as 'protective' or 'vulnerability' factors for emotional adjustment and coping |
| 'Searching for an explanation' | 1. Educational support (causes/ risk factors)  
2. Emotional support (emotional ventilation/ acceptance)  
3. CBT techniques (adaptive thinking) |
| 'Comparison of this self with others' | 1. Focus on retained abilities (use to meet valued activities and/or compensate for lost abilities) and improvements  
2. Problem-solving 'new ways around everyday activities'  
3. Positive appraisal (changed/ retained abilities; draw similarities between 'old' and 'new' ways)  
4. Goal-setting (resume valued activities and/or identify new activities within present abilities)  
5. Activity-scheduling  
6. Self-monitoring improvements (written records)  
7. Accept feedback from others  
8. Maintain hope  
9. Promote social support  
10. Positive self-other comparisons |
| 'Meeting with new life perspectives' | 1. Emotional support (emotional ventilation)  
2. Psychotherapy (promote positive self-concept/ perspectives/ experiences)  
3. Support persons: Enhance perceived control/ reinforce independence/ meet personal needs/ positive attitude |
| 'The uncertain journey' | 1. Psycho-education (expected course/ 'controllable and knowable' Vs. 'uncontrollable and 'unknowable'/ available support)  
2. Emotional support (emotional ventilation/ adjustment)  
3. Psychological care (develop 'problem-focused' and/or 'emotion-focused' strategies)  
4. Foster positive attitude  
5. Exert control (goal-setting/ measure progress/ manage emotions) |
<table>
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</thead>
<tbody>
<tr>
<td><strong>'MANAGING LIFE AFTER THE STROKE': To promote adaptive coping strategies</strong></td>
<td></td>
</tr>
</tbody>
</table>
| **'Making the most of support from others'** | 1. Support persons: Enhance perceived control/reinforce independence/meet personal needs/respectful, positive attitude  
2. Interventions to promote support network  
3. CBT interventions (re-attribution of psychological barriers to accepting help)  
4. Positive appraisal (focus on what facilitates)  
5. Develop reciprocation/good relationships  
6. Maintain areas of control  
7. Use humour |
| **'Drawing on inner resources'** | 1. Adapt past coping strategies/skills  
2. Motivational work (enhance persistence)  
3. Psychological care (enhance self-esteem) |
| **'Finding new ways of doing things'** | 1. Problem-solving skills  
2. Behavioural strategies (planning/pacing/self-monitoring)  
3. Positive appraisal of 'new ways'  
4. Persist in the light of obstacles |
| **'Setting goals'** | 1. Meaningful SMART\(^1\) goals adjusted to abilities  
2. Use smaller goals to reach larger goal  
3. Self-monitoring  
4. Positive appraisal of achievements  
5. 'Emotion-focused' strategies (setbacks)  
6. Professionals: Positive attitude/meaningful goals/co-ordinated rehabilitation/good communication) |
| **'Using thoughts to cope'** | 1. Focus on positives (e.g. retained abilities, improvements, modified abilities)  
2. Positive self-talk  
3. Distract from and/or foster acceptance of 'unchangeable'/negative aspects  
4. Goal-setting and problem-solving for 'changeable'/negative aspects  
5. CBT (challenge 'thinking errors') |
| **'Managing emotions'** | 1. Foster positive attitude  
2. Self-praise and encouragement  
3. CBT (re-attribution of unhelpful beliefs about emotional support from others)  
4. Emotional support  
5. Activity-scheduling  
6. Relaxation |

\(^1\) SMART refers to specific, manageable, achievable, realistic and timed goals